

A Mixed-Methods Study of Eating
Behaviours and Mealtime Experiences in
Relation to Young People with Tourette
Syndrome

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The saying *'I am my ancestors' wildest dreams'* has never felt as true as it does in this very moment as I type this. To my grandparents, I hope you are proud and watching.

Alhaja Amina Ben Cheikh

إِنَّا لِلّٰهِ وَإِنَّا إِلَيْهِ رَاجِعُونَ Mahmoud Loudiyi

Alhaja Omosalewa Abeni Adedayo إِنَّا لِلّٰهِ وَإِنَّا إِلَيْهِ رَاجِعُونَ

Chief Emmanuel Ladimeji Gbadegesin Bamigbade may he rest in peace

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Abstract

Research suggests that young people with neurodevelopmental disorders experience an increased prevalence of selective eating compared with their typically developing counterparts. However, very little research has specifically explored the eating behaviours of young people with Tourette Syndrome (TS). Moreover, the mealtime experiences for young people with TS and their families has yet to be empirically explored. This doctoral study aims to begin to fill these gaps in the literature by exploring the eating behaviours and mealtime experiences of young people with TS and their families. The objective of this PhD was twofold: (1) to identify traits and characteristics associated with TS and/or comorbid disorders that shape the eating behaviours and mealtime experiences of young people with TS and their families. (2) To identify mealtime challenges and how they are managed by young people with TS, mothers of young people with TS, and clinical professionals, if at all.

This pragmatic dissertation drew upon mixed-methods and multiple perspectives to provide a comprehensive understanding of the eating behaviours and mealtime experiences of young people with TS and their families. The quantitative studies were designed to compare the eating behaviours and positive mealtime attributes of young people with TS to typically developing controls; based on both self- and maternal-report. The qualitative studies undertaken followed a multi-perspective Interpretative Phenomenological Analysis (IPA) design. Three perspectives were sought, from: (1) young people with TS, (2) mothers of young people with TS, and (3) clinical professionals. The results are considered in light of a theoretical framework that

incorporates Ecological Systems Theory and the Dialectical Model of Feeding Interactions. The findings suggest that the eating behaviours of young people with TS and mealtime experiences of them and their families are shaped by traits and characteristics associated with TS and comorbid disorders/behaviours. While some experiences mirror those of other populations with the same trait or characteristic (e.g., selective eating), others were categorically different, shaped by the distinct features of TS (e.g., tic-related challenges). The application of the theoretical framework allowed for an appreciation for the systemic complexity of mealtimes; a microsocial phenomenon that is interpersonal and intersubjective.

This doctoral study contributes to understandings of: (1) sensory sensitivity and rigidity as transdiagnostic mechanisms for selective eating, (2) the parent-child feeding dynamic during adolescence, and (3) highlights directive communication as an aspect of family mealtimes that may be a barrier to positive outcomes at best, and facilitate adverse outcomes at worst. The findings also highlight mealtimes as a social context where tics might present challenges that evoke emotional states that can exacerbate them. Tics have the potential to create functional mealtime challenges, affecting a young person's ability to eat, drink and be seated. They also have the power to disrupt the conviviality of mealtimes. Eating out-of-home can be especially challenging, with restaurants in particular being high-pressure environments for young people with TS and their families. Young people with TS and their families can feel self-conscious and stigmatised when eating out-of-home, including friends' houses, which may result in further social isolation and weaken social ties.

Clinicians' accounts often paralleled those of young people and mothers. Although, there were a few notable differences. Clinicians focused more on the impact of appetite suppressing medications on the weight of young people, while young people focused more on weight gain associated with appetite stimulating medications. Additionally, mothers spoke about attempts to change their child's behaviours, while clinicians discussed the importance of managing parental expectations and responses to young people's behaviours. Taken together, the findings suggest that young people with TS and their families would benefit from specialised support to address some of the mealtime challenges they face and demonstrates the importance of clinicians taking a transdiagnostic approach to selective eating.

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Abbreviations, Acronyms, and Initialisms

ADHD	Attention Deficit Hyperactivity Disorder
ARFID	Avoidant/Restrictive Food Intake Disorder
ASD	Autism Spectrum Disorder
BMI	Body Mass Index
BMI-SDS	Body Mass Index Standard Deviation Scores
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
IPA	Interpretative Phenomenological Analysis
NICE	National Institute for Health and Care Excellence
NHS	National Health System
MCAR	Missing Completely At Random
OCD	Obsessive-Compulsive Disorder
PTD	Persistent Tic Disorder
SDS	Standard Deviation Score
TS	Tourette Syndrome
YP	Young People ¹

¹ Abbreviation begins chapter two

Prologue

Within this dissertation, person-first language is used, however it is recognised that disability language is a personal and sensitive topic with individuals having different preferences; while some prefer person-first language (e.g., young people with TS) others prefer identity-first language (e.g., Touretter). Although the American Psychological Association (2020) guidelines permit the use of both, the TS organisations that supported recruitment for this doctoral study use person-first language. Additionally, a peer with lived experience was consulted about language use. As evidenced in the quote below, they highlighted how complicated disability language can be, and how one person can have mixed feelings about person-first and identity-first language depending on their relationship with their condition. Overall, it was decided that person-first language is less likely to cause offense and is more respectful of the community. The only times identity-first language is used is when participants use this language themselves or when referring to samples/groups (e.g., TS group or neurodiverse families/young people).

“I say ‘I have TS’ rather than ‘Touretter’ because I feel it's something I have rather than something I am, but I do say ‘I'm autistic’ and not ‘I have autism’ because I feel autism shapes and defines my every experience. It's different for everyone and that's the tricky part when getting the language right in papers, but I think people with TS is fairly neutral.”

Also, it is important to note that the terms ‘child(ren)’ and ‘young people’ are not used interchangeably; ‘child(ren)’ is used when the emphasis is placed on the familial relationship, where this does not apply, the terms ‘young people’ and ‘young person’ are used, referring to them in their own right. Nevertheless, the term ‘children’ is also

used when differentiating between ‘older children’ and ‘younger children’, and where appropriate ‘adolescent’ is also used.

Finally, there is also a debate about what terminology to use when referring to people who utilise services (Keville, 2018). The term ‘patient’ has been used in this dissertation despite being contested in the field of psychology; due to passive connotations and its roots in the biomedical perspective and a paternalistic healthcare approach. Costa et al. (2019) conducted a scoping review assessing labelling preferences among individuals who utilise healthcare services. They found that ‘patient’ was the most preferred term among those who accessed services and advised that this should be used within the context of research when referring broadly to a group. Moreover, alternatives such as ‘service user’ and ‘client’ have also been contested as they denote an agency that does not reflect how people feel when utilising services, especially within the National Health System (NHS) (Keville, 2018). For example, see below for an extract from an opinion piece by Dimbylow (2017):

“I’m a client when I go to the hairdressers, or book an oven cleaning. I’m a service user when I go to the library or pay my council tax. But when I’m seeing my psychiatrist for a medication review or checking in with my care coordinator, I’m a patient. Let’s face it, mental health treatment is pretty shoddy in the UK.” (sentences 8, 9 and 10)

Chapter One: Introduction

1.1 Tourette Syndrome

TS is a neurodevelopmental disorder with a cross-cultural prevalence of ~1% (Robertson et al., 2009), the prevalence of tics (including all tic disorders) in young people is closer to 3% (Knight et al., 2012). However, it is thought that the current prevalence rate may be higher as the COVID-19 pandemic has not only increased tic rates among those diagnosed with tic disorders, but has also brought about an upsurge in the sudden and new onset of tics, especially for female adolescents (Heyman et al., 2021). These authors suggest that anxiety is a likely precipitating factor which could explain the increase. While further research is needed to investigate this phenomenon, it is clear that tics are not rare and may be on the rise, making it increasingly important to understand the impact of tics on young people's lives. Therefore, the experiences of young people with TS may not be unique to this clinical population, and findings may be generalisable to a broader subset of the general population.

TS is characterised by both vocal and motor tics that often emerge during early childhood. Tics are stereotyped repetitive movements or vocalisations that can be simple or complex. While tics may resemble purposeful movements or have linguistic meaning, they are involuntary. Simple vocal tics tend to be brief and meaningless sounds or noises (e.g., barking or coughing). However, complex vocal tics tend to combine meaningful words or phrases (e.g., repeating words or use of obscene language). Simple motor tics tend to be brief, repetitive movements limited to a small muscle group (e.g., eye blinking or a shoulder shrug).

In contrast, complex motor tics are coordinated patterns of movement that involve several muscle groups, often the combination of several simple tics (e.g., eye blinking, head-turning and shoulder shrugging). There are also several tics which are less prevalent, such as coprolalia/copropraxia (obscene language/gestures), echolalia/echopraxia (repetition or imitation of others' speech/movement) and palilalia/palipraxia (repetition or imitation of one's own speech/movement) (Eapen & Robertson, 2015; Robertson & Eapen, 2013). These phenomena are reportedly seen in approximately a third of TS patients in clinic, with lower levels reported in community samples (Cavanna & Rickards, 2013). Other TS symptoms can include self-injurious behaviours (e.g., self-hitting), obsessive-compulsive behaviours (e.g., repetitive tapping) and non-obscene socially inappropriate behaviours (e.g., insulting others).

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013) criteria for TS specifies that an individual must have had persistent motor and vocal tics for over a year with an onset before the age of 18 years to be eligible for a TS diagnosis. Tics typically onset during early childhood (between age 4 and 6 years) and increase in severity during prepubescence (between age 10 and 12 years) (Bloch & Leckman, 2009). A misconception about TS is that the diagnosis is based on tic severity. In reality TS incorporates a spectrum of severity with tics ranging in form, frequency, complexity and intensity (Cavanna et al., 2017). The TS criteria accounts for the waxing and waning nature of tics, with the diagnosis being based on the persistence of tics and not the frequency nor intensity of tics. TS differs from Chronic Motor or Vocal Tic Disorder and Provisional Tic Disorder in two ways: tic type and persistence. For a Chronic Motor or Vocal Tic Disorder diagnosis, an individual only needs to have the presence of a vocal or motor

tic for over a year to be eligible for diagnosis; for TS, the individual would require both types of tics for over a year to be eligible for diagnosis. A Provisional Tic Disorder diagnosis would apply when tics have been present for less than a year. To be eligible for a tic disorder diagnosis there must be no underlying physiological or medical explanation for tics (e.g., Huntington disease or drug use).

TS is a heterogeneous condition, not only in part due to the breadth and variability of tics but also due to high rates of comorbidity. Research suggests that as many as 90% of people with a TS diagnosis have a comorbid disorder, with more than half having two or more psychiatric disorders (Cavanna & Rickards, 2013; Hirschtritt et al., 2015). Common comorbidities are Attention Deficit Hyperactivity Disorder (ADHD; 11-80%), Obsessive Compulsive Disorder (OCD; 20-60%), depression (18-30%), Autism Spectrum Disorder (ASD; 6-22%), and anxiety (18%) (Cavanna & Rickards, 2013; Cavanna et al., 2009; Hirschtritt et al., 2015; Rizzo et al., 2017; Robertson, 2000). As such, when exploring the experiences of people with TS, it is important to consider the role of common comorbidities as TS rarely presents alone.

Conelea and Woods (2008) noted the importance of understanding contextual factors that evoke feelings of stress, frustration, and anxiety, as these emotional states were found to exacerbate tics. Mealtimes are thought to be a worthy context for exploration within this population for several reasons. It was unknown how, or if, traits and characteristics associated with TS and comorbidities shape the eating behaviours and mealtime experiences of young people with TS and their families. Therefore, this was the starting point for this doctoral study.

1.2 Background

This section emphasises literature that provides sufficient background and context for this dissertation to highlight gaps in current evidence in order to form research questions. Due to the varying terminology for selective eating (see section 1.2.1) and the lack of literature directly exploring the eating behaviours or mealtime experiences of people with TS, a systematic literature review was not practical. Instead, a pragmatic approach was adopted in order to sufficiently explore this research area and the diverse literature base that needed to be reviewed (e.g., eating behaviour literature, mealtime literature, TS literature, neurodevelopmental literature, sociological literature). The literature presented was primarily located through an electronic database search using multiple search terms, including *selective eating, picky eating, food selectivity, family meals, neurodevelopmental disorders, Tourette Syndrome and sensory sensitivity*. Databases searched included SCOPUS, PubMed, CINAHL Plus and Google Scholar. While search terms were used as a starting block to help locate relevant literature, there was an emphasis on backward and forward snowballing to locate seminal work, grey literature and to stay abreast of empirical developments. A systematic literature review was conducted to examine selective eating in middle childhood and its impact on family mealtime experiences (see Appendix A for PRISMA).

This section presents eating behaviour literature and why the eating behaviours of young people with TS are of interest. Attention is then given to the social significance of mealtimes and why young people with TS and their families may experience challenges within this social context. Literature pertaining to the perspectives and experiences of mothers and clinical professionals are detailed in the introductions to later chapters in this dissertation. This literature review sets the foundation for the dissertation's justification and the research presented in the proceeding chapters.

1.2.1 Defining Eating Behaviours

Eating is central to mealtimes, as the whole social occasion revolves around consumption. Therefore, it is vital to understand eating behaviours when exploring mealtime experiences. The term 'eating behaviours' broadly refers to how an individual consumes or does not consume foods. There are other terms that are used which refer to specific eating behaviours and food acceptance patterns (i.e., specific ways of eating). However, these are often poorly defined and inconsistently used. Johnson et al. (2018) attempt to provide distinct definitions for the varying terms. 'Picky eating' typically refers to young people who consume a limited amount, and variety, of foods and reject familiar and unfamiliar foods. On the other hand 'selective eating', also referred to as 'food selectivity', denotes a more extreme and maladaptive form of picky eating. Alongside food refusal, selective eating may also include high-frequency intake of a single food type or group (e.g., predominantly eating pizza or carbohydrates). Selective eating has also been described as having a greater impact on the socio-emotional development of young people as they can struggle to function in social settings due to their eating behaviours (Johnson et al., 2018). While the attempt by Johnson and colleagues to distinguish between terms is helpful on a conceptual level, challenges arise when looking at the literature base as studies rarely use a term consistently, and terms often overlap in the way researchers define them.

For this dissertation, the term 'selective eating' was chosen as an umbrella term to describe an eating behaviour pattern that discriminates between foods based on the sensory characteristics of food such as taste, smell, colour and texture. Selective eating was preferred over the other terms because it was deemed non-judgemental and

descriptive; it was not considered to be laden with negative connotations in the same way that other terms that include words such as 'fussy' or 'picky' are. Additionally, selective eating was deemed to align better with the underlying philosophy of this doctoral study (detailed in chapter two).

Alongside selective eating, this dissertation also considered food neophobia (simply referred to as 'neophobia' throughout) and the effect of appetite changes on eating behaviours. Neophobia refers to a fear-based reluctance to try, and avoidance of, new foods and is characteristically different from selective eating, although often part of the selective eating behavioural profile (Johnson et al., 2018). The distinction lies within the rationale for food refusal, as selective eating transcends beyond the novelty of foods and is typically rooted within the sensory characteristics of food. Neophobia has been more consistently defined in the literature, therefore, it lacks the ambiguity associated with other eating behaviour terms (Callie L. Brown et al., 2016; Johnson et al., 2018). The proceeding sections will detail why these eating behaviours are being explored in relation to young people with TS.

1.2.2 Selective Eating and Neophobia

Given the sensory nature of food discrimination that occurs within selective eating, it is unsurprising that there is a strong evidence base that suggests that sensory sensitivity underlies selective eating (Page et al., 2021). The term 'sensory sensitivity' generally refers to an awareness of sensory input (i.e., sight, sound, taste, smell, touch, and pain). Individuals who are more sensitive to sensory information have a higher awareness, thus a lower tolerance for sensory input. For the purpose of this research, sensory sensitivity refers to heightened sensory awareness (over-responsivity) as opposed to under-

responsivity. Zickgraf and Elkins (2018) found that sensory sensitivity was associated with selective eating in young people and neophobia in adults. Their finding suggested that sensory sensitivity may be a key mechanism in the development and maintenance of selective eating and neophobia. Furthermore, while their sample of young people was receiving treatment for anxiety or OCD, the relationship between sensory sensitivity and selective eating was independent of anxiety and was also found in their adult sample. Nevertheless, it is important to note that sensory sensitivity accounted for less than 15% of the variance in selective eating and neophobia in both samples. This suggests that other factors may support the development and maintenance of selective eating and neophobia.

Sensory sensitivity research is predominantly focused on ASD populations, with less emphasis on other clinical and non-clinical populations (Dunn et al., 2016). Eating challenges in young people with ASD have long been documented (Kanner, 1943), with overall scientific consensus supporting the association between selective eating and ASD (Margari et al., 2020; Mari-Bauset et al., 2014) and a consistent link between selective eating and sensory sensitivities (Page et al., 2021). Research suggests that sensory-based selective eating is most prevalent in the ASD community, with a 45 to 90% prevalence (Neto et al., 2021). As such, there is a substantive literature base exploring their eating behaviours and mealtime experiences.

Additionally, there is a heightened awareness among clinicians and researchers alike due to atypical sensory processing (over and under responsivity) being a part of the DMS-5 criteria for ASD (American Psychiatric Association, 2013). Research exploring differences within the ASD population highlights the role of oral sensitivity in the

development and maintenance of selective eating, demonstrating that people with ASD who exhibit oral sensitivity experienced selective eating at higher rates than people with ASD without oral sensitivity (Chistol et al., 2018; Kral et al., 2015; Zickgraf et al., 2020). This highlights that selective eating is not intrinsically linked to ASD but results from certain traits and characteristics, namely, oral sensitivity alongside other factors.

While sensory sensitivity is a well-established and recognised trait related to selective eating, a more recently explored trait is ‘rigidity’. Rigidity refers to cognitive styles or behaviours, both of which tend to be marked by a lack of flexibility and intolerance of change/difference (Zickgraf et al., 2020). Rigid eating behaviours documented in people with ASD include: (1) an insistence on sameness, (2) food jags (i.e., eating the same meal for a period of time), (3) inflexibility related to the presentation of food, cookware, brands, and packaging, (4) insistence on routine, and (4) engaging in specific eating practices (Ledford & Gast, 2006). Mealtime rigidity is one of four domains of the Brief Autism Mealtime Behaviors (*sic*) Inventory (BAMBI) (DeMand et al., 2015); other subscales include selective eating, food refusal and disruptive mealtime behaviours. This suggests that rigidity can be a challenge for parents which can occur alongside selective eating. DeMand et al. (2015) defined mealtime rigidity as “*limited flexibility with feeding and mealtime routines*” (p.7) - this includes rigidity around how food is prepared or presented. Despite recognising mealtime rigidity as a challenge parents of young people with ASD face, no research has specifically explored the relationship between rigidity and selective eating in other populations until recently.

Zickgraf et al. (2020) was the first to explore the relationship between rigidity and selective eating in several population groups: two clinical (ASD and anxiety/OCD spectrum samples), two non-clinical (representative and undergraduate sample) and two

age groups (aged 5 to 17 years and aged 17 to 22 years). They found that rigidity was significantly correlated with oral texture sensitivity across all samples, which led them to speculate that rigidity may be a maintaining factor in selective eating. In addition, they noted that a repetitive diet, food rules and black and white thinking (e.g., thinking that all new or non-preferred food is bad) may be the manifestation of rigidity in the context of eating and that research should further explore the relationship between rigidity, sensory sensitivity and selective eating in different populations.

As rigidity is a part of the TS cognitive profile (Morand-Beaulieu et al., 2017), it is deemed another factor of interest when exploring the eating behaviours of young people with TS. However, there is a stronger scientific premise for exploring the relationship between sensory sensitivity and the eating behaviours of young people with TS. For example, Houghton et al. (2014) conducted a literature review exploring sensory phenomena and disturbances in people with TS. Despite the literature being inconclusive on whether dysfunctional sensorimotor integration was a key feature of TS or related to other forms of psychopathology, there was still a recognition that sensory disturbances play a part in their experiences (Isaacs & Riordan, 2020). For example, Belluscio et al. (2011) reported that 80% of the adults with TS in their study described themselves as experiencing heightened sensitivity to external stimuli across modalities. Belluscio and colleagues recommended that more attention be given to addressing sensory-based challenges faced by people with TS due to the profound effect sensory sensitivity could have on their quality of life.

To date, very little research has focused on the eating behaviours of people with TS. Research by Smith et al. (2019, 2020) was the first to explore the relationship between selective eating and sensory sensitivity in young people with TS. Smith et al. (2020)

suggested that neurodiverse young people (aged 6 to 15 years with ASD, ADHD, and TS) have higher levels of selective eating than typically developing controls due to higher levels of taste/smell sensitivity, even when accounting for comorbidity. This further supports the idea that sensory sensitivity underlies selective eating and highlights the need for research exploring the eating behaviours of young people with TS.

While research by Smith et al. (2019, 2020) has started to explore the eating behaviours of young people with TS, this research was based on parental reports. As with most eating behaviour 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 behaviours accurately (Bartholdy et al., 2017; Cosi et al., 2010). Therefore, it is crucial to examine whether the same relationship exists based on self-report. More importantly, the 'essence' of the mealtime experiences of young people with TS remains unknown as this has yet to be qualitatively explored.

1.2.3 Young People's Food Choices During Adolescence

Food has been depicted as a means of gaining autonomy for young people and as a tool for parental control. As such, young people's food choices within the context of the family involves daily negotiations and can result in power struggles (James, Curtis, & Ellis, 2009; O'Connell & Brannen, 2014; Paugh & Izquierdo, 2009). These conflicts occur when a young person's right to independent food choices are dissonant to parental responsibility for their child's dietary needs and requirements (Curtiss & Ebata, 2021). Within families, young people's ability to exercise control over their food choices is permitted to an extent, allowing room for a young person's agency whilst remaining

situated within the constraints of a hierarchical relationship (Curtis, James, & Ellis, 2010). Consequently, young people may utilise food as a way to establish themselves as being more autonomous (Boni, 2017).

Food negotiations between parents and their children are also known as the parent-child feeding dynamic; this mealtime interaction is bi-directional and ever-evolving. A key factor that influences this dynamic is a young person's age. As young people enter adolescence, they increasingly gain access to more food environments and opportunities to exercise autonomy (Bassett et al., 2008; Warren et al., 2008). Therefore, food autonomy is central to understanding young people's food choices. For example, Warren et al. (2008) found that younger participants in their study (aged 7 to 8 years) reported less control over their food choices at home, school, and when eating out of home than older participants (aged 10 to 11 years). This finding suggests that young people become more autonomous as they approach adolescence.

Additionally, Fulkerson et al. (2006) found that younger adolescents (US grade 7 to 9, aged ~12 to 14 years) reported more mealtime rules and expectations than older adolescents (US grade 10 to 12, aged ~15 to 18). This supports the idea that young people's food autonomy increases as they progress through adolescence towards adulthood, when they become fully autonomous over their food choices. However, despite the significance of adolescence and the evolution of food autonomy, this age range has been understudied in the eating behaviour literature (Zickgraf et al., 2020). Therefore, little is known about the nature of selective eating during adolescence and what effect it has on their mealtime experiences and interactions. What is known is that an inability to enact autonomy over food choices, interpersonal challenges with family

members, and a dislike of the food served are some of the reasons cited for young people not eating with their families (Neumark-Sztainer et al., 2000).

1.2.4 Medication, Appetite and Weight

Medication is deemed a crucial factor to consider when exploring eating behaviours due to appetite changes being a common side effect (Baeza et al., 2017; Cortese et al., 2013). There are several pharmacological treatments for TS, including antipsychotics (e.g., Risperidone, Aripiprazole and Haloperidol) and alpha-agonists (e.g., Guanfacine and Clonidine) (Dayabandara et al., 2017; Quezada & Coffman, 2018). A common side effect of antipsychotic medication is weight gain (Baeza et al., 2017), which has been associated with physical and psychological complications (Dayabandara et al., 2017). However, weight gain varies depending on the medication taken and, in some cases, may only be a temporary side effect (Dayabandara et al., 2017; Degrauw et al., 2009).

Degrauw et al. (2009) explored the effects of antipsychotic medications on the weight of young people (aged 5 to 15 years) with TS. Young people taking antipsychotics were found to be at risk of weight gain (only during their first year, not second or third) when compared to age and gender-matched controls with TS who were not taking medication. Similarly, Pringsheim et al. (2017) also found a significant increase in weight and waist circumference for young people with TS taking antipsychotics. A review by Deng (2013) suggested that behavioural changes as a result of increased appetite (i.e., increased food intake) alongside metabolic changes (e.g., delayed satiety signalling) account for antipsychotic-related weight gain. However, how antipsychotic medications prescribed to young people with TS affects their eating behaviours, not simply their weight, has yet to be explored. Therefore, it is unknown whether young people adjust their eating

behaviours due to antipsychotic-related weight gain or what impact their weight and eating behaviour changes may have on their mealtime experiences.

An important factor affecting food choice for young people relates to body image and weight. For example, del Mar Bibiloni et al. (2013) found that eating behaviours of young people (aged 12 to 17 years) were associated with body dissatisfaction and weight status. Overweight participants who wished to be thinner reported lower consumption of several food groups than 'normal'-weight participants and overweight participants satisfied with their body image. Research has also found that the impact of weight gain on the physical appearance of young people can result in low self-esteem, social alienation and/or depression (Shin et al., 2008). Dissatisfaction with weight gain due to pharmacological treatment may result in young people being conscious of their eating behaviours and attempting to change their eating behaviours (Shin et al., 2008). Additionally, obesity and TS are already stigmatised identities, therefore the intersection of the two are likely to marginalise young people further and reduce quality of life (Cox et al., 2019; Malli et al., 2016; Pont et al., 2017). Therefore, it is crucial to explore whether young people with TS report weight gain as a result of pharmacological treatment for their tics, how they feel about this, and whether this affects their eating behaviours and mealtime experiences.

Alongside antipsychotic medication, it is also essential to explore the effect of ADHD medications. As previously stated, TS is a multifaceted condition, with a majority having additional diagnoses, most commonly, ADHD. Jewers et al. (2013) found that young people (aged 5 to 10 years) with a dual diagnosis of TS and ADHD were more likely to be prescribed medications for their ADHD and tics than young people with a sole TS

diagnosis. In most cases, ADHD medications were more frequently prescribed than tic medications.

While Jewers et al. (2013) did not detail the ADHD medications taken by their participants, research suggests that stimulants are first-line treatments; methylphenidates (psychostimulants) are predominantly prescribed in Europe, while the US prescribes both methylphenidates and amphetamines (stimulant) (Bachmann et al., 2017). Alongside stimulants, research suggests that agonists and selective norepinephrine reuptake inhibitors are also used to treat TS and ADHD comorbidity (Rizzo et al., 2013). Reported side effects for these medications include appetite suppression which is likely to influence weight and eating behaviours.

While weight gain is a risk associated with antipsychotics, weight loss is associated with psychostimulants. A cross-sectional study found that young people (aged 5 to 17 years) with ADHD who were taking psychostimulants had a greater risk (~60%) of being underweight compared to typically developing controls (Waring & Lapane, 2008). Conversely, young people with ADHD who were not taking psychostimulants had a greater risk (~50%) of being overweight when compared to typically developing controls. These findings suggest that psychostimulants are associated with an increased risk of being underweight and a decreased risk of being overweight in young people with ADHD. The mechanisms behind this are likely to be the appetite suppressing effects of psychostimulants (Cortese et al., 2013). However, how psychostimulant-related appetite loss affects the eating behaviours and mealtime experiences of young people with TS and ADHD comorbidity has yet to be explored.

1.2.5 The Social Significance of Mealtimes

Thus far, attention has been given to eating behaviour literature to justify exploring the eating behaviours of young people with TS. The following section moves beyond eating behaviours, highlighting the importance of understanding mealtime experiences. Consideration is first given to the significance of family mealtimes before turning to the role mealtimes play in shaping young people's social lives and relationships.

Mealtimes have been described as the cornerstone of family life, with there being *“no other daily activity that families share as a group that is practiced [sic] with such regularity”* (Fiese & Schwartz, 2008). However, the term ‘family meal’ has been inconsistently defined and measured within the literature. While some studies have defined family meals as requiring the presence and engagement of all or most family members, others have been more liberal and only require the presence of at least one parent who does not need to be eating at the same time as their child(ren) (McCullough et al., 2016). For this research, the liberal definition was used as it was deemed more inclusive. Therefore, a meal was considered a family meal if at least one adult and one child were seated for a meal together, even if one of them was not eating. Despite inconsistent definitions, family mealtimes have been hailed as a vehicle for social, cultural, and dietary change due to the array of benefits associated with them (Robson et al., 2020). Positive outcomes for young people include lowering the odds for overweight/obesity (Hammons & Fiese, 2011); increasing healthier food choices (Berge et al., 2017; Hammons & Fiese, 2011); increasing psychological wellbeing (Hammons & Fiese, 2011; Neumark-Sztainer et al., 2004); protecting against eating disorders (Hammons & Fiese, 2011; Neumark-Sztainer et al., 2008); and increased academic achievement (Eisenberg et al., 2004).

Larson et al. (2006) also suggested that family meals are a symbol of family unity. This statement is supported by research by Spagnola and Fiese (2007), which links family mealtimes with positive familial outcomes such as providing greater structure, a sense of belonging and family cohesion. While mealtimes are associated with many positive outcomes, it is important to note that merely sitting at a table as a family to eat together is not thought to facilitate these outcomes. Skeer et al. (2017) proposed that instead, the quality of the interactions facilitates positive outcomes. A meta-analysis by Dallacker et al. (2019) identified six components of family meals that facilitate nutritional health outcomes for young people; these were: (1) no television during meals, (2) parents modelling healthy eating, (3) higher food quality, (4) positive mealtime atmosphere, (5) young people's involvement in meal preparation and (6) longer meal duration. While the meta-analysis focused on the nutritional outcomes, a positive mealtime atmosphere was still a crucial factor. Dallacker et al. (2019) suggested that the benefit of family mealtimes lies in how families eat and the quality of mealtime interactions.

In the same way that positive interactions are thought to accrue positive outcomes, negative interactions are presumed to negate positive outcomes at best and facilitate adverse outcomes at worst (Skeer et al., 2017). Negative mealtime interactions are also thought to have a cumulative effect on family functioning and wellbeing due to the repetitive nature of these experiences (Middleton et al., 2020; Wolstenholme et al., 2020). For example, research suggests that the mealtime experiences of families with a young person with ASD differ significantly from those of typically developing populations; with mealtimes being more stressful for families with a child with ASD due to their child's eating and mealtime behaviours (Curtiss, 2017; Thullen & Bonsall,

2017). Studies on the array of positive outcomes associated with increased family meal frequency have primarily involved typically developing families. While greater meal frequency might be positive for typical families, this may not be the case for families of young people with ASD due to the mealtime challenges that unfold. Research has yet to explore the family mealtime experiences of other neurodiverse populations. Nevertheless, their mealtimes are hypothesised to differ from those of typically developing families and may not facilitate positive outcomes.

While mealtimes are recognised to be an important family activity, they have also been found to play a pivotal role in shaping young people's social lives and relationships. Baines and MacIntyre (2019) argued that mealtimes are significant sites for peer relationships and a powerful context for a young person's social, emotional and moral development. Mealtimes also provide an opportunity for young people to expand their friendship group and are a meaningful social context in their lives. Findings by Neely et al. (2014) have indicated that food practices mediate caring, talking, sharing, integrating, trusting, reciprocating, negotiating, and belonging for young people. These findings highlight and operationalise the social significance of mealtimes in the development and maintenance of relationships. Mealtimes also draw a line between intimacy and distance, separating those with whom one does, and does not, 'break bread' with (Baines & MacIntyre, 2019). Thus, allowing young people to affirm relationships and ascertain where they fit within their social network. Mealtimes as a social context are deemed an important area for this clinical population due to the social effects of TS, especially during adolescence. However, similar to family meals, research has yet to explore the role that mealtimes play in the relationships of neurodiverse young people, nor the nature of these mealtime experiences.

1.2.6 Tics, Stigma and Mealtimes as a Social Context

TS has been shown to have a profound effect on the social life of people with TS and their social relationships (Cutler et al., 2009; Eapen et al., 2016; Eddy, Rizzo, et al., 2011); to such an extent that Malli et al. (2019) described TS as a social condition steeped in shame and characterised by loss. Some of the psychosocial challenges that young people with TS experience include stigmatisation (Malli et al., 2016), interpersonal relationship challenges (O'Hare et al., 2015) and low self-concept and -esteem (Lee et al., 2016; Silvestri et al., 2018). TS symptoms affect many social aspects of quality of life, even for those with milder symptoms, although these challenges are intensified for those with higher tic severity and comorbidities (OCD and ADHD) (Eddy, Rizzo, et al., 2011). Such research highlights the social vulnerability of young people with TS. Namely, social vulnerability within the context of peer friendships, although familial strain has also been reported (Eapen et al., 2016).

Mixed-method research by Cutler et al. (2009) exploring the impact of TS on young people's quality of life highlighted the importance of understanding young people's subjective experience of TS; symptom severity only accounted for 47% of the variance in quality of life. Understandably, a young person's subjective experience is intrinsically linked to their tics, as tics play a role in shaping their experiences, perceptions and interactions with others and their environment. This can be particularly challenging during adolescence, where visible differences threaten peer acceptance. For example, a qualitative study by Malli and Forrester-Jones (2017) explored peer perception and found that young people with TS were likely to be on the periphery of social groups with weaker relationships than neurotypical peers due to perceived abnormalities and

fear of stigma-by-association. Understandably, the psychosocial effects of TS can often be more distressing to young people than tics themselves (Cutler et al., 2009). Nevertheless, both tic severity and psychosocial consequences interrelate to make adolescence a particularly challenging life stage; the more severe tics are, the more visible they are to peers, and the higher the likelihood of peer rejection (Cox et al., 2019; Malli & Forrester-Jones, 2017).

According to Psychosocial Theory (Newman & Newman, 1976), one of the predominant developmental tasks associated with adolescence is membership with their peer group. Concordantly, one of the critical psychosocial stressors associated with this life stage relates to group identity and the risk of alienation (Erikson, 1950). Psychosocial Theory posits that young people engage in self-evaluation and where they belong (or do not belong) within the context of their family, peers and school. Thus, this life stage is marked by self-consciousness and a preoccupation with acceptance. In the case of TS, self-consciousness is exacerbated as young people are hyperaware of their visible difference (i.e., tics) which reduces peer acceptance (Malli & Forrester-Jones, 2017). Additionally, Cox et al. (2019) noted that young people with TS are consistently reported to experience stigma and bullying, leading to social withdrawal and loneliness. Rich social relationships are important for quality of life, health, and wellbeing (Umberson & Karas Montez, 2010). Therefore, it is important to explore the experiences of young people within different social contexts and how these experiences affect their social lives and relationships.

Yates and Warde (2017) describe mealtimes as an act of solidarity that cements relationships and fosters collective identity. A qualitative study by Murray and Wills

(2020) echoed this, noting that young people (aged 13 to 15 years) valued school mealtimes due to the opportunity it provided them to cultivate relationships with their peers. While commensality (i.e., eating as a group) can be inclusive, nourishing social relationships and producing belonging, it can also be exclusive (Fiese et al., 2006; Fischler, 2011). For example, one of the themes within a study by Wills et al. (2005) on the food practices of high school students was entitled ‘peer group inclusion, exclusion and commensality’, highlighting the inclusion/exclusion dichotomy that exists within commensality. This hallmark of adolescence has permeated into popular culture, often being used as a common and relatable trope in school-based dramas where canteen scenes symbolise group membership. For instance, the infamous *Mean Girls* (Waters, 2004) line ‘you can’t sit with us’ demonstrated peer rejection (Jachimowski et al., 2021). Considering young people with TS’s experiences of stigma and self-consciousness, mealtimes as a social context are speculated to be pressurised environments that may exacerbate tics due to heightened emotional states that may arise due to concerns surrounding peer acceptance. People with TS struggle to conform to societal norms (Cox et al., 2019; Lee et al., 2019) and mealtimes are steeped in norms surrounding behaviours, such as table etiquette (Packer, 2014). Therefore, mealtimes may not be an affirmative social experience and may heighten ‘othering’ (highlight characteristics that sets them apart from the group), marginalisation and heighten social isolation.

One of the key reasons this dissertation focuses on mealtimes as a social context is the social capital of mealtimes. As previously evidenced, mealtimes present an opportunity for young people to deepen their relationships and sense of belonging. However, whether mealtimes offer the same opportunity for young people with TS is currently unknown. Additionally, the family mealtime experiences of young people with TS and

their families have yet to be explored, and many questions remain unanswered. For example, how does selective eating impact the family mealtime experience for young people with TS and their families? Do family members experience stigma-by-association when dining out? Therefore, considering the social challenges associated with TS, exploring how peer and familial mealtimes intersect with TS are deemed worthy and much-needed areas for exploration.

1.3 A Transdiagnostic Perspective

Thapar et al. (2017) suggest there is clinical utility in viewing neurodevelopmental disorders as traits, rather than distinct disorders, due to the heterogeneity within neurodevelopmental disorders and the overlap between disorders. As such, there may be more clinical significance in focusing on traits and characteristics and how they shape eating behaviours and mealtime experiences rather than attributing particular challenges to a specific clinical group, as research has previously done. Thus, taking on a transdiagnostic perspective by focusing less on the disorder and more on shared traits and mechanisms that may be risk or maintaining factors for mealtime challenges.

As previously detailed, factors of interest that may shape the eating behaviours of young people with TS are sensory sensitivity, rigidity and the side effects of medications for TS and comorbidities such as ADHD. While inferences surrounding the eating behaviours of young people with TS may be made due to shared traits, characteristics, and medications with other populations, the same may not be true in relation to their mealtime experiences. The influence of tics, the prominent (and most visible) feature of TS, on mealtimes has yet to be empirically explored and is thought to be distinct due to the social challenges associated with TS. Nevertheless, the findings relating to the influence of tics on mealtime experience may apply to other populations who also experience tics.

1.4 Research Objectives and Questions

The premise of this thesis is that the eating behaviours and mealtime experiences of young people with TS and their families are shaped by traits and characteristics associated with TS and comorbidities. The objectives for this dissertation are as follows:

1. To identify traits and characteristics associated with TS and/or comorbid behaviours that shape the eating behaviours of young people with TS, their mealtime experiences, and that of their families.
2. To identify mealtime challenges and how they are managed by young people with TS, mothers of young people with TS, and clinical professionals, if at all.

The research questions addressed by this dissertation are as follows:

1. What is the frequency and duration of family meals for families with a young person with TS? Does this differ to typically developing peers?
2. What mealtime challenges, if any, do young people with TS and their families face?
 - (a) How, if at all, does sensory sensitivity shape eating behaviours and mealtime experiences?
 - (b) How, if at all, does rigidity shape eating behaviours and mealtime experiences?
 - (c) How, if at all, does medication influence eating behaviours and mealtime experiences?
 - (d) How, if at all, do tics shape mealtime experiences?
3. What is the impact of eating behaviours and mealtime challenges on young people with TS and their families?
4. How are these challenges navigated?

1.5 Dissertation Structure

This dissertation explores the eating behaviours and mealtime experiences of young people with TS and their families from multiple perspectives using a mixed-method design. The dissertation began with this introductory chapter (**chapter one**) and is followed by a methodology and ethics chapter (**chapter two**). This dissertation then reports findings from six empirical studies using either questionnaires (self- or maternal-report) or data gathered from semi-structured interviews, presented in four empirical chapters. Structurally, each empirical chapter contains a review of relevant literature, details of the methods used (including participant information, recruitment, materials and procedure), findings and a chapter-specific discussion. Empirical chapters have been organised this way so each participant groups' unique contribution can be appreciated in its own right before being compared to others.

The first empirical chapter, **chapter three**, presents the findings of a quantitative study that explored relationships between anxiety, sensory sensitivity, sensory eating behaviours, selective eating and positive mealtime attributes for typically developing young people aged 11-16 years using self-report. This sought to understand how these variables relate to typically developing young people when based on self-report before focusing more specifically on young people with TS in the following chapter.

Chapters four and five explore the perspectives of young people with TS and mothers of young people with TS, respectively. Both chapters present the findings from quantitative and qualitative studies which explore the eating behaviours of young people with TS and mealtime experiences. The results from these chapters contribute novel perspectives, providing the first academic insight into the mealtime experiences of young people with TS and their families. In addition, these chapters provide an understanding

of how young people with TS and mothers of young people with TS perceive traits and characteristics associated with TS and comorbidities to shape the eating behaviours of young people and their mealtime experiences. Finally, these chapters detail the perceived impact of eating behaviours on mealtime experiences and how they navigate these challenges.

Chapter six further explores the role that traits and characteristics associated with TS and comorbidities play in shaping the mealtime experiences of young people with TS and their parents by presenting clinical professionals' understanding and experience. This study's qualitative findings help shed light on what professionals see in practice, framing mealtime experiences within the context of clinical knowledge, expertise, and relevance.

To end, **chapter seven** draws together findings from the empirical chapters and discusses their contribution to knowledge. Finally, reflections on the strengths and limitations of this dissertation are documented alongside recommendations for future research and practice.

Chapter Two: Methodology and Ethics

The literature review in the previous chapter revealed that there is currently a limited amount of research regarding the eating behaviours of young people with TS and no research on the mealtime experiences of them and their families. In this chapter, detail is given relating to the theoretical and methodological framework for this dissertation and how the research questions were addressed. This chapter provides a detailed breakdown of methodological choices that underpinned the research decision-making process, emphasising the rationale for the research approach. As a mixed-method study, different analysis methods were employed dependent on the research questions being addressed by each study. The specifics relating to the data collection methods and analysis for each empirical study will be detailed in the Method section of the associated chapter.

2.1 Theoretical Framework

Mealtimes are complex, dynamic and multidimensional experiences. As such, taking a systems approach to understanding the nature of these experiences is appropriate. Mealtimes do not exist within a vacuum (e.g., Davison et al., 2013). Therefore, understanding all factors that interplay and create nuanced experiences is thought to aid the generation of valuable real-world insight. Accordingly, this dissertation's theoretical framework draws upon two complementary theories that support a comprehensive understanding of lived experiences and interactions.

The overarching theory is Ecological Systems Theory (Bronfenbrenner, 1979, 2001) which provides an all-encompassing framework for understanding ‘child development’ and the influence of all the systems within which a young person is embedded. Ecological Systems Theory supports an understanding of mealtimes within many different social contexts. The second theory is the Dialectical Model of Feeding Interactions (Satter, 1995, 2007, 2012), also referred to as the Dialectical Model, which focuses specifically on the family mealtime context, namely the parent-child mealtime interaction. As Ecological Systems Theory captures various bi-directional relationships between systems, the Dialectical Model sits neatly within it, providing much-needed detail about important family mealtime interactions. Ecological Systems Theory also captures forces external to the Microsystem of the parent-child mealtime interaction, capturing factors that directly and indirectly affect their dynamic and mealtime experiences. Further detail for each theory is provided below.

2.1.1 Ecological Systems Theory

Ecological Systems Theory offers a systemic way of understanding the development of young people (YP), focusing on wider and often unseen features of a young person’s environment that impacts their development. In essence, the theory encapsulates a series of bi-directional relationships between a young person, their family and society. Ecological Systems Theory emphasises circular causality, illuminating the complexities of child development and the many systems within which a young person is embedded. This offers a valuable framework to contextualise the environment for a young person’s development, relationships, and sociocultural influences on their lives and interactions. Ecological Systems Theory defines five socially organised systems that are interconnected. The systems are arranged in a gradient of proximity, starting from the

closest system to a young person with the most direct interactions (**Microsystem**). Each subsequent layer becomes further removed from the young person's direct experiences but still indirectly affects their development. The systems and how they are interconnected are detailed below:

1. **Microsystem:** This system consists of the young person's home, immediate family, school, peers, neighbourhood and community groups; effectively anyone that the young person has regular contact with. There is a bidirectional relationship between the young person and all aspects of their Microsystem (e.g., young person \Leftrightarrow parent, young person \Leftrightarrow teacher, young person \Leftrightarrow neighbourhood).
2. **Mesosystem:** This system consists of interactions between two Microsystems (e.g., home \Leftrightarrow school, home \Leftrightarrow neighbourhood).
3. **Exosystem:** This system consists of indirect environments that affect a young person, such as their parents' workplace or mass media (e.g., parent's workplace \Leftrightarrow home, mass media \Leftrightarrow peers).
4. **Macrosystem:** This system consists of widely shared cultural values, beliefs, customs and laws (e.g., cultural values \Leftrightarrow mass media, laws \Leftrightarrow parents' workplace).
5. **Chronosystem:** This system accounts for transitional influences across the young person's lifespan and patterns of events (e.g., changes in interactions as a young person transitions from early childhood towards adolescence).

In addition to the five systems, Bronfenbrenner (2001) crucially added a layer to Ecological Systems Theory which acknowledged the role of personal characteristics

such as genetics, physical, psychological, and behavioural traits play in shaping a young person's interactions. While this updated version is referred to as Bio-Ecological Systems Theory, the application of his seminal work is often simply referred to as Ecological Systems Theory.

Several scholars have applied Ecological Systems Theory to explain YP's eating behaviours and health outcomes. For example, Davison and Birch (2001) applied Ecological Systems Theory to create a contextual model for understanding childhood overweight. They used Ecological Systems Theory to highlight the contextual and relational nature of risk factors associated with childhood obesity. Walker et al. (2019) built upon the work of Davison and Birch (2001) by extending the framework to YP with disabilities who have higher odds of overweight and obesity than their typically developing peers. By applying a disability lens, Walker and colleagues were able to highlight several additional risk factors for being overweight or obese, including selective eating and the specifics of the disability (individual characteristics and Microsystem), social isolation (Mesosystem) and access to services (Macrosystem). This approach also lends itself to the Social Model of Disability perspective, focusing on identifying systemic barriers, harmful attitudes and social exclusion practices (Bricout et al., 2004).

While there have been several applications of Ecological Systems Theory in this area of study, it was deemed appropriate to utilise the generic Ecological Systems Theory by Bronfenbrenner (1979, 2001). Thus, all insights specific to mealtimes, eating behaviours, and disability can still be incorporated within the original framework whilst remaining open to capturing other systemic influences experienced by YP with TS (e.g., the influence of tics and social stigma on dining out experiences).

The application of Ecological Systems Theory to ‘feeding problems’ has shifted how the eating behaviour field conceptualises YP’s eating behaviours. What was previously considered a ‘young person problem’ is now perceived more broadly in a way that appreciates eating behaviours within a social context and the role that caregivers and the social environment play in the development and maintenance of certain eating behaviours (Black, 1999). This paradigm shifts towards a relational way of exploring YP’s behaviours and paved the way for the Dialectical Model of Feeding Interactions.

2.1.2 Dialectical Model of Feeding Interactions

The Dialectical Model is a more common yet narrower way of understanding a young person’s eating behaviour and mealtime experiences. While Ecological Systems Theory allows for the consideration of broader systemic influences, the Dialectical Model focuses on the parent-child Microsystem related specifically to feeding interactions, thereby adding a deeper understanding of this critical interaction. Food negotiations primarily categorise the parent-child feeding dynamic (e.g., a parent and young person coming to an agreement about what and how much a young person would eat). These food negotiations are dynamic and bi-directional; both parent and young person influence one another in a reactionary cycle as they engage in constant food (re)negotiations (Ventura & Birch, 2008; Wolstenholme et al., 2020).

Walton et al. (2017) stressed how critical it was to reconceptualise selective eating in a way that appreciated the young person’s role as a co-creator of the experience, noting that interactions are the by-product of parent and a young person’s agency. This move

away from a unidirectional perspective allows for the complexity of feeding interactions to be appreciated and to understand how the interactions evolve. This dialectical approach views the parent-child relationship as a social interaction where both parent and young person engage in meaning-making with actions being perceived as cooperative or uncooperative. Parents and YP are both propositioned to have equal agency but different goals. While expressing autonomy over food choices might be a young person's goal, parents might have an opposing goal, seeking to control their child's food choices to align with what they deem appropriate. Both parents and YP influence one another and work to get the other to adapt their behaviour to fit within their *"range of appropriateness for their interaction, including the frequency and intensity of behaviours that can be tolerated"* (Walton et al., 2017, p. 4). This approach values that, in the same way, a parent might view their child's eating behaviour as problematic, a young person may also view their parent's feeding practices as problematic. The term 'parent(al) feeding practices' describes goal-oriented strategies or behaviours utilised by parents to control or modify their child's eating behaviours and dietary range. The meaning-making each party attributes to their feeding interactions influences future interactions by creating expectations for how they will engage in the feeding interaction.

Satter (1995, 2007, 2012) proposed a model for positive feeding interactions that respects the agency of both parents and YP by defining the bounds of their respective roles. Satter's Division of Responsibility in Feeding Model draws clear lines of demarcation between parents and YP. Parents are responsible for the 'what, when and where' of mealtimes and YP for deciding 'how much and whether' they eat. Satter argued that conflict arises when either party tries to take control of responsibilities

outside of their scope. While parents and YP may have different desires, they are invested in finding a mutually beneficial outcome as they are locked into an interdependent relationship (Kuczynski & Mol, 2015). Focusing on fulfilling their roles and not intruding beyond their division of responsibility allows for frictionless feeding interactions.

As it stands, no studies have previously applied or combined Ecological Systems Theory and the Dialectical Model to research mealtime experiences of YP with TS. Therefore, the application of this theoretical framework provides a unique contribution to knowledge. Ecological Systems Theory offers a holistic framework for understanding mealtime experiences, and the Dialectical Model provides a framework for understanding a fundamental family mealtime interaction. Both theories complement one another and allow us to zoom in and out of the Microsystem to gain a comprehensive understanding of how mealtimes are experienced by YP with TS and their parents and an understanding of how systemic factors shape said experiences. This theoretical framework informed methodological decisions, namely adopting a mixed-method and multi-perspective approach, and is utilised in the discussion chapter.

2.2 Philosophical Underpinnings: Pragmatism

The way that a researcher chooses to explore a phenomenon is heavily influenced by their belief surrounding the nature of reality. Crotty (1998) explained that these assertions determine research parameters, setting firm boundaries for how scientific investigations are conducted. Those who follow a more objectivist stance seek ways to measure truth empirically in a replicable, reliable, and generalisable way. In contrast, subjectivists seek to explore the meaning made through interactions, interpretations and appreciate the contextual nature of these understandings. For example, objectivism can tell us *whether* a person is alive and the mechanics of sentience. Subjectivism would tell us what it *means* and how it *feels* to be alive and sentient. Both are important, and as such, the paradigm war is not necessary; both positions have their merits and serve their purpose. While objectivism possesses the power of numbers, subjectivism captivates with stories to enrich our understanding of a phenomenon (Pluye & Hong, 2014). As such, alignment with either side and the related ontological and epistemological positions is seen to be unnecessary, with both paradigms having their merits and utility. Yardley and Bishop (2015) argue that mixed-method research has increased in popularity as it provides a “*convergence on an epistemological middle ground*” (p.2).

Pragmatic research aims to appreciate the complex, multifaced richness of human experience and not to seek an ‘objective’ truth (Yardley & Bishop, 2015). A pragmatic approach empowers researchers to utilise any tool necessary to address their research question(s) adequately. Considering the absence of self-report quantitative studies and literature which explores the mealtime experiences for YP with TS and their families, a mixed-methods design was deemed most appropriate to fill these gaps. Studies were designed to combine methodologies, where appropriate, to suit the study’s aims and

support the researcher on a journey to answering the research questions in a meaningful way.

2.3 Research Design: Mixed-Methods

Bridging the gap between the two ontological positions enriches our understanding of the phenomenon while capitalising on their strengths and minimising limitations. This doctoral study was designed with the end in mind; to contribute a solid foundation to fill the gap present within the literature. It is imperative to note that while pragmatism may allow researchers to feel unburdened by theoretical and methodological considerations, there is still an academic responsibility to have an appropriate degree of ontological, epistemological, and methodological awareness. As such, researchers should still be guided by a rigorous and epistemologically coherent design (Larkin et al., 2019).

Qualitative research requires a separate set of criteria to assess validity and reliability compared with quantitative work (Creswell & Clark, 2017). As the qualitative components of this study adopted IPA guidelines by Smith et al. (2009) (detailed later in this chapter), the assessment of quality also follows their recommendations. Smith et al. (2009) recommends using a quality criterion developed by Yardley (2000) and provides advice on applying this to IPA studies. Yardley's criteria consists of four broad principles to assess the quality of qualitative research; these are (1) sensitivity to context, (2) commitment and rigour, (3) transparency and coherence, and (4) impact and importance. One of the ways that sensitivity to context can be achieved is by familiarising oneself with the existing literature, theory and socio-cultural setting of the phenomenon (Yardley, 2000). This is demonstrated in chapter one and the introductory sections of

each empirical chapter. Smith et al. (2009) also suggests that researchers demonstrate sensitivity to context through their interviewing approach (being empathetic, putting participants at ease and facilitating rich data), analytical approach (sensitivity to the data and how participants make sense of their experiences) and writing (sensitivity to how quotes are used to give voice to participants and to present interpretations cautiously). The interview approach is demonstrated in the ethical consideration part of this chapter, while the latter two ways of demonstrating sensitivity are evidenced in the empirical chapters.

Smith et al. (2009) captured the interdependency of interpretation and phenomenology, stating that “*without the phenomenology, there would be nothing to interpret, without the hermeneutics, the phenomenon would not be seen*” (p.37). IPA findings are not objective, nor do they try to be. Claims can only be made about how the researcher understands participants’ sense-making through the information they share (Pietkiewicz & Smith, 2014). While the findings provide *an* interpretation of the data and not *the only* interpretation (Smith et al., 2009). One of the ways the researcher can evidence sensitivity is through their use of quotes, which are discussed towards the end of this chapter.

Yardley (2000) suggested that commitment is demonstrated through in-depth engagement with the research process. Smith et al. (2009) added that commitment is also demonstrated through attentiveness during data collection, analysis, and write-up, thus overlapping with the demonstration of sensitivity. Rigour relates to methodological competence, how data is collected and the scope of analysis (breadth and depth) (Yardley, 2000). Smith et al. (2009) suggested that interviewing skills (ability to capture

rich and detailed descriptions) are vital for quality IPA research and thorough and systematic analysis that is interpretative, moving beyond simple descriptions. However, without confirming that the findings are plausible to others, reliability claims remain unsubstantiated. Therefore, they cannot be said to be trustworthy (Smith et al., 2009). The supervisory team carried out 'independent audits' to corroborate interpretations, ensuring that they were plausible and credible (Smith et al., 2009). Discussions with the supervisory team supported the hermeneutic circle of questioning the data, uncovering meaning, and further questioning. Exploration based on extensive verbatim quotes allowed different ways of viewing the data to be considered and selecting the most appropriate interpretation that accurately portrayed the essence of what participants said. The supervisory team also verified the final list of common themes.

Smith et al. (2009) suggests that transparency is demonstrated in the methodological write-up of the study and that the final write-up should present a coherent argument and narrative that is nuanced and cautious. Accordingly, the Method section for each empirical chapter presents how each stage of the study unfolded, namely how participants were recruited, how data was collected, and how data was analysed. Where appropriate, reference is made to items in the appendix to evidence the process.

The final principle by Yardley (2000) was impact and importance, suggesting that real validity can only be established if the work tells the reader something interesting and valuable. The need for 'real world' importance is also a central element to a pragmatic approach. As such, the quality of the research was at the forefront of the researcher's mind alongside the acceptability of the findings to the research community (i.e., ability to publish and disseminate), clinical community (i.e., the clinical utility of research and

findings) and TS community. The integration of qualitative and quantitative methods in mixed-method studies has been used for decades in public health as *“stories have the power to change policies, and statistics traditionally provide a strong rationale to make changes”* (Pluye & Hong, 2014, p. 30). By combining the two methodologies, the impact and importance of this research is hoped to be amplified.

2.3.1 Triangulation and Mixed-Method Integration

Triangulation is a method used in research to increase the trustworthiness and validity of findings. There are distinct types of triangulation depending on what biases the researcher is trying to mitigate. The four types of triangulation are triangulation of data (e.g., time, space, and person), the investigator (i.e., interviewer, observer, researcher, or data analyst), theory, and methodology (Denzin, 2017). These are based on the belief that no one source of data, theory, investigator, or method can capture all aspects of a phenomenon. Integration is a crucial part of mixed-method research and falls under method triangulation. Researchers who conduct mixed-method research need to consider when, where, and how insights generated by various qualitative and quantitative data sources are integrated (Poeh, 2018). While some studies co-analyse results undertaking full data integration (converting one form of data into the other), others analyse results independently and only integrate interpretations (Fielding, 2012). Within this doctoral study, the mixed-method findings are woven together in the empirical discussion sections, while the findings from all studies are weaved together in the discussion chapter, using a discussion ‘point of interface’ (where the methods meet, termed by Morse and Niehaus (2009)). This enables findings to come together like pieces of a puzzle to create a fuller picture of the research topic in a way that respects

the unique contribution of each method/perspective while allowing complementary insights to layer meaning onto important findings.

By employing more than one data source, investigator, theory or method, a researcher can ‘cross-check’ findings (Denzin, 2017). For example, in this dissertation, quantitative findings can be cross-checked against qualitative findings, and one participant perspective can be cross-checked against another. While the goal of cross-checking is convergence validity (i.e., increasing confidence in findings), Brannen (2005) described four outcome possibilities for triangulation: corroboration, elaboration, complementarity, contradiction. While these possibilities were described concerning method triangulation, the categories also apply to data triangulation as accounts may produce the same results (corroboration), exemplify with particularities (elaboration), contribute towards new insights (complementarity), and diverge (contradiction).

Due to the relational and systemic nature of the phenomenon in question, it is valuable to capture the voices of multiple stakeholders, increasing the breadth of experiences captured. The benefits accrued from capturing various vantage points would be nullified by simply seeking to reduce the findings into a unified experience among all participant groups (Larkin et al., 2019). All the particularities of each participant’s experiences and perspective are worthy of exploration in their own right. Additionally, experiences are likely to be diverse as TS is a heterogenous condition featuring a range of tic presentation, tic severity and high comorbidity (Hirschtritt et al., 2015). Triangulation can add depth to the data collected or add breadth (Brannen, 2005). In the case of this doctoral study, the focus is on capturing a breadth of experiences and documenting the many ways in which TS and the other intersectionalities of participants’ lives can shape

mealtimes. Everyone is undeniably unique, and so while there might be commonalities in participants' experiences, the contexts and meaning attributed to their experiences will vary.

This dissertation aims to capture all the layers of complexities that exist and the social nuances different foodscapes and perspectives contribute to our understanding of the eating behaviours and mealtime experiences of YP with TS and their families. Triangulation was used here to increase the completeness of the *map* of the mealtime experiences of YP with TS and their families (i.e., breadth), highlighting all the *landmarks* worthy of further exploration.

2.3.2 Writing Mixed-Method Chapters

Writing a mixed-method chapter has been said to require mastery of qualitative and quantitative language, methods, and an ability to write a synchronous discussion which weaves together the findings in a comprehensible and meaningful way (James & Slater, 2014; Tashakkori & Teddlie, 2010). The qualitative and quantitative data were analysed, and findings were drafted before the researcher created an integrated write-up that appropriately merged the two. In essence, the separate write-ups served as a reference point to ensure nothing of value was lost in integrating the findings and that the combined write-up paid due respect to both methodological approaches. James and Slater (2014) explained that writers are tasked with simultaneously explaining similar yet distinct stories while supporting the reader on a journey to developing a deeper understanding of the phenomenon in question; in this spirit, chapters four (young person's perspective) and five (mothers' perspective) were written.

2.4 Qualitative Design: Interpretative Phenomenological Analysis

IPA explores the lived experiences of people and how meaningful experiences are within the context of their lives (Willig & Rogers, 2017). 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. Despite IPA having a rich phenomenological and hermeneutical history, it remains open to several epistemological positions (Larkin et al., 2006), as is the case for this research. 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 et al., 2005, p. 22). There is also an interpretative necessity to contextualise participants' experiences and make sense of their accounts (Larkin et al., 2006). To remain committed to the idiographic, IPA studies tend to have small sample sizes. This allows for rich data that maintains each account's idiosyncrasy while allowing exploration of convergences and divergences. The downside of such an approach is that the inferential range is limited (Larkin et al., 2019). Therefore, a multi-perspective approach was adopted to produce a more substantive body of work that will significantly contribute to the literature.

2.4.1 Multi-Perspective Interpretative Phenomenological Analysis

The multi-perspective approach seeks to systematically include additional perspectives while maintaining IPA's commitment to idiosyncratic depth (Larkin et al., 2019). By capturing diverse perspectives, patterns within and across cases may emerge, illuminating a deeper understanding of the phenomenon in question and the various meanings attached to lived experiences. This is particularly important for phenomena which are interactional by nature, as is the case with mealtimes. Larkin et al. (2019) described such phenomena as being located within the accounts of individuals who

belong to the same ‘lived worlds’ as the group of interest. In the case of this dissertation, while the focus is on the eating behaviours and mealtime experiences of YP with TS, mothers of YP with TS and clinical professionals who work with YP with TS are viewed as possessing perspectives that can enhance our understanding of the phenomenon. This is particularly useful for complex phenomena and allows for exploration of the “*relational, intersubjective, and microsocioal*” (Larkin et al., 2019, p. 183). Thus, this approach also aligns with the theoretical framework, taking a systemic approach.

When conducting multi-perspective research, the researcher is tasked with putting the puzzle pieces together, integrating the multiple-lived experiences to create a more comprehensive picture. Each puzzle piece is distinct yet interconnected, with insights layering meaning to develop an appreciation for the phenomenon in question. Such triangulation supports the development of more credible findings than can be achieved from a single sample study, thus allowing a greater capacity for impact.

Perspective of Young People with TS

As noted in chapter one, most research on eating behaviours and family meals are rooted in the parental perspective and reports. This project sought to capture the perceptions, experiences, and feelings of YP with TS concerning their eating behaviours and mealtime experiences. This was particularly pertinent in understanding how it felt to experience traits and characteristics, such as tics and sensory sensitivity, during mealtimes and the perceived impact of associated challenges. Additionally, YP with TS can shed light on their mealtime experiences outside of the family home, such as in school with their peers and at their friends’ houses. This is particularly important

considering the social significance of mealtimes and the role mealtimes play in maintaining and developing relationships. Capturing various mealtime experiences within different social contexts also supports an understanding of the contextual nature of mealtime challenges and which foodscapes are perceived to be most troublesome. The geography term ‘foodscapes’ refers to a food environment and is used to situate YP’s lived experiences within particular food contexts, spaces, relations and practices (Cairns, 2016). Foodscapes of interest in this study include the family food environment, school food environment, and out-of-home food environment. The ability to explore multiple foodscapes allows an appreciation for the social complexities surrounding food and varying social dynamics. The assumption is that mealtime experiences are nuanced by such contextual factors.

Perspective of Mothers of Young People with TS

Mealtime experiences are co-created by all those present as mealtimes are a social phenomenon. They are particularly shaped by the parent-child feeding interaction, an interaction that is bi-directional (Walton et al., 2017). Therefore, while the phenomenon is located within the accounts of YP with TS, it is also located within the accounts of others who share those experiences with them. Thus, the mealtime experiences of YP with TS are not exclusively situated within the accounts of YP with TS.

In most families, mothers tend to undertake most of the domestic labour, including foodwork. The term ‘foodwork’ describes the labour involved in making meals and snacks. Foodwork encompasses many forms of labour, namely: cognitive labour (e.g., meal planning), physical labour (e.g., cooking and cleaning) and emotional labour (e.g.,

the emotional toll of labour associated with foodwork and feeding) (Bove & Sobal, 2006). In addition, maternal identity is entangled with their roles as caregivers and their ability to nourish their child(ren) (Ristovski-Slijepcevic et al., 2010; Zivkovic et al., 2010). As such, mothers are central to family mealtimes, undertaking most of the foodwork and being responsible for their child's diet.

Additionally, across all three significant child developmental stages (early childhood, middle childhood, and adolescence), mothers are more likely to be present at mealtimes than fathers (McCullough et al., 2016). Even during the COVID-19 pandemic, when both parents were present within the family home, mothers spent more time than fathers doing foodwork (Carroll et al., 2020). Therefore, this dissertation included mothers of YP with TS, as opposed to fathers, to understand the primary parent-child mealtime interactions, deeming their perspective to be a valuable addition to this multi-perspective study. The theoretical framework supports an understanding of the bi-directional interaction within the mother-child Microsystem and other systemic factors that interplay to shape their mealtime experiences (e.g., societal pressures, gender roles and notions of good mothering).

Perspective of Clinical Professionals

While the mealtime experiences of YP with TS and their families are undocumented from the vantage of academic literature, there is thought to be a wealth of practice-based knowledge garnered through a comprehensive assessment of, and experience working with, YP with TS and their families (Martino & Pringsheim, 2018). A variety of clinical professionals work closely with YP with TS and their families, assessing for day-to-day life challenges. Considering that clinical professionals are an important part of the ecosystem of YP with TS and their families, their perspective was deemed to be a valuable addition to this multi-perspective study. Additionally, with professionals working with a diverse range of families, they are also well placed to act as informers and to voice the experiences of the families that they have worked alongside. Clinical professionals further broaden the scope of experiences captured within this research and frame these experiences within the context of their clinical knowledge and expertise. This information can raise awareness of potential mealtime challenges YP with TS, and their families face. Drawing attention to the clinical relevance of the eating behaviours and mealtime experiences also highlights the need for a more holistic and longitudinal care approach towards working with YP with TS and their families. While tic management is important, it is also imperative to support healthy lifestyles, quality of life and social relationships for those with chronic disorders and those who care for them (Eapen et al., 2016; Ludlow et al., 2018). By incorporating clinical professionals into this dissertation, the clinical utility and impact is amplified.

2.5 Ethical Considerations

All procedures undertaken for empirical studies within this dissertation were in accordance with ethical standards of the institutional committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Ethics approval was granted by both the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with delegated authority (see **Appendix B**) and the charity, Tourette's Action. Details on ethical issues considered throughout this PhD are described below.

2.5.1 Research with Young People: Power, Consent and Confidentiality

A review by Kirk (2007) noted three ethical issues researchers should consider when conducting research with YP, these were: power relations, informed consent, and confidentiality. While these ethical issues are also relevant to research conducted with adults, Kirk (2007) suggested that the way they are managed may differ due to crucial differences in how YP conceptualise the world, communicate, and the increased unequal power dynamic between an adult researcher and young participant. As YP within this doctoral study were recruited through gatekeepers which required parental consent, the power dynamic between both the researcher and young person and the young person and their gatekeeper (teacher and/or parent) had to be considered.

Gatekeepers were informed that YP had the right to decide whether or not they wished to participate in the study and that they had the right to withdraw at any time without needing to provide a reason. Gatekeepers were also informed that YP should not face any consequences as a result of their choices. This was particularly pertinent for the

school-based study (chapter three) where teachers supported data collection; both teachers and students needed to know that the usual rules which applied to classwork did not apply to participation in the study, as completion of the questionnaires was voluntary (Demkowicz et al., 2020). Despite this being explicitly stated, some students may have felt pressured to complete the questionnaire (Heath et al., 2007). To counterbalance this, students were informed that they had the right to decide whether or not to hand their questionnaires to the researcher at the end of the class. Those who did were consenting to be included in the study, while those who did not were withdrawing their consent.

In the case of interviews, parents were also informed that YP would be interviewed alone. However, should the young person wish someone else to be present during their interview, this would be permitted. If parents were present during the start of an interview, YP were asked whether they wished for their parents to stay or to speak in private. In most instances, YP preferred their parent to stay despite being aware that this would compromise confidentiality.

At the beginning of interviews, YP were verbally reminded of key information, including the project aims, the nature of participation, and their rights, mainly that participation was entirely voluntary. It was recognised that YP might feel uncomfortable enacting their right to skip a question or end the interview without reason due to the power differential between them and the adult researcher (Punch, 2002). Therefore, the researcher searched for visual and verbal cues that may indicate that a young person felt uncomfortable answering a question or wished to terminate the interview (e.g., body language which showed they were becoming tired or a change in speech that suggested

they were uncomfortable with the questions being asked). In these instances, the researcher would remind the young person of their rights and ask a close-ended question to see whether they wanted to move onto the next question or end the interview (e.g., you do not have to answer any questions that you do not feel comfortable answering, would you prefer us to move on to next question?).

Regarding informed consent, the researcher ensured that the language was age-appropriate when describing the study, what participation required and YP's rights (Kirk, 2007). In addition, all documents shared with YP (i.e., information sheet, consent forms, questionnaire, debrief) were reviewed by two high-school-aged YP to check comprehension. Participants were also allowed to ask questions before participating and seek further clarification if needed (Demkowicz et al., 2020).

In addition to seeking written consent from YP, consent was also sought from parents and schools (Heath et al., 2007). Parents were required to provide written consent for interviews with YP, whereas, for the questionnaire-based studies an opt-out process was adopted. The online studies involved a retrospective opt-out where parents could request their child's data be removed from the study. The school-based study also included a prospective opt-out where parents could also request their child not participate in the research. None of the parents opted their child out of the study. Beyond an opt-out option, written parental consent was not sought for quantitative studies in most cases. The only exception related to one participating school with a policy that mandated written parental consent before participation. Schools also provided written consent prior to participation.

YP were informed of the bounds of confidentiality and steps that were taken to protect their data. It was considered important that YP were aware that their data would not be shared with their schools, teachers or parents (Demkowicz et al., 2020). Limitations to confidentiality were also clearly expressed in the information sheet, ensuring that YP were aware that any information disclosed which suggested they may be at risk would need to be shared with the relevant authorities to ensure their safety (Kirk, 2007). The procedure for participation is detailed in the Methods section for each empirical chapter.

2.5.2 Participant and Patient Confidentiality and Anonymity

An ethical challenge that could have arisen during the exploration of family life was the disclosure of sensitive information about the family unit or individual family members, with the potential that this could pose a safeguarding risk (Kirk, 2007). As previously stated, participants were informed of the bounds of confidentiality before participation. No information was shared which required confidentiality to be broken for safeguarding purposes.

While confidentiality did not need to be breached due to safeguarding concerns, other considerations had to occur regarding unintentional ways that confidentiality may be breached. For example, one of these dilemmas related to the location of participation. The school study took place within classrooms where students may have been able to see each other's responses (Demkowicz et al., 2020). Interviews took place either online or in participant's homes. For online interviews, the researcher ensured that they were in a private setting and used headphones so participants could not be overheard. Participants were also advised to find a private setting. However, this was not always

possible due to their housing arrangements (Kirk, 2007). This was particularly true for participants who took part during the COVID-19 pandemic, as there were more people in the household throughout the day. Participants were aware that those around them could overhear the interview and were advised to keep this in mind when answering questions.

Qualitative researchers also need to be aware of the risk of inadvertently breaching confidentiality by providing rich descriptions of participants and their accounts. Researchers are tasked with balancing the requirement for rich accounts with their responsibility to protect participants' identities (Kaiser, 2009; Wiles et al., 2008). The same is true for clinical professionals who participated in this doctoral study, as they also need to uphold client confidentiality and ensure that they protect the identities of their clients (NHS England, 2019). Clinical professionals were acutely aware of their responsibility and only shared information necessary to convey the points they were trying to make. Participants' names, locations, and other identifying information were not disclosed.

Any identifiable information shared by participants about themselves or others were anonymised in transcripts and removed from databases. Confidentiality was ensured through the data management and security procedures outlined towards the end of this chapter. Another additional threat to confidentiality was internal anonymity. Study participants are likely to recognise their quotes and, therefore, link the quotes from their pseudonym to that of the other participant from their dyad (Larkin et al., 2019). Two practices were adopted to minimise harm to participants that may be caused by reading quotes from their mother/child. Firstly, participants were able to redact comments from

their transcript before analysis (after receiving their transcript). Only two participants (a young person and a mother, not a dyad) requested redactions; neither were related to the research topic, so redactions did not impact data analysis. Additionally, the researcher considered the risk to participants when reporting their experiences and sharing information that could be perceived as sensitive to the dyad; the pros and cons of using pseudonyms and quotes to highlight idiographic details were carefully considered.

2.5.3 Psychological Considerations

While mealtimes might seem innocuous, participants may have experienced mealtime challenges that could be emotionally charged and lead to distress upon reflection. Eating behaviours may also be a sensitive topic, especially in disordered eating or eating behaviours which result in mealtime conflict. More generally, distress may also rise from discussion surrounding diagnoses and associated challenges. Participants were made aware of the types of questions they would be asked during the interview and were reminded of their rights. This included the right not to answer questions, not elaborate more fully if they did not feel comfortable; to take a break if and when needed; withhold or retract sensitive information and terminate the interview without explanation. Participants were treated with empathy and compassion by the researcher and were also reminded of the aforementioned at times where distress was visible. At the end of the interview, all participants were provided with a debrief sheet that included relevant resources and advised to seek appropriate support if needed. An additional psychological consideration related to the emotional labour involved in interviewing participants about their lives and the challenges they face. For instance, care was taken

to schedule ample time in-between interviews for self-care and reflection by the researcher.

2.5.4 Lone Working and Safety Considerations

As some of the data collection occurred offsite (e.g., in participants' homes and schools), safety measures needed to be put in place to protect the researcher. Therefore, the University's Centre for Research in Public Health and Community Care Lone Working Policy for Researchers was followed. The process included undertaking a risk assessment, completing a proforma (visit log), sharing the proforma with the nominated supervisor, and notifying them before and after the home visit.

2.5.5 Transcription and Tics

Unique to this research, an ethical dilemma arose during transcription of whether vocal tics should be transcribed. To avoid erasing the identity of participants and to respect their ability to determine how they wished to be represented, participants with vocal tics were asked whether they wanted their tics to be transcribed. Tics are signified in quotes and transcripts using the following brackets "<>". Additionally, participants were able to specify if there were particular vocal tics they wanted to be redacted. This was particularly important for those who have coprolalia (the involuntary use of obscene language). The researcher consulted a peer with lived experience and a Neurodiversity Consultant to ensure that research practices were respectful towards the TS community and sensitive to their needs.

2.5.6 Writing Qualitative Findings and use of Quotes

The final ethical dilemma relates to how the researcher integrates quotes into their writing. The researcher must be fair in selecting quotes to ensure that all participants' voices are equally valued and appropriately shared. A barrier to this could be the temptation to use provocative yet unrepresentative quotes or the overreliance on quotes from a select number of eloquent participants. To select quotes ethically, Lingard (2019) suggests that the following principles of authenticity should guide researchers:

1. Quotes should be illustrative of the point the writer is making about the data.
2. Quotes should be reasonably succinct whilst also remaining faithful to the participant's intended meaning.
3. Quotes should represent patterns in the data, thus remaining faithful to the overall sentiment of many of the participants the quote is used to represent.

During the writing and editing process, these three principles were considered to ensure that the final draft, fairly and authentically, illuminated participants' voices. In addition to the selection of quotes, Lingard (2019) also suggested that where necessary, quotes may be lightly edited for grammatical errors (e.g., correcting errors that may occur when speech is transformed into text) as not to do a disservice to participants (e.g., to avoid representing them as inarticulate). However, no edits were made that changed the meaning, only the readability, namely through re-punctuations and consistency of tenses (Corden & Sainsbury, 2006). This was seen as particularly important as a few participants responded to their transcript by commenting negatively on their articulation. While participants were informed that speech rarely translates into text without some grammatical 'errors' (due to different grammatical conventions for speech), it was still deemed important to ease any discomfort that may arise when

reading publications that use their quotes as participants may be able to identify themselves through their quotes despite the use of pseudonyms.

2.6 Data Protection

A robust data protection plan was put in place to ensure that participants' data was handled with care and practices were in line with the UK General Data Protection Regulation. The following measures were undertaken to ensure adequate data protection:

- Explicit consent was given for all the data that was stored. No data was kept that was not relevant to the study.
- Only the approved research team had access to the data collected.
- Research data was anonymised prior to storage. Transcripts and questionnaire responses were saved using a participant identification number or a pseudonym to protect their identities. These were saved and stored separately from their consent forms.
- All hard copies of data, including consent forms, were stored in a locked filing cabinet that only the research team has access to. In addition, an electronic copy of hard data was created to preserve data in the event of a fire or other circumstance where data may be destroyed.
- All electronic data was stored in a password-protected environment and within a password-protected file (different password for an added layer of security) on the University's OneDrive. A backup was also saved on the researcher's encrypted MacBook Pro to minimise loss of data.

- Where data needed to be reviewed by the research team, this was accessed via the secure university file-sharing system. Data files, such as SPSS or NVIVO databases, were not shared via email with the supervisory team.
- Copies of transcripts and other personal information collected by the researcher about the participant were shared with participants via email for ease of access. However, these documents were password protected and encrypted for security purposes. Each password was unique to the participant and was not explicitly written in the email.
- Data will be stored for up to 5 years after completing the PhD, after which it will be destroyed under secure conditions.

2.7 Chapter Summary

The philosophical foundation for this dissertation was pragmatism. The aim was to design studies that meaningfully answered the research questions. As such, a mixed-method approach utilising both quantitative and qualitative methods was deemed most appropriate. The qualitative aspect of this research adopted a multi-perspective IPA design. Specifics relating to data collection and analysis are detailed in the Methods section of the following chapters. The next chapter presents the first empirical study for this doctoral study which quantitatively explored the eating behaviours and mealtime environments of typically developing YP from three English Secondary Schools.

Chapter Three: Selective Eating and Positive Mealtime Attributes in Typically Developing Young People

3.1 Introduction

Selective eating is characterised by pronounced preferences and dislikes, often rooted in the sensory characteristics of food (e.g., taste, smell, colour and texture). As mentioned in chapter one, there are other terminologies used within the literature which refer to similar eating behaviours, such as ‘food selectivity’, ‘eating problems’, ‘problematic eating’, ‘restrictive eating’, ‘picky eating’, and ‘fussy eating’. The distinction between terms is contested. Nonetheless, they are all perceived to overlap exploring similar eating phenomena, all falling within the aforementioned definition of selective eating. Studies addressing the prevalence of selective eating during early childhood have reported conflicting results, in part due to inconsistent terminology, definitions, assessments, and varying sample characteristics (Callie L. Brown et al., 2016; Jacobi et al., 2008; Taylor et al., 2015; Wolstenholme et al., 2020).

Selective eating is considered a relatively common phenomenon during early childhood, with a prevalence between 6 to 60% (Callie L. Brown et al., 2016; Taylor et al., 2015). However, a population study by Cardona Cano et al. (2015) found that almost a third of early-onset selective eaters remitted within three years, leading to them calling selective eating a ‘transient behaviour’ that is part of normal child development. Furthermore, despite a peak prevalence around the age of three years, studies have

reported the stability of selective eating, noting the persistence of selective eating from early childhood into adolescence and adulthood (Mascola et al., 2010; Taylor et al., 2019; Van Tine et al., 2017). In contrast to selective eating, neophobia, a reluctance to try novel foods, has been more consistently defined and measured within the literature, with a prevalence rate of 40 to 60% (Callie L. Brown et al., 2016) and has also been found to persist into adulthood.

Across the lifespan, selective eating (which can sometimes also include neophobia) has been consistently associated with poor psychosocial outcomes (Ellis et al., 2018; Zucker et al., 2015); adverse effects on general health and wellbeing (Jacobi et al., 2008); risk of being overweight or underweight (Callie L. Brown et al., 2016); and nutritional deficiencies due to reduced fruit and vegetable consumption (Taylor et al., 2015).

It is unclear why some individuals do or do not exhibit selective eating and/or why some continue to experience persistent selective eating outside of the normative developmental period. Research has explored both parent and child factors that influence the development and maintenance of selective eating. Parental factors thought to inform selective eating include controlling feeding practices, such as using pressure to eat (Moroshko & Brenman, 2013; Powell et al., 2011), breastfeeding duration (Shim et al., 2011), maternal dietary variety (Galloway et al., 2003), maternal ethnicity and low parental income (Cardona Cano et al., 2015). Child-related factors found to predict selective eating include sex, birth weight (Cardona Cano et al., 2015), temperament (Kidwell et al., 2018), anxiety, rigidity and sensory sensitivity (Zickgraf & Elkins, 2018; Zickgraf et al., 2020).

To date, much of the research has primarily focused on the link between sensory properties and selective eating. For example, there is a strong evidence base demonstrating the relationship between selective eating and sensory sensitivity (e.g., Farrow & Coulthard, 2012; Zickgraf & Elkins, 2018). In addition, research suggests that typically developing YP and adults with severe forms of selective eating often present at eating disorder clinics for treatment (Zickgraf et al., 2019). Thus, the current consensus is that there is a continuum from subclinical selective eating to more severe manifestations such as feeding and eating disorders (e.g., Avoidant/Restrictive Food Intake Disorder, ARFID), with sensory sensitivity being a transdiagnostic process (i.e., a mechanism which is present across disorders as a risk or maintaining factor) (Dovey et al., 2019; Galiana-Simal et al., 2017).

The term ‘sensory sensitivity’ refers to awareness and tolerance of sensory input (sight, sound, taste, smell, touch and pain). Sensory sensitivity can be an obstacle to engaging in many everyday tasks and activities such as bathing, dressing and feeding (Bagby et al., 2012). Dunn (1997) created a conceptual model to explain how sensory processing abilities impact the lives of YP and their families. A key contribution of this model was an explanation of the relationship between neurological thresholds and behaviour. The model posits that behaviours provide an indication of internal thresholds. For example, a person who is sensitive/reactive to stimuli demonstrates a low threshold (i.e., sensitive to stimuli) and acts in accordance with their threshold (i.e., reactive to stimuli). Additionally, this person may also respond in a way to counteract their threshold by avoiding triggers. This can explain why people with higher taste, smell, and touch sensitivity have been shown to be neophobic and eat fewer fruits and vegetables (Coulthard & Blissett, 2009; Farrow & Coulthard, 2012).

Dunn (2007) suggested that by understanding sensory processing, professionals and parents can understand and interpret behaviours to support them to work with their patient or child's sensory needs and not against them. This model is widely accepted and partially explains selective eating; sensory sensitivity accounts for 15% of the variance in selective eating and neophobia (Zickgraf & Elkins, 2018). People with lower sensory thresholds and heightened sensory awareness may avoid foods with sensory properties they find troublesome (e.g., strong flavours), thus present behaviourally as selective eaters.

Anxiety has also been noted to play a role in the relationship between sensory sensitivity and selective eating. Farrow and Coulthard (2012) undertook the first study to explore whether selective eating was associated with anxiety and sensory sensitivity. The measures they used included the short Sensory Profile (Dunn, 1999), Spence Children's Anxiety Scale for Parents (Spence, 1998) and Child Eating Behaviour Questionnaire (Wardle et al., 2001). Based on parental reports, they found that anxiety and sensory sensitivity were both related to selective eating in children (aged 5 to 10 years). More importantly, they found that sensory sensitivity fully mediated the relationship between anxiety and selective eating. Thus, greater sensory sensitivity explained higher rates of selective eating in children with anxiety.

Zickgraf and Elkins (2018) replicated their study with a clinical sample of YP (aged 8 to 18 years) and adults (aged 18 to 22 years) using the following parent-report measures: Multidimensional Anxiety Scale for Children 2 (March et al., 1997), Sensory Over-responsivity Scales (Schoen et al., 2008), and the Nine Item Avoidant/Restrictive Food Intake Disorder Screen (Zickgraf & Ellis, 2018). The adult self-report measures used

were the Sensory Over-responsivity Scales (Schoen et al., 2008), Anxiety subscale for the short form Depression Anxiety and Stress Scale (Henry & Crawford, 2005), and Food Neophobia Scale (Pliner & Hobden, 1992). Sensory sensitivity was also found to mediate the relationship between selective eating and anxiety for YP and neophobia and anxiety for adults. While their sample of YP were receiving treatment for anxiety or OCD, the relationship between sensory sensitivity and selective eating was independent of anxiety and was also found in their non-clinical adult sample. A key limitation of both these studies is their reliance on parental reports. Parents answer questionnaires based on observations of their child's behaviours and inferences that they make about what they see and not on their child's actual experience. Anxiety and sensory sensitivity relate to inner experiences; as such, YP are believed to be best placed to report on their levels of anxiety and sensory sensitivity.

As studies have been primarily rooted in parental reports, this study aimed to add to the literature base by investigating whether the relationship between anxiety, sensory sensitivity and selective eating can be found when utilising self-report with a sample of YP aged 11 to 16 years. Self-report is considered important for three reasons, firstly because eating behaviour research relies on parental reports, which are less accurate for YP aged 11 to 16 years who begin to engage in more food activities outside of the home, thus making it harder for their parents to report their food preferences accurately and eating behaviours (Bartholdy et al., 2017; Elkins & Zickgraf, 2018). Secondly, parent-child agreement on anxiety has been found to be low, with parents reporting fewer severe symptoms than children and being less accurate than children when compared to an interview assessment (Cosi et al., 2010). Thirdly, it is unknown whether parent-

child agreement on sensory sensitivity is also low. Nevertheless, utilising self-report for this measure is also deemed to be important.

This research also contributes towards an understudied age group in eating behaviour research (Zickgraf et al., 2020). While the presentation of selective eating might be characteristically similar across the lifespan, inevitably, there will be developmental differences as children gain increased autonomy and independence. According to research, selective eating during adolescence is less prevalent, falling outside of the normative period where it is usually evident (Cardona Cano et al., 2015). As such, selective eaters within this age range are likely to be persistent selective eaters who warrant the attention of clinicians due to their increased risk of underlying or subsequent disorders (Dovey et al., 2019).

This research also contributes to the eating behaviour literature by including two additional measures, one to capture specific sensory-based eating behaviours and another to measure the family mealtime environment. The recently developed Sensory Eating Problem Scale (Seiverling et al., 2019) allows for a more detailed assessment of specific sensory eating behaviours than can be captured by other available measures. This measure was initially developed as a parent-report measure for use with clinical samples recruited from a feeding clinic (ASD, other additional needs and no additional needs). Therefore, this would be the first study to employ the measure with typically developing YP from the community, relying on self-report. Additionally, this study sought to explore whether anxiety, sensory sensitivity and eating behaviours are related to the family mealtime environment. Skeer et al. (2017) stressed the importance of moving beyond family meal frequency and the necessity to understand different

dimensions of family mealtimes. They created the Family Dinner Index based on interviews with YP (age 6 to 17 years) and their parents (predominantly mothers, 91.2%). Several items were taken from their larger questionnaire to create a brief measure for positive mealtime attributes.

This study aimed to explore whether sensory sensitivity and anxiety are related to selective eating in typically developing YP based on self-report. Additionally, this study sought to investigate the relationship between anxiety, sensory sensitivity, sensory-based eating behaviours and positive mealtime attributes. It was expected that fewer YP would be identified as selective eaters compared to younger children. However, based on previous research, it was hypothesised that there would be a significant relationship between selective eating, sensory sensitivity and anxiety. Specifically, that greater levels of sensory sensitivity and anxiety being related to greater levels of selective eating. Additionally, sensory eating behaviours were anticipated to be positively correlated with sensory sensitivity, taste reactivity and selective eating. Finally, it was also hypothesised that positive mealtime attributes would significantly correlate with eating behaviours (selective eating and sensory eating behaviours), sensory sensitivity, taste reactivity and anxiety.

3.2 Method

3.2.1 Participants

YP aged 11-16 (n=188) were recruited from three secondary schools based in Northern England and London. Participants were asked to self-disclose if they had any neurodevelopmental diagnoses. Those who disclosed other diagnoses such as mental health conditions (e.g., anxiety), dyslexia or health conditions (a thyroid condition and

seizures) were included in the study as they were still deemed typically developing. Seven participants were excluded from the study as they disclosed neurodevelopmental diagnoses (ADHD and ASD). The remaining sample consisted of 181 YP who were considered typically developing. Additionally, a further three students were excluded because their data were incomplete (i.e., they completed less than 50% of the questionnaires). Data from the remaining 178 YP were included in the analysis.

Results in Table 1 show that participants' age ranged between 11-15 years ($M = 12.84$, $SD = 1.13$), a majority were female (53.4%) and considered themselves white (69.9%). Participants were also asked for their weight. Less than a third of YP ($n=58$) knew their weight. Of those that did, their reported weights ranged between 30kg and 90kg ($M=51.02$, $SD = 11.37$).

Table 1. Demographic and mealtime characteristics

n=178	
Gender¹	
Male	78 (44.3%)
Female	94 (53.4%)
Other	4 (2.3%)
Age¹	
Mean (SD)	12.84 (1.13)
Range	11-15 years

Ethnicity¹	
White	123 (69.9)
Black	17 (9.6%)
Mixed Ethnicity	20 (11.4 %)
Asian	10 (5.7%)
Arab	6 (3.4%)
NOTES	
1. (n=176), 2 missing	

3.2.2 Procedure

Participating schools signed a consent form before participation (see **Appendix C**) and randomly selected one or two classes from each year group, where possible, to take part in the study. Due to exam preparation, no year 11 classes were available to participate. Parents/guardians of students in the selected classes were informed of the research by the school up to two weeks before the study (see **Appendix D**). This allowed parents/guardians an opportunity to opt their child out of the study (see **Appendix E**). Participating students were also given a debrief to share with their parents/guardians, which allowed them to retrospectively opt-out their children from the study (see **Appendix F**). No parents/guardians requested that their child's data was removed from the dataset. Data for this study were collected in July 2019 (before the COVID-19 pandemic).

Each student was given a pack containing an information sheet (see **Appendix G**), consent form (see **Appendix H**), questionnaire (see **Appendix I** for non-standardised questions) and debrief (see **Appendix F**). The information sheet was read to the class

by the researcher, and any questions were answered before consent forms were signed. Students who wished to participate in the study returned their questionnaire and consent form to the researcher at the end of class. Those who did not wish to participate were allowed to undertake other schoolwork during the session or complete the questionnaire but not hand it to the researcher at the end of class. Fewer than 5 of the students from all three schools decided not to participate.

3.2.3 Measures

Participants were asked to complete demographic questions and five self-report questionnaires concerning sensory processing, anxiety, eating behaviours and their family mealtime environment. Demographic information captured included ages, gender, height, weight, ethnicity, diagnosis history, and family evening meal frequency and duration. Detail relating to the self-report questionnaires used are listed below.

Adult/Adolescent Sensory Profile (AASP) (Brown & Dunn, 2002)

The AASP is a 60-item self-report questionnaire which assesses sensory processing patterns in daily life across six modalities. The AASP is scored based on Dunn's (1997) model with four quadrants related to neurological threshold (high vs low) and behavioural response (passive vs active). The 'Sensory Sensitivity' 15-item subscale was used in this study to assess self-reported low neurological threshold and passive behaviour (e.g., *"I am distracted if there is a lot of noise around"*). Participants responded to items using a 5-point Likert scale from 1 to 5 (1 = almost never, 2 = seldom, 3 = occasionally, 4 = frequently and 5 = almost always). Items from the score are summed, with higher scores indicating that the participant displayed higher levels of

sensory sensitivity, unlike the Sensory Profile (Dunn, 1999) where lower scores indicate higher sensory impairment. The scale has been validated for people aged 11 years and older in diverse clinical and community samples. Reliability statistics for the AASP quadrants ranged between .64 and .78 (Brown & Dunn, 2002). In this study, the Cronbach's alpha for sensory sensitivity was good ($\alpha = .78$).

To measure Taste Reactivity, four items from the Taste/Smell and Touch modalities of the AASP were used in accordance with Avery et al. (2018); items 2, 5, 7, and 34, with item 2 reverse scored. These items assess neophobia and reactivity to strong tastes and textures (Avery et al., 2018). Unfortunately, there were no reliability statistics for Taste Reactivity published that can be used to compare with this study. However, it is important to note that the Cronbach's alpha for the current study was unacceptable ($\alpha = .43$).

Screen for Child Anxiety Related Emotional Disorders-Child (SCARED-C)
(Birmaher et al., 1999)

The SCARED-C is a 41-item self-report questionnaire which assesses anxiety-related symptoms across five domains: Panic Disorder or Significant Somatic Symptoms (e.g., *"When I get frightened, I feel like throwing up"*); Generalized Anxiety Disorder (e.g., *"I worry about being as good as other kids"*); Separation Anxiety (e.g., *"I have nightmares about something bad happening to my parents"*); Social Anxiety (e.g., *"It is hard for me to talk with people I don't know well"*); and Significant School Avoidance (e.g., *"I get stomach aches at school"*). Participants were advised to consider the past three months and how true the statements were for them using a 3-point Likert Scale from 0 to 2 (0 = not true or hardly ever true, 1 = somewhat true or sometimes true, 2 =

very true or often true). The total score across all subscales was used to assess anxiety levels, with higher scores indicating higher levels of anxiety. Scores above 25 are considered diagnostic of an anxiety disorder. The scale has been validated for use with YP age 8 to 18 years in diverse clinical and community samples. Reliability statistics for SCARED-C domains ranged from .78 to .87 (Birmaher et al., 1999). In this study, the Cronbach's alphas was excellent ($\alpha = .95$).

Adult Eating Behaviour Questionnaire (AEBQ) (Hunot et al., 2016)

The AEBQ is a 35-item self-report questionnaire which assesses eating behaviours across eight subscales. The AEBQ was originally designed for use in adult populations but was recently validated for use with adolescents aged 11 to 18 years (Hunot-Alexander et al., 2019). The 'Food Fussiness' subscale from the AEBQ was used in this study to assess self-reported perceptions of selective eating. This 5-item subscale assesses refusal of new and unfamiliar foods, food neophobia (e.g., *"I refuse new foods at first"*) and limited diet variety, picky eating (e.g., *"I enjoy a wide variety of foods"* reverse scored). Participants responded to items using a 5-point-Likert scale ranging from 1 to 5 (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree). Some items were reverse scored before calculating the mean selective eating score. Higher scores indicate higher levels of selective eating. To determine whether a participant was a selective eater or not, their mean score for the food fussiness scale needed to be above 4, suggesting that their average response to items on the scale were agree or strongly agree. The selective eating subscale was internally valid with YP ($\alpha = .78$) in Hunot-Alexander et al. (2019). In this study, the Cronbach's alpha for selective eating was good ($\alpha = .80$).

Positive Mealtime Attribute Scale - Child, PMAS-C (Items currently unpublished, extracted from the development of the Family Dinner Index (FDI), see Skeer et al., 2017)

The PMAS-C is a 5-item self-report measure which assesses positive mealtime attributes associated with family mealtimes based on a recently developed unpublished self-report questionnaire with YP. The development of the measure was informed by interviews with American YP aged 6 to 16 years and their parents. They asked about family mealtimes and their context, namely: family meals, parent-child relationship and family practices (Skeer et al., 2017). The larger survey for YP included 12-items related to various mealtime attributes. Based on three major themes identified in the qualitative study by Skeer et al. (2017) (feelings about family meals, use of technology and communication) and literature (e.g., Dallacker et al., 2019) the following items were assessed: Expectations (*“How often are you supposed to be at dinners with your family?”*), Togetherness (*“During a typical week in the school year, how much do you like being with your parents/guardian during family dinners?”*); Enjoyment (*“How much do you think your parent(s) enjoy family dinners in general [note: this does not include the food that is served]?”*); Communication (*“In general, how much do people talk to each other during family dinners?”*); and Digital Distractions (*“How often are people allowed to talk, send messages, or watch something during family dinners using personal devices [for example, phones]?”*). Participants responded to items using a 6-point Likert scale from 0 to 5 (0 = n/a, 1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = always). The Digital Distractions item was reverse coded before the total score was calculated and was included to assess a mealtime attribute that detracts from the commensality of mealtimes (e.g., Spence, Mancini & Huisman, 2019) and has been associated with negative child outcomes (e.g., Berge et al., 2014). To aid interpretation, Dr Skeer

advised to rescale between 0 and 100, then median split at 70. Scores above 70 represented higher positive mealtime attributes and a warmer mealtime environment, while scores under 70 represented lower positive attributes. As an unpublished measure, there are no reliability statistics for comparison. In this study, the Cronbach's alpha for the PMAS-C was acceptable ($\alpha = .76$).

Modified Sensory Eating Problem Scale (M-SEPS) (Seiverling et al., 2019)

The SEPS is a recently published 22-item parent-report questionnaire which examines specific sensory eating problems, allowing for more detailed measurement of sensory eating problems than existing measures, such as Dunn's sensory profiles which explore sensory challenges across many domains (Seiverling et al., 2019). The present study modified the measure by rewording items to allow for self-report (e.g., "*My child has a sensitive gag reflex*" was changed to "*I have a sensitive gag reflex*"). The measure assesses six sensory eating problems: Food-Touch Aversion (e.g., "*I have a clear dislike for food touching my lips*"), Single-Food Focus (e.g., "*I accept only one flavour of a certain type of food [e.g., strawberry yogurt]*"), Gagging (e.g., "*I gag when food touches my tongue*"), Temperature Sensitivity (e.g., "*I will only eat foods that are warm*"), Expulsion (e.g., "*I use my fingers to take food out of my mouth*"), and Overstuffing (e.g., "*I attempt to swallow bites of food without chewing*"). Participants responded to items using a 5-point Likert scale from 0 to 4 (0 = never, 1 = rarely, 2 = sometimes, 3 = often and 4 = always). The modified version was piloted with two girls age 13 and 15 for comprehension. One further modification was made to make the measure more acceptable to the target age-range, which was to include a definition of 'expel' for question 10 (e.g., "*My child expels food or liquid*" in the original scale was changed to "*I expel [definition: to force something out of the body] food or liquid*"). Each subscale was summed to create a

score. Higher scores indicated that the participant displayed higher levels of the attribute. As this study modified the measure, there are no reliability statistics for self-report that can be used for comparison to this study. Nevertheless, reliability statistics for the SEPS subscales when used with parents ranged between .70 and .85 (Seiverling et al., 2019). In this study, the modified self-report version scores varied from unacceptable to good, ($\alpha = .43$ to $.75$), see Table 3.

3.2.4 Handling Missing Data

Data collected across all measures had low levels of missing values (<6.15%). A Little's Missing Completely At Random (MCAR) was not significant for all but one measure ($p > .05$, see **Appendix J**), indicating that data were missing completely at random. Therefore, Pearson mean imputation at item-level was deemed an appropriate way to manage low levels of missing data (Eekhout, 2015). In person mean imputation, the mean score of the available items for the participant is calculated, and each missing item score is imputed with the mean score. For example, if participant 54 has a mean score of 3, then their missing item is substituted with their mean, in this case, 3. The one measure that had a significant MCAR was the AEBQ measure ($p = .001$) which indicated data was not missing at random. However, less than 1% of values were missing for this measure, therefore mean imputation at item-level was still deemed appropriate.

3.2.5 Analysis

All analyses were computed using the Statistical Package for the Social Sciences (SPSS) version 26. The assumption of normality was violated for most measures based either on kurtosis, skewness or Shapiro-Wilk (see **Appendix K**). The AASP subscales were

deemed to be normally distribution. Nevertheless, correlation analysis utilised non-parametric tests (Spearman's correlation) as other variables were not normally distributed.

Two-tailed Spearman's correlations allowed for the strength and direction of associations between two variables to be assessed. Data was analysed to establish whether age, weight² or gender were related to the two main factors of interest. Two-tailed Spearman's correlations indicated that selective eating was not significantly associated with age $r(174)=.04$, $p = .56$, weight $r(56) = -.16$, $p = .24$, or gender $r(174) = .05$, $p = .55$. Similarly, positive mealtime attributes were not significantly associated with age $r(174) = -.12$, $p = .12$, weight $r(56) = -.24$, $p = .07$, or gender $r(174) = .06$, $p = .42$. Therefore, these characteristics were not controlled for in analyses.

3.3 Results

3.3.1 Descriptive Results

As detailed in Table 2, participants most reported to having 4 or more family dinners (evening meal) a week, with mealtimes often lasting 30 minutes or less.

Table 2. Family evening meal frequency and duration

n=178

Family Evening Meal Frequency (per week)¹

² Weight was used instead of BMI-SDS (Body Mass Index Standard Deviation Scores) for YP as results were beyond the norm of -1 to 1, with most within the 3 to 5 range. Therefore, no inferences can be made about the weight classification of YP (e.g., underweight, 'normal' weight, overweight or obese), only their weight in relation to one another (not accounting for height).

0	23 (13%)
1	12 (6.8%)
2	19 (10.7%)
3	16 (9%)
4	18 (9.6%)
5	17 (7.3%)
6	13 (7.3%)
7	59 (33.3%)

Average Evening Meal Duration²

N/A	3 (1.7%)
15 minutes or less	58 (32.8%)
30 minutes	74 (41.8%)
45 minutes	29 (16.4%)
An hour or more	13 (7.3%)

NOTES

1. (n=54), 124 missing
2. (n=177), 1 missing

Means and standard deviations for the measures are presented in Table 3. Higher mean scores indicate higher levels of the attribute were reported. With a cut-off of 4, most participants were not deemed selective eaters (95.5%). The mean anxiety score in this study is above the cut-off, which suggests there may be a presence of an anxiety disorder. Positive mealtime attributes were also above the cut-off, suggesting that participants experienced high levels of positive mealtime attributes and a warm mealtime

environment. Sensory sensitivity scores fell within the normal range suggesting that sensory sensitivity was normative within this sample. However, over a third (35.9%) of YP reported sensory sensitivity levels that were more (25.8%) or much more (10.1%) than most people their age.

Table 3. Mean and standard deviations for measures

Measure	Subscale	Alpha	Mean	SD
AASP	Sensory Sensitivity	.78	36.99	9.82
AASP	Taste Reactivity	.43	10.92	3.13
AEBQ	Selective Eating	.80	2.59	.79
M-SEPS	Temperature Sensitivity	.61	1.19	.75
M- SEPS	Single-Food Focus	.51	.84	.66
M- SEPS	Food-Touch Aversion	.60	.51	.61
M- SEPS	Gagging	.55	.53	.56
M- SEPS	Expulsion	.43	.53	.57
M- SEPS	Overstuffing	.75	.84	.86
SCARED	Anxiety	.95	28.59	16.57
PMAS-C	Positive Mealtime Attributes	.76	70.74	18.93

NOTES

Higher scores indicate higher levels of the attribute for all measures

COLOUR KEY

Yellow highlight suggests that the measure is above the cut-off.

Grey highlights suggest that the measure is below the cut-off.

Purple highlights suggest that the alpha is <.60.

3.3.2 Correlations

Two-tailed Spearman’s correlations were used to explore the relationships between selective eating, anxiety, and sensory sensitivity. As indicated in Table 4, YP’s reports of selective eating were significantly correlated with greater reports of anxiety, $r(172) = .20$, $p = .01$. YP’s levels of anxiety were also significantly correlated with higher levels of sensory sensitivity, $r(167) = .57$, $p < .001$. However, selective eating and sensory sensitivity were not significantly correlated in this sample.

Table 4. Two-tailed Spearman’s correlations for selective eating, sensory sensitivity and anxiety

	Selective Eating		Anxiety	
	<i>R</i>	<i>p</i>	<i>R</i>	<i>p</i>
Sensory Sensitivity	.10	.21	.57	<.001
Anxiety	.20	.01	-	-

COLOUR KEY

Orange highlights indicate significance $p < .05$

Two-tailed Spearman’s correlations were used to explore whether sensory eating problems were related to selective eating, sensory sensitivity and taste reactivity. As indicated in Table 5, YP’s reports of selective eating were significantly correlated with greater reports of single-food focus, $r(176) = .32$, $p < .001$. YP’s report of selective eating were not significantly correlated with the other sensory eating behaviours. YP’s levels of sensory sensitivity were significantly correlated with higher levels of temperature sensitivity $r(169) = .18$, $p = .02$, single-food focus $r(170) = .40$, $p < .001$, food-touch

aversion $r(168) = .38, p < .001$, gagging $r(168) = .34, p < .001$, and expulsion $r(168) = .29, p < .001$. Sensory sensitivity was not significantly correlated with overstuffing. Levels of taste reactivity were also significantly correlated with higher levels of temperature sensitivity $r(167) = .16, p = .04$, single-food focus $r(168) = .34, p < .001$, food-touch aversion $r(166) = .20, p = .01$, and gagging $r(166) = .25, p = .001$. Taste reactivity was not significantly correlated with expulsion or overstuffing.

Table 5. Two-tailed Spearman's correlations for sensory eating problems, selective eating, sensory sensitivity and taste reactivity

	Selective Eating		Sensory Sensitivity		Taste Reactivity	
	<i>R</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Temperature Sensitivity	-.03	.66	.18	.02	.16	.04
Single-Food Focus	.32	< .001	.40	<.001	.34	<.001
Food-Touch Aversion	.09	.24	.38	<.001	.20	.01
Gagging	.11	.15	.34	<.001	.25	.001
Expulsion	.09	.22	.29	<.001	.08	.30
Overstuffing	-.01	.86	.13	.09	-.06	.46

COLOUR KEY

Orange highlights indicate significance $p < .05$

Two-tailed Spearman’s correlations were used to explore relationships between positive mealtime attributes and all factors of interest. As indicated in Table 6, YP’s reports of positive mealtime attributes were significantly correlated with lower levels of selective eating $r(176) = -.26, p < .001$, temperature sensitivity $r(175) = -.29, p < .001$, single-food focus $r(176) = -.17, p = .03$, and expulsion $r(174) = -.17, p = .02$. Positive mealtime attributes were not significantly correlated to the other factors.

Table 6. Two-tailed Spearman’s correlations for positive mealtime attributes and all other factors

	Positive Mealtime Attributes	
	<i>r</i>	<i>p</i>
Selective eating	-.26	< .001
Taste Reactivity	-.14	.07
Sensory Sensitivity	-.29	< .001
Temperature Sensitivity	-.02	.78
Single-Food Focus	-.17	.03
Food-Touch Aversion	-.13	.09
Gagging	-.12	.13
Expulsion	-.17	.02
Overstuffing	-.14	.07
Anxiety	-.07	.38

COLOUR KEY

Orange highlights indicate significance $p < .05$

3.4 Discussion

This study aims to establish whether a high proportion of YP would show selective eating and understand whether sensory sensitivity and anxiety are related to selective eating in typically developing YP based on self-report. Additionally, this study sought to investigate the relationship between anxiety, sensory sensitivity, taste reactivity, eating behaviours and positive mealtime attributes. The main findings of this study are discussed below in relation to other research and their implications for future research. To aid narrative flow, subheadings are used.

3.4.1 Selective Eating in Adolescence

It was hypothesised that relatively low proportions of YP would be identified as selective eaters compared to what would typically be found in younger children, where transient selective eating is normative. As expected, the proportion of selective eaters within this sample was low, 4.5%, lower than the early childhood prevalence rate of 6 to 60% (Callie L. Brown et al., 2016; Taylor et al., 2015). A longitudinal study by Cardona Cano et al. (2015) found that 4.2% of their sample had persistent selective eating, being classified as a selective eater during all assessment points from age 1.5 years through to 6 years. The selective eaters within the current study were considered to experience persistent selective eating as they fall outside of the normative period where selective eating is usually outgrown. This is the first study to report selective eating prevalence rates in typically developing YP aged 11 to 16 years based on self-reported eating behaviours. Future research should longitudinally explore the trajectory of selective eating during adolescence utilising self-report with larger and more ethnically diverse samples as research has suggested that maternal ethnicity can predict late-onset selective eating (Cardona Cano et al., 2015). Cardona Cano and colleagues suggest that genetics,

environmental factors, cultural influences and different parental feeding practices may factor into ethnic differences. More research is needed to clarify the relationship between maternal ethnicity and selective eating.

3.4.2 Selective Eating, Sensory Sensitivity and Anxiety

Based on previous research, the second hypothesis was that there would be significant positive correlations between selective eating, sensory sensitivity and anxiety. While YP's reports of anxiety were positively associated with sensory sensitivity and selective eating, sensory sensitivity was not associated with selective eating. YP who reported higher anxiety levels also reported higher levels of sensory sensitivity and selective eating, although this correlation was weak. However, YP who reported higher levels of sensory sensitivity did not report higher levels of selective eating. This finding was surprising and contradicted Zickgraf and Elkins (2018) and Farrow and Coulthard (2012) who found that parental reports of children's selective eating, sensory sensitivity and anxiety were all associated; in fact, sensory sensitivity was found to mediate the relationship between selective eating and anxiety. Zickgraf and Elkins (2018) found that the relationship between sensory sensitivity and selective eating was independent of anxiety, further strengthening the theory that sensory sensitivity is a precipitating factor for selective eating and anxiety is a maintaining factor. In other words, they suggested that people who experienced more sensory sensitivity were more likely to be selective eaters irrespective of whether they were anxious or not. Within this study, the notion that sensory sensitivity underlies selective eating is challenged, although the notion that anxiety is linked to sensory sensitivity and selective eating is supported. It is unclear why the same relationship between sensory sensitivity and selective eating previously found in parent report studies was not found in this self-report study.

A plausible reason for this contradictory finding may be due to differences in the perceptions and reports of YP and parents. A major contribution of this study is the use of self-report measures with a typically developing sample aged 11 to 16 years, as findings are rooted in YP's assessments of themselves and not parental observations of their children. Previous research found low parent-child agreement for anxiety (measured with the same anxiety questionnaire as used within this study), with parent report being less accurate than child report when compared to interview assessment (Cosi et al., 2010). Additionally, the same might be true for selective eating, where YP are thought to be more reliable reporters of their eating behaviours than their parents (Bartholdy et al., 2017; Elkins & Zickgraf, 2018). Whether this is the case for sensory sensitivity is unclear. However, parent report of their child's sensory sensitivity is based on parental observations. Therefore, parents may only observe more severe forms of sensory sensitivity that create a behavioural reaction. YP are thought to have a better awareness of their internal state, as with anxiety, thus are likely to respond more accurately regarding their sensory sensitivity and not simply reporting their sensory reactivity (what parents observe). Therefore, the relationship between sensory sensitivity and selective eating in parent-report studies might be inflated because both factors rely on observable behaviours. Future research should assess whether low parent-child agreement may account for the lack of relationship between sensory sensitivity and selective eating found in this sample of typically developing YP aged 11 to 16 years.

Another likely reason for this contradictory finding could be due to the use of different questionnaires. However, Farrow and Coulthard (2012) and Zickgraf and Elkins (2018) used different parent-report questionnaires and still found the same relationship. Considering that the self-report measures for selective eating, sensory sensitivity and

anxiety were all validated for use with the current study sample and had acceptable alphas, it is thought that the main difference is likely rooted in the parent/child report difference than the measure difference or poor internal reliability. This further supports the importance of this study and its use of self-report to contribute towards the eating behaviour literature. However, more research is needed to unpack the relationship between selective eating, anxiety, and sensory sensitivity during adolescence using self-report measures with clinical and non-clinical samples.

YP within this sample also demonstrated above-average anxiety levels and were mostly not selective eaters. Considering that anxiety has a median onset during adolescence (Ramsawh et al., 2011), which is after the onset of selective eating (Cardona Cano et al., 2015), it makes sense that YP with anxiety alone are not more likely to be selective eaters as selective eating would have likely been established before the onset of anxiety. Therefore, while all selective eaters may report greater anxiety levels, not all people with anxiety report greater levels of selective eating.

3.4.3 Sensory Eating Problems, Selective Eating, Sensory Sensitivity and Taste Reactivity

It was predicted that sensory eating behaviours would be correlated with sensory sensitivity, taste reactivity and selective eating. Notably, many sensory eating behaviours (temperature sensitivity, single-food focus, food-touch aversion and gagging) were associated with sensory sensitivity and taste reactivity. Taking temperature sensitivity as an example, this meant that YP who reported higher levels of temperature sensitivity also reported higher levels of sensory sensitivity and taste reactivity. Notably, single-food focus was the only sensory eating problem that was also associated with selective eating.

YP who reported higher levels of single-food focus also reported higher levels of sensory sensitivity, taste reactivity and selective eating. This finding is important as selective eating was not associated with sensory sensitivity as hypothesised based on the literature (Farrow & Coulthard, 2012; Zickgraf et al., 2020); however, single-food focus was. This suggests that it is important to disentangle the relationship between overall sensory sensitivity and selective eating to identify specific sensory challenges YP experience in an eating context and how this shapes their eating behaviours.

However, it is important to note that the Sensory Eating Problem Scale (Seiverling et al., 2019) was not originally developed for use with YP as a self-report measure, nor with community samples; it was originally developed for use with clinical populations of young children with feeding issues. More importantly, some of the Sensory Eating Problem Scales demonstrated unacceptable internal reliability; namely expulsion, single-food focus and Gagging. Cronbach's alphas for temperature sensitivity, food-touch aversion and overstuffing were all acceptable. The internal reliability for taste reactivity was also unacceptable.

Seiverling et al. (2019) found that food-touch aversion, gagging, temperature sensitivity and expulsion were more prevalent in younger children than older children. Seiverling and colleagues suggest that this finding could indicate that sensory-based eating behaviours decrease as YP become repeatedly exposed to different textures, tastes and temperatures of foods. The specificity of the Sensory Eating Problem Scale could support a more nuanced understanding of the trajectory of selective eating over the life course and the role that sensory processing plays in the development and maintenance of these different eating behaviours.

Single-food focus could be considered as a measure of selective eating, given that cognitive and behavioural rigidity was found to be a neurobehavioral predictor of selective eating, alongside sensory sensitivity (Zickgraf et al., 2020). For example, Zickgraf and colleagues have suggested that rigidity may be a transdiagnostic mechanism that may maintain selective eating. They described the manifestation of rigidity in the context of selective eating as a proclivity towards a repetitive diet, inflexible food rules, and black and white expectations concerning trying new or non-preferred food. Single-food focus is thought to capture these eating behaviours asking the following: “*I only accept one flavour of a certain type of food (e.g., strawberry yogurt)*”, “*I will only eat one food for weeks or months at a time*”, “*I will refuse entire food categories (e.g., all fruits, all vegetables)*”, and “*I avoid mixed textures of foods (e.g., spaghetti and meatballs)*” (Seiverling et al., 2019). While this study did not measure overall cognitive and behavioural rigidity, single-food focus is conceptually thought to have captured an eating behaviour characterised by rigidity. The lack of association between selective eating and sensory sensitivity and the association between single-food focus and sensory sensitivity within this sample could indicate that single-food focus may develop due to sensory sensitivity but that it becomes engrained by rigidity. As such, persistent selective eaters remain selective eaters even after sensory sensitivity attenuates over time in typically developing samples (Dovey et al., 2019). Future research should explore whether YP classified as persistent selective eaters demonstrate greater levels of rigidity and how the relationship between single-food focus, selective eating and sensory sensitivity evolves. While the findings of this study suggest that the Sensory Eating Problem Scale may be a useful measure in future research, it is important to note that some of the Cronbach’s alphas were unacceptable. Although this may result from the floor effect; a high

proportion of participants responded 'never' for many subscale items (ranging from 11.9% to 37.5%), possibly due to the specificity of sensory-based eating challenges that are uncommon in typically developing samples. Future research should seek to validate the measure for use with typically developing YP and further explore the relationship between sensory sensitivity, rigidity and persistent selective eating.

3.4.4 Positive Mealtime Attributes, Eating Behaviours, Sensory Sensitivity and Anxiety

The final hypothesis for this study was that positive mealtime attributes would be significantly correlated with eating behaviours (selective eating and sensory eating behaviours), sensory sensitivity and anxiety. Higher reported levels of positive mealtime attributes were all associated with lower reports of selective eating, sensory sensitivity, single-food focus and expulsion. This suggests that eating behaviours and sensory sensitivity are associated with less positive mealtime attributes, such as child family mealtime enjoyment and perceived parental mealtime enjoyment. Skeer et al. (2017) suggested that the positive outcomes associated with family mealtimes are likely due to positive mealtime interactions. As such, these findings may indicate that YP who experience selective eating, sensory sensitivity, single-food focus and expulsion may be prevented from experiencing the benefits typically associated with positive family mealtime and interactions and a warm mealtime environment. However, correlations between positive mealtime attributes and taste reactivity, temperature sensitivity, food-touch aversion, gagging, overstuffing and anxiety were not significant. It is unclear why the aforementioned factors were not correlates of positive mealtimes. Further research should further explore the effect of eating behaviours and sensory sensitivity on mealtimes and outcomes.

3.5 Chapter Summary

This was the first exploratory study assessing selective eating levels in typically developing YP aged 11 to 16 years based on self-report and investigating the relationship between eating behaviours, sensory processing and anxiety. Compared to reported prevalence rates of selective eating in YP, a relatively lower proportion of YP within this study were classified as persistent selective eaters (4.5%). An important finding was that sensory sensitivity was not significantly correlated to selective eating but to single-food focus. The lack of association between selective eating and sensory sensitivity and the association between single-food focus and sensory sensitivity suggest that single-food focus may develop due to sensory sensitivity, but that it becomes engrained by rigidity. Therefore, persistent selective eaters remain selective even after sensory sensitivity attenuates over time. This finding contributes to understanding the mechanisms behind selective eating in typical development, highlighting the possible importance of rigidity, as possibly captured by single-food focus, as a maintaining factor during adolescence rather than sensory sensitivity. The next chapter focuses on the accounts of young people with TS, firstly exploring their eating behaviours and mealtime environments and how they compare to their typically developing peers. Secondly, capturing the nature of young people with TS's mealtime experiences and identifying mealtime challenges they face.

Chapter Four: A Mixed-Method Study on the Eating Behaviours and Mealtimes of Young People with TS

4.1 Introduction

Smith et al. (2019, 2020) undertook the first studies to investigate the relationship between selective eating and sensory sensitivity in YP with TS. Smith et al. (2020) found that neurodiverse YP (aged 6 to 15 years with ASD, ADHD and TS) demonstrated greater levels of selective eating than typically developing controls due to greater levels of taste/smell sensitivity; even when accounting for comorbid neurodevelopmental disorders. This further supports the idea that sensory sensitivity underlies selective eating and illustrates the importance of exploring the eating behaviours of populations who experience sensory sensitivity. While research by Smith et al. (2019, 2020) highlighted the importance of exploring selective eating in YP with TS, their work relied solely on parental reports. The quantitative study compares the eating behaviours and mealtime attributes of YP with TS to typically developing controls selected from the previous study utilising self-report measures.

This chapter also contains a qualitative study conducted to explore further the eating behaviours of YP with TS and what factors they felt shaped their eating behaviours and mealtime experiences. A key trait anticipated to distinguish the mealtimes of YP with TS from typically developing YP is tics. Tics have the potential to be disruptive for people with TS due to their involuntary nature. For example, an arm or hand tic could result in accidentally dropping or throwing something, while a leg tic could result in struggling to walk or falling over. A review by Rindner (2007) noted that YP experience

embarrassment due to their tics in social situations, often leading to increased self-consciousness and social isolation. A dissertation on embarrassment experienced by YP with TS by Rindner (2004) found that embarrassment stemmed from being caught ticking, losing control over tics in public and feeling different to others, although embarrassment was found to decrease over time. How tic-embarrassment relates to mealtime experiences has yet to be empirically explored.

While there is no academic literature that details how tics might impact mealtimes, anecdotal evidence does exist. Anecdotal evidence from online forums (e.g., Reddit's subreddit [r/Tourette's](https://www.reddit.com/r/Tourettes/) [https://www.reddit.com/r/Tourettes/]) contain first-hand accounts of challenges people with tic experience during mealtimes. Tics were noted to inhibit a person's ability to eat (e.g., upper limb tic (NikkiT96, 2019)), the conviviality of mealtimes (e.g., throwing tic (NikkiT96, 2019)) and could also be a choking hazard (e.g., inhaling tic (veryberryblue, 2018)). Additionally, a Channel 4 documentary following the Davies-Monk family, a British family with two boys with TS and coprolalia, demonstrated how socially uncomfortable eating out could be due to socially inappropriate tics (e.g., swearing) and the stares tics attract from fellow diners (Coates & Kay, 2018). The prevalence and impact of functional and socio-emotional tic-related mealtime challenges on the lives of YP with TS also remains unknown.

This chapter aims to explore the eating behaviours and mealtime experiences of YP with TS to begin to fill the literature gaps highlighted above. Structurally, this mixed-method chapter first presents the quantitative findings before turning to the qualitative findings. Each study consists of aims, methods, findings and a summary. The discussion section focuses more broadly on the contribution of both studies to understanding the

eating behaviours and mealtime experiences of YP with TS. Namely, how traits and characteristics associated with TS influence their eating behaviours and mealtime experiences, what challenges they face, the impact of these challenges, and how they navigate said challenges.

4.2 Selective Eating and Positive Mealtime Attributes in Young People With and Without TS

4.2.1 Aims and Hypotheses

This study replicated the study presented in the previous chapter with a sample of YP with TS. This study aimed to investigate whether there were differences between YP with TS and their typically developing peers regarding family mealtime characteristics (frequency and duration), correlates of selective eating and positive mealtime attributes, and assessing whether there were relational differences between groups. Lee et al. (2008) found no differences in meal frequency for families with and without YP (aged 3 to 17) with ASD. Thus, it is hypothesised that the same may be true for families with YP with TS. Based on previous research, it was hypothesised that there would be significant differences between groups, with YP with TS reporting higher levels of selective eating, anxiety and sensory sensitivity than typically developing controls (Hovik et al., 2015; Smith et al., 2019). It was also hypothesised that there would be differences in sensory-based eating behaviours and positive mealtime attributes.

Furthermore, it was hypothesised that the same correlates of selective eating and positive mealtime attributes would be found for YP with TS and typically developing controls. However, this study also explored the role of premonitory urges, sensory phenomena

that precedes tics, and whether this may be a correlate for positive mealtime attributes in the TS sample (i.e., whether experiencing greater premonitory urges impacts young people's mealtime experiences).

4.2.2 Method

Participants: TS Sample

YP with TS aged 11-16 years (n=15) were recruited online to participate in this study. Participants were asked to self-disclose if they had TS (and any other diagnoses) and were asked to complete the Premonitory Urge for Tics Scale (PUTS) (Woods et al., 2005) to assess the intensity of sensory sensations that precedes tics. Total PUTS scores for the TS group ranged from 14 to 36 (M = 27.33, SD = 5.77), with the minimum and maximum range being 9 to 36. Almost half of YP with TS (46.6%) had PUTS scores between 25 and 30.5 which indicated high intensity, which may be associated with marked impairment. A third of YP with TS also scored higher than 31, which is considered high intensity with probable severe impairment, suggesting that this TS sample is towards the higher end of the spectrum when it comes to experiencing premonitory urges. All participants also reported having comorbid diagnoses, often several. Most commonly, participants reported another neurodevelopmental disorder; ADHD (n=5), ASD (n=3) and OCD (n=2). Additional comorbidities were anxiety (n=6), sensory processing disorder (n=2), sleep disorder (n=1), PTSD (n=1) and seizures (n=1). A third of YP with TS also reported that they were taking medication. Medications reported were as follows: Aripiprazole (n=1), Guanfacine (n=1), Sertraline (n=2), Melatonin (n=2), Risperidone (n=1) and Xaggitin XL (n=1). A Mann-Whitney U test was used to determine if there were differences in eating behaviours, sensory processing and anxiety between participants who self-reported that they were taking

medication and those who were not taking medication. Results indicated that there was not a statically significant ($p >.05$) difference between participants on medication and those not on medication.

Participants: Typically Developing Controls

An age-, gender- and, where possible, ethnicity- matched control group (n=15) was selected from the typically developing school dataset (n=178, presented in the previous chapter). Two of the matched participants disclosed mental health challenges (anxiety and anger issues). However, they were still deemed appropriate controls as they did not disclose neurodevelopmental diagnoses.

Demographic information was collected for all participants and included: age in years, gender and ethnicity. As outlined in Table 7, participants' age ranged between 11-15 years (M = 12.80, SD1.21), a majority were male (53.3%) and considered themselves white (86.7% and 100%). Participants were also asked for their weight. Less than half reported their weight. YP with TS (n=6) reported themselves to weigh between 30kg and 76kg (M = 50.21, SD = 18.25) and typically developing controls weighed between 16.70kg and 53kg (M = 35.82, SD = 12.42).

Table 7. Demographic and family mealtime characteristics

	TS (n=15)	Controls (n=15)
Gender		
Male	8 (53.3%)	8 (53.3%)
Female	7 (46.7%)	7 (46.7%)
Age		
Mean (SD)	12.80 years (1.21)	12.80 years (1.21)
Range	11-15 years	11-15 years
Ethnicity		
White	13 (86.7%)	15 (100%)
Black	1 (6.7%)	-
Mixed Ethnicity	1 (6.7%)	-

Recruitment and Procedure

YP with TS (n=15) were recruited with the help of Tourette’s Action, Tourettes Hero, via their websites and social media platforms (e.g., Twitter, Reddit, Instagram and Facebook). Participants took part using the onlinesurveys.ac.uk platform (see **Appendix G**) and had the option to opt-in to a prize-draw. Once the survey was closed, a winner was randomly selected and contacted to claim their £25 Amazon voucher. Implied consent was obtained from young people with TS (see **Appendix L**). Only those with a TS diagnosis aged 11-16 years with parental/guardian consent could participate. The researcher contacted parents/guardians to confirm their child’s participation in the study and were given two weeks to opt-out (see **Appendix M and N**). None of the

parents/guardians requested their child opt-out from the study. Data for the TS group was collected between April 2020 and October 2020 (during the COVID-19 pandemic). The procedure for the typically developing group was described in the previous chapter.

Measures

YP with and without TS completed the same demographic questions and five self-report questionnaires concerning sensory processing, anxiety, eating behaviours and their family mealtime environment. Demographic information captured included age, gender, height, weight, ethnicity, diagnosis history, and family evening meal frequency and duration. Detailed descriptions for the five self-report questionnaires were provided in the previous chapter. Therefore, this chapter will only provide reliability statistics for this sample. Participants with TS completed one additional measure and one additional question. The additional measure was the Premonitory Urge for Tics Scale (Woods et al., 2005) and the additional question related to anxiety levels and the pandemic. Further detail for these additions are provided below.

Premonitory Urge for Tics Scale (PUTS) (Woods et al., 2005)

The PUTS is a 9-item self-report questionnaire that assesses premonitory urges for tics. This measure includes statements capturing different sensory phenomena experienced before a tic (e.g., *“Right before I do a tic I feel ‘wound up’ or tense inside”*). Participants responded to each statement using a 4-point Likert scale ranging from 1 to 4 (1 = not at all, 2 = a little, 3 = pretty much, 4 = very much). Responses were summed to create a score. Higher scores indicated higher premonitory urges for tics. This measure was used instead of a tic severity measure in order to specifically assess the sensory component of

tics and whether this had any impact on mealtime experiences. Research suggests that there is a positive correlation between premonitory urge severity and tic severity (Kyriazi et al., 2019). Greater premonitory urges are also associated with greater tic awareness (Barnea et al., 2016). All of which may influence how tics shape the mealtime experiences of YP with TS.

PUTS has been validated for use with YP age 8 to 16 years. Reliability statistics for PUTS with a sample of YP age 10 to 16 years was .89 (Woods et al., 2005). In this study, the Cronbach's alpha was good ($\alpha = .83$).

Screen for Child Anxiety Related Emotional Disorders-Child (SCARED-C)
(Birmaher et al., 1999)

Data collection for the TS group began during the first national lockdown due to the COVID-19 pandemic. Therefore, it was considered necessary to capture how participants perceived their anxiety levels at the time of completion to compare to their 'usual' anxiety levels. At the end of the SCARED questionnaire, participants were asked to select which of the following three statements most applied to them: (1) I feel LESS anxious than I was before COVID-19 and lockdown, (2), I feel the SAME as before COVID-19 and lockdown (3) I feel MORE anxious than I was before COVID-19 and lockdown. A majority (53.3%) of YP with TS reported feeling more anxious than before the pandemic. Only a third reported feeling the same, and 13.3% felt less anxious. Therefore, the effect of the pandemic on anxiety levels must be taken into consideration when comparing SCARED total scores for the TS group (who took part during the COVID-19 pandemic) with typically developing controls (who participated before the

pandemic began). The Cronbach's alphas for anxiety were excellent for the TS group ($\alpha = .97$) and good for controls ($\alpha = .86$).

Adult/Adolescent Sensory Profile (AASP) (Brown & Dunn, 2002)

The Cronbach's alphas for sensory sensitivity in the current study were questionable for the TS group ($\alpha = .61$) and controls ($\alpha = .62$). Cronbach's alphas for taste reactivity in the current study was acceptable for the TS group ($\alpha = .71$) but unacceptable for controls ($\alpha = .17$).

Adult Eating Behaviour Questionnaire (AEBQ) (Hunot et al., 2016)

The Cronbach's alphas were good for both the TS group ($\alpha = .80$) and for controls ($\alpha = .80$).

Positive Mealtime Attribute Scale - Child, PMAS-C (Items currently unpublished, extracted from the development of the Family Dinner Index, see Skeer et al., 2017)

The Cronbach's alphas for the PMAS-C was poor for the TS group ($\alpha = .53$) and acceptable for controls ($\alpha = .79$).

Modified Sensory Eating Problem Scale (M-SEPS) (Seiverling et al., 2019)

The Cronbach's alphas for each subscale of the SEPS ranged from unacceptable to acceptable for the TS group ($\alpha = .34$ to $.76$) and from unacceptable to questionable for controls ($\alpha = -.31$ to $.69$), see Table 9.

Handling Missing Data

Data collected across all measures for the TS group had low levels of missing values (<2%). A Little's Missing Completely At Random (MCAR) was non-significant for all measures ($p > .05$, see **Appendix O**), indicating that data were missing completely at random. Therefore, person mean imputation at item-level was deemed appropriate for managing low levels of missing data (Eekhout, 2015). Each participant's missing item was imputed with their mean score for the scale, as described in the previous chapter.

Analysis

All analyses were computed using SPSS version 26. The assumption of normality was violated for most measures based either on kurtosis, skewness or Shapiro-Wilk (see **Appendix P**). However, mealtime characteristics were normally distributed, therefore an independent samples t-test was used to assess differences. Also, the AASP subscales were deemed to be normally distributed, therefore differences between groups for the AASP factors (sensory sensitivity and taste reactivity) utilised parametric-tests (independent samples t-test). However, correlation analysis utilised non-parametric tests (Spearman's correlation) as other variables are not normally distributed. Differences between groups for all other variables were assessed using Mann-Whitney U.

Data was analysed to establish whether age, weight³, gender were related to the two main factors of interest for each group. Two-tailed Spearman's correlations indicated that selective eating was not significantly associated with age $r(13) = -.18, p = .53$, weight $r(4) = .71, p = .11$, or gender $r(13) = .14, p = .62$ for YP with TS. Similarly, selective eating was not significantly associated with age $r(13) = .16, p = .57$, weight $r(5) = .02, p = .97$, or gender $r(13) = .22, p = .43$ for typically developing controls. Therefore, these characteristics were not controlled for in selective eating analyses.

Two-tailed Spearman's correlations indicated that positive mealtime attributes were not significantly associated with age $r(13) = -.06, p = .82$, weight $r(4) = -.67, p = .15$, or gender $r(13) = .08, p = .78$ for YP with TS. Similarly positive mealtime attributes were not significantly associated with age $r(13) = -.12, p = .66$, weight $r(5) = .02, p = .97$, or gender $r(13) = -.21, p = .47$ for typically developing controls. Therefore, these characteristics were not controlled for in positive mealtime attribute analyses.

4.2.3 Results

Descriptive Results

³ As with previous chapter, BMI-SDS were beyond the normative range suggesting errors with the data, therefore weight alone was used to see whether there was any relationship between a young person's weight and factors of interest.

On average, evening family meals were longer and more frequent for YP with TS than controls (see Table 8). Half of YP with TS reported having an evening family meal every day of the week compared to less than a quarter of controls. Additionally, two-thirds of YP with TS reported that mealtimes often lasted 30 minutes, whereas two-thirds of controls reported mealtimes to last less than 15 minutes. However, the results of an independent t-test indicate that there was no significant difference in family evening meal frequency between families with and without a young person with TS, $t(27) = -1.12$, $p = .27$, equal variance assumed. Also, there was no significant difference in family evening meal duration between families with and without a young person with TS, $t(27) = -.64$, $p = .54$, equal variance assumed.

Table 8. Evening family meal frequency and duration for YP with TS and typically developing controls

	TS (n=15)	Controls (n=15)
Evening Family Meal Frequency (per week)		
0	1 (6.7%)	3 (21.4%)*
1	1 (6.7%)	1 (7.1%)*
2	-	-
3	1 (6.7%)	-
4	3 (30%)	3 (21.4%)*
5	1 (6.7%)	1 (7.1%)*
6	-	3 (21.4%)*
7	8 (53.3%)	3 (21.4%)*

Average Evening Family Meal Duration

15 minutes or less	4 (26.7%)	9 (64.3%)*
30 minutes	9 (60%)	1 (7.1%)*
45 minutes	1 (6.7%)	3 (21.4%)*
An hour or more	1 (6.7%)	1 (7.1%)*

* mealtime frequency and duration missing for one control participant so valid percentage provided.

Means and standard deviations for the measures are presented in Table 9. Higher mean scores indicate higher levels of the attribute were reported. With a cut-off of 4, most of the participants were not deemed selective eaters (93.3% for YP with TS and 100% for controls). The mean anxiety scores for both groups were above the cut-off (≥ 25), suggesting there may be a presence of an anxiety disorder. For the TS group, the mean score was above 30, suggesting that participants may have a specific anxiety disorder. Positive mealtime attributes were also above the cut-off (≥ 70), suggesting that participants experienced high levels of positive mealtime attributes and a warm mealtime environment. The mean sensory sensitivity scores for both groups fell within the normal range (26-41), suggesting that sensory sensitivity was normative within this sample. However, almost half of YP with TS had sensory sensitivity scores that were either more (33.3%) or much more than most people (13.3%). For controls, this was proportionally lower, with a third (33%) reporting sensory sensitivity levels more than most people their age.

Differences Between Groups

Mann-Whitney U tests were conducted to explore differences between groups for all measures apart from sensory sensitivity and taste reactivity. Distributions of most factors for the TS group and controls were not similar, as assessed by visual inspection. Those that were similar were the positive mealtime attributes, food-touch aversion and temperature sensitivity. As such, medians were reported for these factors. The other factors have median rank reported due to dissimilar distributions.

As indicated in Table 9, there were statistically significant differences in selective eating and anxiety between the TS group and controls using a sampling distribution for U (Dineen & Blakesley, 1973). Distribution for selective eating and anxiety scores for the TS group and control were not similar, as assessed by visual inspection. Selective eating scores reported by YP with TS (mean rank = 19.23) were significantly higher than those reported by controls (mean rank = 11.77), $U = 168.50$, $z = 2.33$, $p = .02$. Also, anxiety scores reported by YP with TS (mean rank = 20.20) were significantly higher than those reported by controls (mean rank = 10.80), $U = 138.00$, $z = 2.93$, $p = .003$. Scores for positive mealtime attributes, food-touch aversion, overstuffing, gagging, temperature sensitivity, expulsion and single-food focus were not significantly different.

Differences in sensory sensitivity and taste reactivity were assessed using independent samples t-tests as these variables were deemed to be normally distributed. There was not a statistically significant difference in sensory sensitivity scores between YP with TS ($M = 35.20$, $SD = 10.90$) and controls ($M = 35.67$, $SD = 7.84$), $t(28) = .14$, $p = .89$, equal variance assumed. An independent-samples t-test was also run to determine if there were differences in taste reactivity between YP with TS and controls. There was not a statistically significant difference in taste reactivity scores between YP with TS and

controls, with a mean difference of .67(95% CI, -2.12 to 3.45), $t(22.32) = .59$, $p = .63$, equal variance not assumed.

Table 9. Means, standard deviations and Mann-Whitney U test results for measures that were not normally distributed for YP with TS and typically developing controls

Measures	Subscale	TS (n=15)					Controls (n=15)					Mann-Whitney U		
		Alpha	Mean	SD	Mean	Median	Alpha	Mean	SD	Mean	Median	U	z	p
					Rank				Rank					
AEBQ	Selective Eating	.80	2.84	.85	19.23	-	.80	2.11	.74	11.77	-	168.50	2.33	.02
M-SEPS	Temperature Sensitivity	.34	1.10	.62	-	1.00	.69	1.25	.84	-	1.25	123.00	-.44	.68
M-SEPS	Single-Food Focus	.69	1.07	.76	17.63	-	.68	.75	.82	13.37	-	144.50	1.34	.19
M-SEPS	Food-Touch Aversion	.68	.55	.64	-	.50	.35	.18	.37	-	.00	154.50	1.93	.08
M-SEPS	Gagging	.76	.67	.91	16.67	-	-.31	.23	.29	14.33	-	130.00	.79	.49

M-SEPS	Expulsion	.36	.96	.72	18.50	-	.48	.49	.60	12.50	-	157.50	1.91	.06
M-SEPS	Overstuffing	.86	1.78	1.41	18.40	-	.68	.84	.86	12.60	-	156.00	1.83	.07
SCARED	Anxiety	.97	48.40	21.86	20.20	-	.86	25.33	10.65	10.80	-	183.00	2.93	.003
PMAS-C	Positive	.53	72.00	15.57	-	76.00	.79	74.67	17.15	-	76.00	97.50	-.63	.54
	Mealtime													
	Attributes													
AASP	Sensory	.61	35.20	10.90	-	-	.62	35.67	7.84	-	-	-	-	-
	Sensitivity													
AASP	Taste	.71	10.33	4.51	-	-	.17	11.00	2.60	-	-	-	-	-
	Reactivity													

NOTES

Higher scores indicate higher levels of the attribute for all measures

COLOUR KEY

Orange highlights indicate significance $p < .05$.

Yellow highlights indicates that the measure is above cut-off.

Purple highlights suggest that the alpha is $< .60$.

Correlations

Two-tailed Spearman's correlations were used to explore relationships between selective eating, anxiety, and sensory sensitivity. As indicated in Table 10, YP's reports of selective eating were not significantly correlated with anxiety or sensory sensitivity for both groups. Anxiety was also not significantly correlated with sensory sensitivity for both groups.

Table 10. Two-tailed Spearman's correlations for selective eating, sensory sensitivity and anxiety for YP with TS and typically developing controls

	TS				Controls			
	Selective Eating (AEBQ)		Anxiety (SCARED)		Selective Eating (AEBQ)		Anxiety (SCARED)	
	<i>r</i>	<i>p</i>	<i>R</i>	<i>P</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Sensory Sensitivity (AASP)	-.38	.16	-.05	.86	-.09	.76	-.28	.31
Anxiety (SCARED)	.47	.08	-	-	-.01	.99	-	-

Two-tailed Spearman's correlations were used to explore whether sensory eating problems were related to selective eating, sensory sensitivity and taste reactivity in both groups. As indicated in Table 11 YP with TS's reports of selective eating was significantly correlated with greater reports of single-food focus, $r(13) = .66, p = .01$. However, YP's reports of selective eating were not significantly correlated with other sensory eating behaviours for the TS group and none of the sensory eating behaviours for the typically developing controls.

Table 11. Two-tailed Spearman's correlations for sensory eating problems, selective eating, sensory sensitivity and taste reactivity for YP with TS and typically developing controls

	TS						Controls					
	Selective Eating (AEBQ)		Sensory Sensitivity (AASP)		Taste Reactivity (AASP)		Selective Eating (AEBQ)		Sensory Sensitivity (AASP)		Taste Reactivity (AASP)	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>R</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
M-SEPS												
Temperature Sensitivity	-.02	.95	.20	.47	.18	.53	-.34	.21	.26	.35	-.00	.99
Single-Food Focus	.66	.01	-.33	.24	-.12	.68	-.13	.65	-.02	.94	.07	.80
Food-Touch Aversion	.27	.33	-.04	.90	-.00	.99	-.15	.60	.18	.53	-.31	.27
Gagging	.48	.07	.12	.68	.01	.99	.04	.90	-.11	.69	.22	.44
Expulsion	-.02	.93	.29	.29	-.02	.94	-.19	.51	.37	.18	-.19	.49
Overstuffing	.00	1.00	-.08	.78	-.10	.72	.21	.45	-.28	.32	.26	.35

COLOUR KEY

Orange highlights indicate significance $p < .05$

Two-tailed Spearman's correlations were used to explore the relationships between positive mealtime attributes and all factors of interest. As indicated in Table 12, YP's reports of positive mealtime attributes were not significantly correlated to any of the factors measured.

Table 12. Two-tailed Spearman's correlations for selective eating and positive mealtime attributes and variables of interest for YP with TS and typically developing controls

		Positive Mealtime Attributes (PMAS-C)			
		TS		Controls	
		<i>r</i>	<i>P</i>	<i>r</i>	<i>p</i>
AEBQ	Selective Eating	-.06	.82	-.22	.44
AASP	Taste Reactivity	.03	.93	-.50	.06
AASP	Sensory Sensitivity	-.10	.74	-.37	.18
M-SEPS	Temperature Sensitivity	.19	.50	-.01	.97
M-SEPS	Single-Food Focus	-.16	.58	-.34	.22
M-SEPS	Food-Touch Aversion	-.43	.11	.07	.82
M-SEPS	Gagging	-.19	.50	.05	.85

M-SEPS	Expulsion	-.01	.97	-.33	.23
M-SEPS	Overstuffing	.04	.88	.07	.81
SCARED	Anxiety	-.47	.08	.08	.77

Finally, two-tailed Spearman’s correlations were used to explore relationships between premonitory urge severity and positive mealtime attributes. YP with TS’s reports of premonitory urge severity was not significantly correlated with positive mealtime attributes, $r(13) = .06, p = .83$.

4.2.4 Summary

This study aimed to explore the eating behaviours and positive mealtime environments of YP with TS and how they compare to their typically developing peers. Particular attention was given to suspected correlates of selective eating. Similar to findings for the typically developing YP presented in the previous chapter, YP with TS also reported relatively low rates of selective eating, with only one young person (6.7%) being classified as a selective eater. However, in the present study, none of the typically developing controls were classified as selective eaters. YP with TS also reported significantly higher levels of anxiety than controls. While this finding aligns with previous research that found greater anxiety levels in YP with TS than typically developing controls (Hovik et al., 2015), it is important to note the likely effect of the pandemic and national lockdowns may have had on anxiety levels reported by YP with TS. Most YP with TS

in this study perceived their anxiety levels increased during the pandemic and lockdown. This finding is supported by Robertson et al. (2020) who suggested that media coverage during the pandemic, parental anxiety, OCD, confinement and quarantine have affected the anxiety levels of YP with TS. Therefore, an increase in anxiety due to the pandemic may account for the differences in anxiety levels between groups (typically developing controls participated before the start of the pandemic). Additionally, there was no significant difference in sensory sensitivity and taste reactivity between groups, despite previous parent report research finding higher levels of sensory sensitivity and taste/smell sensitivity in YP with TS compared to typically developing controls (Smith et al., 2019).

In this study, selective eating, anxiety and sensory sensitivity were not correlated with one another for either sample. This differs from the larger typically developing study (previous chapter), which found a relationship between selective eating and anxiety, anxiety and sensory sensitivity but not selective eating and sensory sensitivity. Interestingly, sensory eating behaviours were also not related to sensory sensitivity, taste reactivity or selective eating for either group in this study; except single-food focus, which was positively correlated with selective eating for YP with TS. Positive mealtime attributes were also not significantly correlated to any of the other factors measured for either sample. A relationship between premonitory urge severity and positive mealtime attributes was not found.

Taken together, it is unclear why YP with TS report significantly higher levels of selective eating than their typically developing peers. While anxiety and sensory sensitivity are recognised correlates of selective eating, they were not correlates in this study. Many questions about how YP with TS perceive their eating behaviours and the nature of their mealtime experiences remain unanswered and are aimed to be addressed in the qualitative study that follows.

4.3 Phenomenological Examination of the Eating Behaviours and Mealtime Experiences of Young People with TS

4.3.1 Aims and Research Questions

This study aimed to capture the mealtime experiences of YP with TS and what challenges, if any, they may face. Particular attention was also given to the effect that traits and characteristics associated with TS, such as rigidity and sensory sensitivity, may have on their eating behaviours and mealtime experiences. The research questions addressed in this study are as follows:

1. What eating and mealtime challenges, if any, do YP with TS face?
 - a. How, if at all, do tics shape mealtime experiences?
 - b. How, if at all, does sensory sensitivity shape eating behaviours and mealtime experiences?
 - c. How, if at all, does rigidity shape eating behaviours and mealtime experiences?
 - d. How, if at all, does medication influence eating behaviours?
2. What is the perceived impact of these eating and mealtime challenges?
3. How do YP with TS navigate these challenges?

4.3.2 Method

Design

This qualitative phenomenological study explored the accounts of six YP with TS and their mealtime experiences, capturing both richness and diversity of accounts. The primary focus was on the nature of their mealtime experiences and how they believed their symptomatology shaped said experiences. Mealtimes were explored within multiple social contexts to provide a rich understanding of the contextual nature of mealtimes. Namely exploring mealtimes: at home with their family, eating out of home at a friend or relatives' houses, or visiting dining establishments such as restaurants and cafes with friends or family. As detailed in chapter two (Methodology), IPA was embraced as the methodological framework for this study because it centres around the lived experiences of YP with TS and the meaning they attribute to their experiences.

Recruitment

Tourette's Action and Tourette's Hero helped disseminate information about the study among their networks of people with TS. In all cases, mothers of YP with TS reached out to the researcher to find out more about the study (mothers of all the YP in this study also participated, their findings are presented in chapter five). All communication surrounding a young person's involvement was mediated through their mothers. Mothers were sent an information sheet (see **Appendix Q**) that detailed the study's aims and objectives and how data would be used and protected. Mothers of YP who agreed to participate then arranged a day and time for the interview. Mothers' involvement in the interviews varied based on a young person's wishes, see Table 13. 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 (see **Appendix H and R**) 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.

Participants

YP were eligible for inclusion if they were aged between 12 and 16 years and had a diagnosis of TS. Almost all of the participants had more than one comorbidity: OCD (n=4), anxiety disorder (n=4), ADHD (n=3), learning disability (n=2), sensory processing disorder (n=2), sleep disorder (n=1), see Table 13. One participant was also awaiting sensory processing disorder and ASD diagnoses. Only one participant did not have a formally diagnosed comorbidity; although he was suspected of having anxiety and OCD, but these were considered part of his TS. This sample is thought to reflect the spectrum of presentations within this population, with TS being a multifaceted condition with a complex clinical presentation due to high comorbidity rates (Cavanna & Rickards, 2013; Hirschtritt et al., 2015). Participants can shed light on how symptoms of their TS and associated comorbid conditions interplay to make mealtimes complex. Participants were equally split between gender (50% female) and medication status (50% taking medication). Medications taken included Aripiprazole (n=2), Sertraline (n=2), Melatonin (n=1) and Phenergan (n=1). All participants were white.

Table 13. Participant characteristic, interview type, comorbidities and medication

Pseudonym	Age	Gender	Interview type	Comorbidities¹	Medication¹
Annabelle	13yo	Female	Joint interview with mother	6 diagnoses	Takes antipsychotic
Ivy	14yo	Female	Alone	2 diagnoses, 2 pending	None
Talia	13yo	Female	With mother present	2 diagnoses	None
Thomas	14yo	Male	Joint interview with mother	3 diagnoses	Takes antipsychotic, antidepressant and antihistamine.
Warren	12yo	Male	With mother present	4 diagnoses	Takes antidepressant and melatonin
Zack	14yo	Male	Alone	2 traits	None

NOTE:

1. The specific diagnoses of YP and list of medications that they take have not been listed within the table in order to preserve confidentiality.

Data Collection

Almost all semi-structured 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 pandemic). Interviews ranged from 25 to 89 minutes and took place between October 2018 and August 2020. Half of the interviews (Ivy, Annabelle and Warren) took place during the COVID-19 pandemic and national lockdowns in 2020. All interviews were audio-recorded and were transcribed verbatim by the researcher.

Empirical literature and anecdotal evidence guided the creation of the interview schedule (see **Appendix S**). The supervisory team also reviewed the schedule. The first part of the schedule captured contextual information about participants and their families, including diagnoses, parental occupation, and work patterns. In most cases, mothers provided this information. The second part of the schedule focused more specifically on mealtimes, asking the following:

1. Can you walk me through a day in your life, using yesterday as an example?
2. When was the last time you sat down to eat a meal with your family? Can you describe that mealtime for me?
3. What are your favourite and least favourite things about mealtimes?
4. What types of food and drinks do you like or dislike?
5. When was the last time you ate out as a family? Can you describe it to me?
6. When was the last time you ate out with, or at, your friends? Can you describe it to me?
7. Can you talk me through your mealtimes at school? What are they like?
8. How, if at all, do your TS/tics influence your mealtimes?

9. Do you take any medication? If so, have you noticed any changes to your appetite and weight? If yes, can you talk to me about that?

Interviews were conducted in-line with Smith and Osborn (2003) recommendations for IPA studies, to: prioritise rapport building with participants over the ordering of the questions; use probes to further explore areas of interest; and allow room for the interests and concerns of participants to shape the interview. This approach situated participants as co-creators of the interview process and encouraged them to lead the conversation. This approach also permitted the exploration of alternative and unanticipated views.

Data Analysis

IPA guidelines by Smith et al. (2009) were used to analyse transcripts. NVivo 12 software was used to code and organise emergent 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 in a case summary document (see **Appendix T**). This document allowed for identifying emerging patterns within a particular case, documentation of these observations, and bracketing these observations 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 (Smith et al., 2009).

Once all transcripts were coded, initial codes were grouped based on association and relevance to the research questions. Emerging patterns across cases were noted in a diary, and themes started taking shape. These emergent themes continued to develop

throughout the write-up process as connections between cases deepened and a narrative materialised. The final superordinate and subordinate themes presented in the next section arose through abstraction, the combining of similar codes and themes, and subsumption, deriving superordinate themes based on emerging subthemes. Mind maps were used to aid the process visually (see **Appendix U**). Case summaries were also regularly consulted throughout the process to ensure that each participant's nuances were not lost during synthesis and the write-up process.

4.3.3 Themes

The following themes address the research questions for this study by detailing the mealtime challenges YP with TS raised during their interview; how they conceptualised these challenges, i.e., what behavioural trait or characteristic associated with TS and comorbidities interplay with mealtimes to create challenges; the perceived impact of these challenges; and how they navigate said challenges. 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 cognitive rigidity shape eating behaviours, and (3) how medication affects appetite and weight, see Table 14. These themes captured YP's thoughts surrounding, and the meaning they attributed to, their eating behaviours and mealtime experiences. Some of the words YP 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 behaviours and characteristics associated with TS and comorbidities.

Table 14. Theme structure for young people with TS

Superordinate themes	Subthemes
	Disruptive tics
How tics shape mealtime experiences	Anxiety and self-consciousness when eating out of home
How sensory sensitivity and cognitive rigidity shape eating behaviours	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

How Tics Shape Mealtime Experiences

This superordinate theme details the tic-related mealtime challenges that YP with TS experienced and what impact, if any, it had on them. 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

Tics were described by most YP as presenting a challenge during mealtimes, although the intensity of this varied from a minor inconvenience to being extremely disruptive.

Throwing tics, spitting tics, and choking tics were noted as tics that were particularly problematic during mealtimes.

Annabelle and Ivy both experienced throwing tics, which resulted in drinks being spilt and cups being smashed. However, the smashing of cups and spilling of drinks seemed to be viewed as a minor inconvenience for both girls as they did not dwell on how these tics impacted their overall mealtime experience, only noting that it was something that did happen on occasion.

"I had a bad tic day a couple of days ago, and I think that was on Monday and I threw a cup and it smashed." (Ivy)

What was more challenging was throwing tics aimed at specific people or when tics would *"destroy"* food. Furthermore, the tics, despite being unintentional, 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." (Annabelle)

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 empathise 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.

Annabelle: My little sister is a target. She gets stuff thrown at her occasionally and she gets annoyed. But then, why wouldn't you?

Susan: Trying to keep everyone at the table is difficult.

Annabelle: is difficult.

Susan: is difficult because when Annabelle's tics are unkind to her sister, her sister gets very upset and things escalate. It seems to be a time when/ I guess because you're in close proximity trying to eat together.

[...]

Sandra-Eve: **cross talk** has lockdown made it better or worse?

Annabelle: Worse, I think, because we're spending more time together. So it's kind of like everyone/ well not getting fed up with my tics, but it's like people are starting to think/

Susan: Sometimes they'll eat separately.

Annabelle: Yes, because... yeh.

Susan: It's easier.

[...]

Susan: No we try to have dinner together. Don't we?

Annabelle: We try to have dinner together but [not] like lunch or breakfast/

Another disruptive tic noted was spitting tics. For example, Ivy and Thomas experienced spitting tics whilst drinking, albeit a rare tic for them both. 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.

The final disruptive tic being discussed was a choking tic. When asked how the tic impacted him, Warren said: "*I worry sometimes [...] that I might... die*", highlighting the fear the experience evoked for him. Warren was uncomfortable talking about the tic as it made the tic resurface, so he could not elaborate fully on how impactful this tic had been on his mealtimes. However, he was able to note how the tic felt briefly.

"It makes me worry uhh it scares me sometimes... it feels blocked, and so I can't breathe sometimes. I don't know, what to say really." (Warren)

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.

Sandra-Eve: Okay, and what does that do to your mealtime experience?

Warren: It makes me not want to eat as much.

Jessica: You struggle.

Sandra-Eve: And have you then had moments then when you've avoided eating?

Warren: Yeh, sometimes.

Overall, there appeared to be a few different tics that were disruptive during mealtimes, although the disruption level varied.

Anxiety and Self-Consciousness When Eating Out of Home

Most YP noted some anxiety surrounding eating out of home, specifically dining out at a restaurant and eating at a friend's house. Their anxiety appeared to be rooted in concerns about how others would react to their tics and perceive them. This was particularly challenging for those with coprolalia, the involuntary and repetitive use of obscene language. This subtheme will first explore YP's dining experiences before turning to experiences eating at friends' houses. However, it is important to note that Annabelle provided the most detailed account and discussed the nuances of different mealtime experiences. Therefore, her experiences are extensively detailed in this chapter. Despite this, many of the experiences she discussed were touched upon by other participants.

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 the family's mealtime experience.

"[...] umm 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 <dildos, butt plugs> [...], you can see them getting more and more annoyed, more and more worried, because they've got young children or children that don't really know this stuff and there's this other child, teenager kind of, whatever, who is shouting that stuff at those children. And those children are getting

curious as to why I'm shouting that stuff and what that stuff means <wow, look at the size of your fanny>." (Annabelle)

Annabelle's verbal tics above demonstrate the type of things she would tic during these encounters. Annabelle was hyperaware of the socially inappropriate nature of these comments, especially around young children. Annabelle's repetition of *"more and more"* also highlights 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 meals. While Ivy had yet to experience this, Annabelle had. 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 <wow, look at the size of his cock>. Umm people are like looking over 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 ritual around eating out that eased some of the discomfort associated with eating out and the public gaze. Part of that ritual included getting mentally prepared to eat out, calling ahead to update the staff on her condition and what

to expect, requesting a corner table, wearing a lanyard and badge to signal that she has a disability and asking her mum to speak with nearby tables, so they were aware of her disability.

"Okay, so I have to know in advance so I can like mentally prepare myself and I have to wear a lanyard with it on, and I have to wear badges and <Woop, I'm a light>. And then mum has to ring up in advance, book the table ask to be in a corner and then she asks for the waiters to be told. [...] We'll sit down and get ready. And then people on the tables kind of figured it out 'cause they've seen me walk in and they can read the lanyard, but then when they get up and leave, the new people who come and like sit on the table near us don't know and just think I'm misbehaving. And umm so then I asked mum to tell them. If they're glancing over it does bother me [...]" (Annabelle)

When asked why she prefers a corner table, 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, they reserved eating out for birthdays. Annabelle would be preoccupied with others' experiences during the rare meal out instead of enjoying her own meal. Annabelle and her mother felt the need to undertake much labour to manage others' reactions to Annabelle and soothe Annabelle's anxiety around being viewed as *"misbehaving"*. Annabelle's mother appeared to be pivotal to her mealtime experiences, acting as an ally and shield. Annabelle explained that she would also need her mum to accompany her to restaurants with her friends because *"people think that when there isn't an adult around, it's [...] acceptable to say something"*. Despite feeling as though it was *"a bit awkward"* having her mum come along, she felt that it was best to have her there *"backing*

[her] up". It also appeared as though having her mother there shifted the attention of adults from Annabelle onto her mother; people would comment on "what a bad mum she must have to let her swear and shout like that all the time".

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

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

It appeared as though 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 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 been, 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 Tourette's is and they won't understand it. I don't want to get kicked out with my family or anything like that..." (Thomas)

Thomas had grown to be a recluse, often avoiding going out in general. He explained that he had several threatening encounters due to people's lack of awareness of coprolalia. Thomas was also concerned about the consequences of his tics that both he and his family might have to face. While Thomas did not say that he feared embarrassing his family, this was a reasonable fear based on the scenario he gave of him and his family being kicked out of a *"posh restaurant"*.

Dining out was not always a challenging experience. 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 notable 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 them and might react to their coprolalia.

Another social context where mealtimes were challenging was 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

judgement 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 like motor tics worse.” (Talia)

Talia explained that anticipating their response usually increased the severity of her tics. Annabelle also noted this feedback loop between tics and anxiety in reference to dining out. While Talia emphasised how others would respond to the things she says, Annabelle focused more broadly on her behaviour 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 Tourette's better”* as Annabelle likened her behaviour to that of a toddler.

“[...] where they've got younger children, they're still used to having like food thrown about so they're fine with it and they are accepting. Umm, but 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 Tourette's as having an uncontrollable toddler trapped inside of me <woop, bop, shake it> 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 behaviour. 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. It was unclear how she would manage as the discrepancy widened. For example, would her self-concept be negatively affected by feeling unable to act in a manner that is socially appropriate for her age?

How Sensory Sensitivity And Cognitive Rigidity Shapes Eating Behaviours

This superordinate theme discusses YP's eating behaviours and how sensory sensitivity and cognitive rigidity shapes them. Most YP noted sensory influences on their food choices, although none felt that this limited their dietary range. Instead, they viewed their food choices as preferences, with some considering themselves as selective eaters due to the specificity of their preferences. Preferences also related to how the food was plated, and some YP engaged in specific eating practices. This superordinate theme consists of two subthemes: (1) food choices and (2) plating preferences and specific eating practices.

Food Choices

YP's food choices had a sensory basis, with YP describing the sensory properties of food they liked or disliked. However, they did not perceive their diets to be restricted by these sensory preferences. Most YP noted varying degrees of sensory influences across all sensory modalities, although texture appeared to be the most common reason for disliking foods.

"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." (Annabelle)

"I don't like sandwich meat. [...] Texture and floppiness and umm the taste sometimes." (Warren)

Texture also influenced food preparation preferences. 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, fills me with disgust, kind of. Like... like you have like a really annoying like an 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"*. There appeared to be a sensory basis for this preference that was also noted by Zack, although only about carrots as he felt they were *"too gooey"* when cooked.

None of the YP described their diets in a way that appeared to be heavily influenced by sensory sensitivities despite having some sensory preferences. Preferences also rarely had a negative effect on mealtimes as YP were typically served foods that met their preferences, except for Warren, who felt he had little food autonomy. For example, he said: *"I have very limited choice because I can't choose what we eat for tea"* [...] *"I'd like*

more freedom". It was rigidity that appeared to be a more prominent influence on eating behaviours than sensory sensitivity.

Plating Preferences and Eating Rituals

This subtheme will discuss rigidity and how it shaped eating behaviours. Mealtime rigidity appeared in two main ways: plating preferences and engaging in specific eating practices. Plating preferences appeared to be rooted in rigidity more so than sensory sensitivity as YP accepted the different textures on their plate; the challenge occurred when different meal components touched on the plate. Nevertheless, there did appear to be a sensory component to plating preferences. Annabelle, Talia and Ivy all accepted the different sensory properties of each component of the meal. However, they 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)

A sign that this was rooted in rigidity was the fact that there were exceptions to the rules. 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.

“So, things that are like meant to be touching, like I’m fine with ‘cause like you can’t really separate like cereal from milk.” (Talia)

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 minimised their discomfort. Although, the fact that it was served touching still affected their mealtime experience, albeit to a lesser extent than if wet and dry components touched. 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. 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.

"[...] if the plate is, if it, if/ depends on what way/ what part is facing towards me first.
[...] I usually go umm to my right and turn it to my right." (Ivy)

All three girls noted that they had eaten this way for as long as they could remember. It also appeared that their preparation and plating preferences were accommodated. In instances where their preferences were not catered to, no overt emotional reaction was noted. As such, food conflicts were not raised as a challenge.

Annabelle: I do like them separate and in a certain way on a plate. Mum always does them in a certain way.

[...]

Sandra-Eve: Okay, and what about if food is served in a way that you don't like? Let's say that the pasta sauce is on top of the pasta?

Annabelle: Yep.

Sandra-Eve: Move it to the side and still eat or would you not eat it?

Annabelle: I can still eat it, just it will put me off and I won't eat as much of it.

Sandra-Eve: Okay.

Annabelle: I'll kind of sit there and just stare at it for a bit and try and separate it myself. But, yeah.

Overall, it appeared that mealtime rigidity, strong preferences and inflexibility in food preparation and presentation, were more prominent among YP than restricted diets.

While YP did note some sensory preferences, texture was the more prominent domain that influenced preferences and underlies some rigidity. In most cases, YP could eat meals aligned with their preferences, thus not creating many challenges during mealtimes.

How Medication Affects Appetite and Weight

This superordinate theme details the effect medication had on YP's appetite and weight and the subsequent effect on them. All the YP taking medication noted an effect on their appetite although only those on Aripiprazole (antipsychotic) found that this had a knock-on effect of increasing their weight, which then created some socio-emotional challenges. This section is split into two subthemes noting both the direct effect of medication and indirect effect: (1) appetite stimulation, (2) socio-emotional effect of weight gain and weight management attempts.

Appetite Stimulation

This subtheme will discuss appetite stimulation as a side effect of medication. YP on medication all noted an increase in appetite, although the extent of appetite stimulation varied from a slight increase to an insatiable appetite. 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. Both Annabelle and Thomas felt that their appetite increase was a result of their medication. With Annabelle said: *"I think that was the main reason for the struggle with my appetite"*. Thomas described his appetite as insatiable:

"Umm 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. I don't know what but yeh that's the routine." (Thomas)

Thomas described 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] don't have breakfast 'cause I don't eat early in the morning. Umm [I] go to school, [and] 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 (laughs). So umm... yeh, so that's it really, that's all I really do but sometimes I do save it until lunch obviously. So, yeh." (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 behaviours changed, which resulted in weight gain. Their weight gain led them to attempt to manage their weight, which had a socio-emotional effect on them; this will be discussed in the next subtheme.

Socio-Emotional Effect of Weight Gain and Weight Management Attempts

Only two participants were taking antipsychotics (Aripiprazole) at the time of the study. Both Annabelle and Thomas were upset about the weight they had gained as a result of their medications and subsequently desired to control their eating behaviours to either mitigate against any further weight gain or lose weight. For Thomas, there was a sense of helplessness associated with his eating behaviours 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. Other than that/'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. So, I can't really help it." (Thomas)

The way that Thomas describes his insatiable appetite and inability to control his eating behaviours has an air of defeat to it. He knows that he will gain weight if he continues to eat as much as he does, but he is unable to do anything about it. Contrary to Thomas's experience, Annabelle was able to control her eating behaviours, although her weight management attempts had a different socio-emotional effect on her.

"[...] I was running out of energy, so I was constantly tired and grumpy and I didn't really want to eat anything 'cause I didn't want that comment to be made again. But then we got rid of that person." (Annabelle)

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 don't have like loads of food but like I have more than most children have. And umm they/ people are always making comments. Like 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)

Annabelle explained that she became conscious of her eating habits and worried about what her peers thought about her weight. She explained that she was *"definitely smaller"* than when this comment was initially made—noting that the comment spurred her to begin watching her weight. Saying: *"I was getting worried about what people were thinking, and so I started eating less"*. Annabelle noted that this had a negative effect on her mood and energy levels, saying: *"I was running out of energy, so I was constantly tired and grumpy"*.

Thomas and Annabelle's experiences highlight the socio-emotional effect that an increase in appetite due to medication has on their eating behaviours, weight and wellbeing. Both Annabelle and Thomas had a desire to modify their intake to manage the effect on their weight. While Thomas felt unable to do so, leaving him feeling helpless about his situation (e.g., 'can't help it' comment quoted above), Annabelle was able to; however, this also negatively affected her wellbeing (e.g., affecting her energy levels). While Annabelle wanted to lose weight to avoid negative comments (weight-stigma) from her peers, it was more functional for Thomas. He said:

"I just don't like it, I just never wanted to put on weight. I used to actually be fit and now I can't even run an 100 metre sprint without gasping for air. And it's like urgh. [...]" (Thomas)

Thomas went on to say that he used to be a runner on his school team, however he was unable to keep up and enjoy running due to his weight gain.

“[...] obviously this appetite, so even if, if I did want to be a runner again, I wouldn’t be able to ‘cause now I’ve put on so much weight. It’s like urgh.” (Thomas)

Thomas’s repetition of “*urgh*” when talking about his weight gain demonstrates his frustration. Thomas described being unable to continue with a team sport due to his weight. This is notable as Thomas was very socially isolated; at the time of the interview he had not attended school in some time (pre-pandemic) and rarely left the house. This made his withdrawal from social activities due to his weight more notable and increased the time he spent at home alone. As such, it was also possible that boredom played a role in Thomas’s increased food consumption.

4.3.4 Summary

This study aimed to capture the mealtime experiences of YP with TS, paying particular attention to challenges and how traits and characteristics shaped their eating behaviours and mealtime experiences; a topic and perspective that had not been qualitatively explored. Attention was also paid to the perceived impact of these challenges and how YP with TS navigated them. The findings illuminated the role tics played in mealtime experiences; disrupting mealtimes to varying degrees and being a source of anxiety and self-consciousness when eating out of home. Eating behaviours appeared to be influenced by sensory sensitivities, rigidity and appetite stimulation attributed to Aripiprazole. Sensory sensitivity and rigidity influenced food preferences, including the

preparation and presentation of food. However, preferences were not viewed as a mealtime challenge by YP due to food autonomy and parental compliance. Notably, the factor that appeared to be identified as the most challenging for YP, was the uncomfortable nature of eating out of home. Additionally, two YP also struggled with managing the indirect effect Aripiprazole had on their weight, eating behaviours and self-concept.

4.4 Discussion

Considering the diverse influences on YP's eating behaviours, their mealtimes are best understood in the context of their lived experiences and through their accounts. This mixed-method chapter presented two of the first studies to explore the eating behaviours and mealtime experiences of YP with TS centring their perspective. This chapter had two overarching aims, firstly to explore the eating behaviours and mealtime environments of YP with TS and how they compare to their typically developing peers. Secondly, to identify mealtime challenges experienced by YP with TS and understand their impact and how they are navigated. The proceeding paragraphs will discuss the findings, focusing on eating behaviours and then turning to mealtime experiences.

4.4.1 Eating Behaviours

YP with TS reported greater levels of selective eating than controls, although the prevalence of selective eating within this sample was still relatively low (6.7%) in comparison to early childhood prevalence (Callie L. Brown et al., 2016; Taylor et al., 2015). Unexpectedly, there were no significant differences in sensory sensitivity and taste reactivity between YP with TS and typically developing controls, despite previous parent report research finding higher levels of sensory sensitivity and taste/smell sensitivity in

YP with TS compared to typically developing controls (Smith et al., 2019). Nevertheless, as mean sensory sensitivity scores were normative for both groups and did not differ significantly between groups, it is understandable that YP with TS also reported similar levels of sensory-based eating problems to controls. However, it is unclear why selective eating levels were greater for YP with TS if sensory sensitivity levels did not differ.

While research has consistently highlighted sensory sensitivity as a common underlying mechanism for selective eating, sensory sensitivity only accounts for 15% of the variance (Zickgraf & Elkins, 2018). Research by Zickgraf et al. (2020) suggests that cognitive and behavioural rigidity may be a maintaining factor for selective eating. Thus, this may explain greater levels of selective eating in the TS sample, as rigidity has also been noted as part of the TS cognitive profile (Morand-Beaulieu et al., 2017). Interestingly, single-food focus was positively associated with selective eating for the TS group, which supports the notion that selective eating in YP with TS may be rooted in rigidity (as previously discussed in chapter three, single-food focus may be a proxy for rigid eating). Single-food focus was not significantly related to sensory sensitivity or taste reactivity for both groups. Selective eating was also not associated with any of the other sensory-based eating behaviours for both groups, and there were no significant differences between groups for any of the sensory eating behaviours. While rigidity was not measured in the quantitative study, it did arise as a theme in the qualitative study supporting the notion that rigidity may maintain selective eating.

In the qualitative study, eating behaviours appeared to be influenced by both sensory sensitivity and rigidity. In most cases, YP with TS did note some sensory-based food preferences, although they did not view these as problematic. This aligns with findings by Zickgraf and Elkins (2018) that suggest there may be developmental differences in

the role that sensory sensitivity plays in the maintenance of selective eating, as the relationship between sensory sensitivity and selective eating was significantly stronger for children and young adults. Research with typically developing and neurodiverse populations suggest that sensory challenges may attenuate over time as people desensitise to their environments (Dovey et al., 2019; Zickgraf et al., 2020). So while sensory problems may lead to selective eating during early childhood, other factors such as rigidity may maintain selectivity. Also, YP with TS in the qualitative study did not view their diet as limited due to their sensory preferences, which may explain the lack of relationship between sensory sensitivity and selective eating in the quantitative study. Therefore, rigidity may maintain selective eating beyond the normative period (age six years) by codifying what foods are and are not preferred rather than selective eating being an expression of their ‘current’ sensory sensitivity. For example, Zickgraf et al. (2020) described the manifestation of rigidity in the context of eating as a repetitive diet, food rules and black and white thinking (e.g., thinking that all new or non-preferred food is bad). Thus, these rigid behaviours and cognitions solidify preferences and establish inflexibility, which may maintain and characterise selective eating.

While YP in the qualitative study drew upon sensory language to explain their preferences, what appeared to be more prominent was their lack of flexibility. The qualitative study also found that sensory preferences and rigidity were entwined. For example, some YP described sensory-based food rules (e.g., wet foods must not mix with dry foods) and sensory-based black and white thinking (e.g., cooking vegetables makes the taste and texture unpleasant). This demonstrates the codification of sensory preferences into food rules and expectations. The level of rigidity notably varied between participants, as did the specificity of sensory preferences. For example, many

YP with TS noted preferences related to how food was cooked and plated, and described engaging in specific eating practices. This form of mealtime rigidity has also been documented in YP with ASD (e.g., Rogers et al., 2012).

Nevertheless, this was the first study to document mealtime rigidity in YP with TS. Future research is needed to unpack the relationship between sensory sensitivity and rigidity to improve our understanding of persistent selective eating. In the same way, the Brief Autism Mealtime Behaviors Inventory (BAMBI) (DeMand et al., 2015) separates selective eating from mealtime rigidity when assessing mealtime challenges parents of a young person with ASD may face, future research would benefit from exploring these as separate, albeit interlinked, factors to gain a deeper understanding of how rigidity shapes the eating behaviours of YP with TS.

It is also important to note that almost all of the YP in the qualitative study had OCD or traits of OCD as part of their TS symptomology. This is to be expected as research has found that OCD and TS are entwined, sharing genetic overlap and traits (Hirschtritt et al., 2018); although the OCD experienced by people with TS is clinically and statistically different to ‘pure’ OCD (Cavanna et al., 2009). Therefore, obsessive-compulsions may account for some of the mealtime rigidity. For example, a review by Bozzini et al. (2018) found that patients with OCD demonstrated greater levels of anxiety, disgust and eating behaviour inflexibility. Common selective eating characteristics of patients with OCD are: rejecting food others touched or that had been mixed, food that touched a plate, and texture-based food refusal. Considering that literature exploring the relationship between OCD, rigidity, and their relationship with selective eating and other non-anorexia-based eating behaviours is scarce (review by

Bozzini et al., 2018 only found four studies), future research needs to further explore the complex relationships between obsessive compulsions and rigidity around food and mealtimes.

Another influence on eating behaviours that arose from the qualitative interviews was medication. Two YP with TS were taking Aripiprazole, both of whom found the appetite-stimulating side effect challenging due to the undesired weight gain that followed. Both attempted to manage their weight to varying degrees of success and noted socio-emotional consequences. While Annabelle discussed her weight dissatisfaction stemming from negative comments from her peers, Thomas discussed the impact his weight gain had on his athletic ability. While only based on findings from two participants, this finding mirrors that of Wills et al. (2006) who found that gender influenced how boys and girls felt about their weight. In Wills et al. (2006), boys were concerned with being 'slowed down' by their weight, whereas girls were concerned by how their weight impacted their ability to wear 'nice' clothes. Considering that appetite stimulation and weight gain are common side effects of antipsychotics (Baeza et al., 2017) and that antipsychotics are regularly prescribed to YP with TS (Quezada & Coffman, 2018), future research should further explore the effect of medication on the eating behaviours, mealtime experiences and psychosocial wellbeing of YP with TS. Such research should account for gender differences. This is particularly important as recent evidence suggests a surge in sudden onset tic disorders in adolescent girls (Heyman et al., 2021). YP with TS may benefit from support managing the side effects of Aripiprazole and other medications known to influence weight. YP with TS already feel stigmatised due to their tics. It is possible that weight stigma may further complicate

the relationship YP with TS have with their bodies, which could increase their risk of engaging in risky behaviours (e.g., self-harming) or disordered eating (Pont et al., 2017).

Lastly, findings from this study also reflected that of the wider literature, with most YP with TS expressing autonomy over their food choices. Adolescence as a life stage is marked by increasing autonomy and responsibility in main domains of life (Wray-Lake et al., 2010), food included. Bassett et al. (2008) found that YP (aged 13 to 19 years) exercised considerable autonomy over their food choices. They noted that food autonomy was constructed by YP and their parent(s) as a process of give and take. Increasing levels of food autonomy also came with a responsibility to make wise food choices. More research is needed to understand the process of autonomy during adolescence and how it relates to selective eating. In this study, YP with TS did not view their eating behaviours or mealtime rigidity as problematic, instead merely a preference. Presumably, parents might have a different perspective, as research suggests that mothers of YP with ASD find selective eating and mealtime rigidity stressful (Rogers et al., 2012; Suarez et al., 2014; Thullen & Bonsall, 2017). The following chapter provides more information about the maternal perspective on the eating behaviours of YP with TS and how their behaviours shape the family mealtime experience.

4.4.2 Mealtime Experiences

In the quantitative study, there was no significant difference in the evening family meal frequency and duration between groups despite proportionally more YP with TS reporting longer (30 minutes vs 15 minutes) and more frequent (50% of YP with TS reported daily evening family meals compared to less than a quarter of controls) evening

family meals. Considering the key role that mealtime interactions and atmosphere play in mediating the positive outcomes associated with family meals (Dallacker et al., 2019; Skeer et al., 2017), research should explore the nature of family meals for YP with TS. To capture family mealtime quality beyond using frequency as a proxy, the Family Dinner Index was used. This measure assessed YP's reports of positive mealtime attributes associated with their family meals, providing an indication of the warmth of their mealtime environment. There was no significant difference found in reports of positive mealtime attributes between groups, and the mean score was above the cut-off, suggesting that both groups experienced warm and positive family mealtime environments. However, the measure demonstrated poor internal consistency for the TS group; this was due to the digital distraction item (*"How often are people allowed to talk, send messages, or watch something during family dinners using personal devices [for example, phones]?"*) being reverse scored (as per the authors' instructions).

Skeer et al. (2017) suggest that less use of electronic devices during family meals is a positive mealtime attribute for typically developing families. However, based on the findings of the quantitative study, not being allowed to use electronic devices during family mealtimes was negatively correlated with YP with TS's reports of togetherness (their enjoyment of family mealtimes), enjoyment (their parents perceived enjoyment of mealtimes) and mealtime communication. This suggests that using technology during mealtimes may not be a negative distraction that subtracts from the mealtime experience of YP with TS, but one that supports them to have a more positive mealtime environment.

However, Liguori et al. (2020) found that young adults would eat significantly less when distracted by a computer game than when they were not distracted. Whether this is the case for YP with TS and selective eaters needs to be explored, alongside what impact distraction has on their food intake. It is possible that less attention to their food may support selective eaters to consume more during mealtimes. Several studies have sought to improve selective eating in young children using technology (Kadomura, Li, et al., 2014; Kadomura, Tsukada, et al., 2014; Zhao et al., 2021). Though, few studies look at older selective eaters and digital distractions that take attention away from the food, as opposed to gamifying the mealtime. It is also likely that digital distractions may be an issue for parents but not for YP (Chen et al., 2019). Although, Skeer et al. (2017) developed the scale based on interviews with both parents and YP.

Why digital distractions are positive for YP with TS is unclear and requires further investigation. However, a possible explanation for this finding may be that YP with TS use technology during mealtimes to help reduce their tics or self-consciousness as technology shifts their focus (Babbage, 2021). While no correlation was found between tic severity and positive mealtime attributes for YP with TS (even when the digital distraction item was not reverse-scored), this may be because overall tic severity was assessed rather than tic severity during mealtime specifically. Research should explore what aspects of family mealtimes supports positive outcomes for YP with TS and their families as they may be different to those typically developing populations.

YP with TS in the quantitative study reported higher levels of anxiety than typically developing controls. As previously mentioned, an increase in anxiety due to the pandemic may account for the differences in anxiety levels between groups (typically

developing controls participated before the start of the pandemic, whereas YP with TS participated during). The quantitative study also searched for correlates of positive mealtime attributes; none were found for either group suggesting that YP's eating behaviours and anxiety levels are not related to their mealtime environments.

While premonitory severity and anxiety were not related to positive mealtime attributes in the quantitative study, the qualitative findings suggest that tics and anxiety factors may shape mealtime experiences. A novel finding from the qualitative interviews was how tics shaped mealtime experiences, as this was the first academic piece of work to document how tics can present a challenge during mealtimes from the perspective of YP with TS. These findings provide initial evidence supporting anecdotal evidence reported on the online forums (Bbshea2020, 2019; Goliath_Gamer, 2018; NikkiT96, 2019; rubber__toe, 2018; veryberryblue, 2018). YP with TS noted several tics (e.g., throwing, spitting and choking tics) that were disruptive to their mealtime experiences. Based on the qualitative findings, tics may affect the conviviality of family mealtimes, affecting both the ability of the young person with TS to enjoy their mealtime due to their tics and the enjoyment of other family members. YP also described tics as affecting their ability to eat and drink. Some tics made YP throw, spit, and spill food and drink. How the frequency of these tics impact the amount of food and drink they consume is unclear and would benefit from further investigation.

Another crucial mealtime challenge noted in the qualitative study was eating out of home. YP with TS found this particularly challenging due to concerns about how others perceived them and whether they would be confronted; a common challenge documented in the literature (Davis et al., 2004; Malli et al., 2016) and noted by two YP

in the qualitative study. Thomas had been physically and verbally assaulted by members of the public as a result of his tics and Annabelle experienced verbal hostility. Interestingly, 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 YP 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 conscious of their atypical behaviour, which increases anxiety, which often intensifies tics (Coffey et al., 2000; Conelea & Woods, 2008). This also aligns with the findings of Rindner (2004) who noted that embarrassment stemmed from being caught ticking and losing control over tics in public. As a result, YP with TS can become trapped in an anxiety-tic feedback loop that can seriously hinder their ability to engage in the mealtime, thus not reaping the benefits of positive mealtime experiences.

Conelea and Woods (2008) noted the importance of understanding contextual factors that evoke feelings of stress, frustration and anxiety as these emotional states were found to exacerbate tics. The qualitative findings from this chapter suggest that mealtimes, mainly eating out of home, would be a worthy context for further exploration of the relationship between emotional states and tic severity within different out-of-home food contexts (e.g., different types of dining establishments and eating at friend's houses). YP's concern about being perceived as misbehaving also highlights how stigmatised YP with TS are/feel (Cox et al., 2019; Davis et al., 2004).

Furthermore, an interesting dichotomy appeared to exist surrounding the visibility and invisibility of TS as a disability. While tics are an outward expression of TS visible to onlookers, tics do not always act as an identifier of a disability to the public. Tics can

easily be misconceived as behavioural and purposeful action (Davis et al., 2004). YP described being made visible by their disability yet also being aware that their status as someone with a disability was not necessarily visible to those who lack awareness of TS. In essence, their disability was invisible, but their difference was not.

YP experienced anxiety while eating out of home, stemming from a belief that onlookers negatively judged them and a fear of being confronted by members of the public. This subsequently had a negative effect on their mealtime experience, making mealtimes marked by anxiety, self-consciousness, and stress. These experiences align with research on TS's social impact, especially for those with coprolalia (Cox et al., 2019; Eddy & Cavanna, 2013). Cox et al. (2019) also highlighted how public perception could lead to poor self-concept, noting that YP become hyperaware that they do not conform to social norms and behavioural expectations. Poor self-concept often leads to low self-esteem, which is associated with adverse health and social outcomes; namely, internalising problems (e.g., depression and anxiety), externalising problems (e.g., substance abuse), and social problems (Mann et al., 2004). Therefore, it is crucial that YP with TS are supported in navigating activities, such as eating out of home, that may have a depleting effect on their self-concept and -esteem. Future research would benefit from exploring the mealtime experiences of adults with TS and whether these challenges persist beyond adolescence, and if so, what effect do they have on their quality of life and relationships.

In general, public spaces are challenging for people with TS as public spaces are *“saturated with regulations of ‘proper ways’ to perform symbolic display and self-representation”*, making them exclusionary by nature (Davis et al., 2004, p. 105). Mealtimes are also steeped in behavioural expectations (Packer, 2014). Therefore, the

intersection between mealtimes and being in a public space that occurs when dining out can be particularly challenging for people with TS.

Previous experiences of physical violence and hostility from others as a consequence of their tics, may lead many avoiding and fearing public spaces. In the qualitative study, most YP either avoided dining out (e.g., Thomas) or took steps to mitigate the discomfort associated with the public gaze and pressurised 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). However, the long-term effects of these experiences on YP'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 et al., 2014). This is particularly worrisome because people with TS tend to have difficulties with social and romantic relationships and struggle with loneliness (Cavanna et al., 2013; Malli et al., 2019). Malli et al. (2019) dubbed TS as a social condition "*laden with a sense of shame and loss*" (p. 841) due to the profound effects of TS on the social lives of people living with TS. For instance, stigmatisation (Malli et al., 2016), interpersonal relationship challenges (O'Hare et al., 2015) and low self-concept and self-esteem (Lee et al., 2016; Silvestri et al., 2018). Nevertheless, it is important to note that not all YP found eating out challenging (e.g., Zack and Warren), therefore only those who avoid eating out may be at risk of social isolation.

4.5 Chapter Summary

Prior to this research, mealtimes as a social context that can be challenging for people with TS had been ignored. This was the first mixed-method study to explore the eating

behaviours and mealtime experiences of YP with TS. Anxiety and selective eating were higher in YP with TS than typically developing controls, although there was no correlation between the two variables. While the quantitative study suggested that traits and characteristics associated with TS (anxiety, sensory sensitivity, and tic severity) did not shape eating behaviours or mealtime environments, the qualitative findings suggested otherwise. This demonstrates the utility of method triangulation, as different data sources can produce the same results (corroboration), exemplify with particularities (elaboration), contribute towards new insights (complementarity), or diverge (contradiction) (Brannen, 2005).

The qualitative findings highlighted the role of tics, sensory sensitivities, rigidity, and the side effects of medication have in shaping YP's eating behaviours and mealtime experiences. Tics impacted mealtimes in two ways: being disruptive during mealtimes and a source of anxiety and self-consciousness when eating out of home. Sensory sensitivity and rigidity influenced food choices, preparation, and presentation preferences. However, preferences were not viewed as a mealtime challenge by YP due to food autonomy and parental acceptance. Challenges that were noted by YP included eating out of home, and for two YP, managing their weight while on Aripiprazole. Taken together, these findings suggest some YP may benefit from support managing the side-effects of Aripiprazole and the discomfort associated with eating out of home due to the potential effect on their self-concept, quality of life and social relationships. The next chapter replicates this chapter, providing findings from the maternal perspective.

Chapter Five: A Mixed-Method Study on the Eating Behaviours of YP with TS and their Family Mealtime Experiences, Based on Maternal Accounts

5.1 Introduction

Nourishing a child forms a significant part of a caregiver's role, particularly for mothers as mothering identity is strongly tied to their role as feeders. Zivkovic et al. (2010) explained that society holds women accountable for the health and wellbeing of their child from the very moment they find out they are pregnant (e.g., see Start4Life pregnancy advice (PHE, n.d.)). Mothers internalise notions of what it means to be a 'good mother' and their child's body can serve *"as a visible metric of their mother's ability to feed and care for them"* (Elliott & Bowen, 2018, p. 502). A recent study by Gorlick et al. (2021) highlighted this as mothers were found to experience weight stigma-by-association as their child's weight called their parenting skills into question by relatives and clinicians alike. Ristovski-Slijepcevic et al. (2010) noted that maternal identity and food practices become entangled as mothers feel that part of their job as a 'good mother' involves staying apprised of developments in nutritional science so they can prepare nutritious meals and teach their children about 'healthy' eating.

Mothers are held to an unrealistic standard, by themselves and others, when it comes to feeding their families (Thompson et al., 2021); often feeling morally obliged to engage in invisible and underappreciated intensive foodwork (Bowen et al., 2014). While family mealtimes can be a source of joy, they can also be a source of stress and dissatisfaction

as mothers struggle to recreate their ideal family mealtimes (Thompson et al., 2021). Common child-related barriers to positive family mealtime experiences and sources of maternal mealtime stress are selective eating and disruptive mealtime behaviours (Middleton et al., 2020; Thompson et al., 2021).

Although feeding can be a source of stress for caregivers, in families with a selective eater this stress is magnified (for review, see Wolstenholme et al., 2020). Selective eating is normative and common during early childhood (Cardona Cano et al., 2015), however, it has been found to persist beyond early childhood and to be present in greater levels for neurodiverse YP (aged 6 to 15 years with TS, ASD and ADHD) (Smith et al., 2020). Disruptive mealtime behaviours have also been noted to be more prominent in YP with ASD, than without, and persist beyond early childhood (Curtin et al., 2015). Mealtime behaviour challenges include: (1) refusing to come to the table when it is time to eat, (2) mealtime tantrums, (3) complaining about what is served, (4) not remaining seated during meals, (5) fidgeting while eating, (6) poor table manners, (7) overfilling their mouth with food, (8) meal refusal, and (9) attention seeking during mealtimes (Curtin et al., 2015).

Considering how intertwined maternal identity is with feeding children, it seemed crucial within this doctoral study to capture maternal accounts of their child's eating behaviours and family mealtime experiences. This is particularly true for mothers of children with chronic conditions as these identity struggles are thought to be exacerbated (Tabatabai, 2020). Additionally, caregiver stress is already high for families of YP with chronic conditions (Cousino & Hazen, 2013; Lach et al., 2009). Therefore, the additional stress resulting from negative mealtime experiences and interactions could decrease familial

and caregiver resilience (Curtin et al., 2015). Stewart et al. (2015) found that parenting stress was greater for parents of YP (aged 6 to 16 years) with TS than parents of typically developing YP; with ADHD and OCD comorbidity being correlates of parenting stress, not tic severity. How selective eating and parenting stress influences the mealtime experiences of families with a young person with TS has yet to be empirically explored.

While there is no literature on the mealtime experiences of mothers of YP with TS, ASD literature can provide some insight due to the overlap between ASD and TS due to shared traits, characteristics, and comorbidity (Darrow et al., 2017). Several studies exploring the mealtime experiences of families with a young person with ASD have noted that parents face additional mealtime challenges as a result of their child's selective eating and mealtime behaviours (Curtiss, 2017; Margari et al., 2020; Thullen & Bonsall, 2017).

Lazaro and Ponde (2017) conducted a study with eighteen mothers of boys and men (aged 5 to 28 years) with ASD. They found that traits and characteristics associated with ASD shaped the food choices of boys and men with ASD, namely organic factors such as sensory sensitivity, rigidity, difficulty sucking or chewing. They also noted the role that maternal behaviour played in both reinforcing their child's food choices and encouraging a more varied diet. Lazaro and Ponde (2017) suggested that mothers who conceptualised food choices as rooted in their child's ASD were more likely to encourage permissive parenting, and that mothers who viewed their child's food choices as intrinsic also reported fewer attempts to expand their child's dietary range. This highlights the importance of understanding how mothers conceptualise their child's eating behaviour, as this influences how they respond to their child's behaviour and may

account for the persistence of selective eating (Zohar et al., 2021). For example, mothers may believe that their child's food choices are intrinsic (i.e., related to their condition) so they adopt a permissive parenting approach which means they reduce exposure to non-preferred foods and only serve safe foods which reinforces their child's selective eating. Lazaro and Ponde (2017) focused on eating behaviours and less so on the experiential aspect of mealtimes. Also, considering the large age discrepancy between the sons of the mothers who participated in the study, it is surprising to see no mention of age-related differences in the results or interpretations.

Other qualitative studies have also noted challenges mothers of YP with ASD experience. A Canadian study by Rogers et al. (2012) found that mothers of YP with ASD (aged 4 to 11 years) had to contend with more extreme forms of selective eating, beyond the normative 'picky' eating that most YP experience. Mothers described having to manage sensory aversions, a need for sameness, rigidity, and food jags (repeatedly eating the same meal for an extended period before cycling to another safe meal). Mothers also described their child as engaging in disruptive mealtime behaviours such as constantly getting up from the table and throwing food. Mothers found the combination of these challenges stressful and felt alone in trying to manage their child's eating behaviours due to system-wide barriers to accessing services.

Suarez et al. (2014) had similar findings, although they focused more on mealtime experiences than eating behaviours. Difficulty staying seated and selective eating were reasons for mealtime stress and mothers had attempted to improve their family mealtime experiences on several occasions but with little success. There was a sense of hopelessness and dissatisfaction as they were unable to create the mealtime experiences

they desired due to the eating and mealtime behaviour of their child with ASD. Ausderau and Juarez (2013) also found that mothers described mealtimes as unsatisfactory due to their child's selective eating, disruptive mealtime behaviour and the additional labour they had to undertake to make mealtimes 'work' for their families. While an inability to recreate ideal mealtimes is not unique to mothers of YP with ASD (Thompson et al., 2021), the barriers to mothers' ideal mealtimes in the ASD literature were typically attributed to their child's ASD. Mothers had to create individualised mealtime routines to accommodate the needs of their child with ASD, however, adaptations came at a cost to other members of the family (Ausderau & Juarez, 2013). Namely, typically developing siblings who needed to be mother's 'little helper' and model 'good' behaviours, and mothers who had to undertake additional foodwork with little support or understanding from their partners, friends, and relatives.

The ASD literature highlights the complexity of maternal mealtime stress and raises important questions about how mothers of YP with other neurodevelopmental diagnoses, such as TS, navigate mealtimes and what personal cost are associated with adaptations and additional foodwork. While mothers of YP with TS are anticipated to experience similar selective eating challenges to mothers of YP with ASD (and typically developing selective eaters), they are also hypothesised to experience challenges that have not been documented in the literature, for example, challenges associated with their child's tics. Families with YP with TS face system-wide barriers to accessing support for their TS and mental health needs (Bhikram et al., 2021; Ludlow et al., 2016), partly due to lack of National Institute for Health and Care Excellence (NICE) guidelines. The same is expected to be true for eating challenges, although, those with an ASD comorbidity are anticipated to have more support as eating challenges have been well-

documented in the ASD population (Neto et al., 2021), and there are NICE (2013) guidelines.

The aims of this chapter are to explore the eating behaviours of YP with TS from the perspective of mothers and to explore the effect mothers perceive their child's eating behaviours have on themselves and their family mealtime experiences. Structurally, this mixed-method chapter mirrors the structure of the previous chapter, presenting the quantitative and qualitative findings separately before discussing their joint contribution to knowledge. This chapter seeks to contribute a novel perspective on the eating behaviour of YPs with TS, the mealtime challenges mothers, and their families face, and how mothers navigate said challenges.

5.2 Selective Eating, Positive Mealtime Attributes, and Parenting Stress in Mothers of Young People with and without TS

5.2.1 Aims and Hypotheses

This quantitative study aimed to explore the differences in eating behaviours between YP with TS and typically developing controls. Additionally, this study explored differences in mealtime characteristics (frequency and duration) and correlates of selective eating, positive mealtime attributes and parenting stress. It was hypothesised that mealtime characteristics would be the same in both groups. It was hypothesised that mothers of YP with TS would report higher levels of selective eating, sensory eating behaviours, neophobia and anxiety in their children than typically developing controls. Mothers of YP with TS were also hypothesised to report higher levels of parenting stress and possibly lower positive mealtime attributes. Literature suggests an association

between maternal and child eating behaviours (Thorsteinsdottir et al., 2021; Yelverton et al., 2021), therefore, maternal selective eating was also hypothesised to be correlated with reports of YP's selective eating for both groups. Selective eating in YP was also hypothesised to be related to sensory eating problems, neophobia, anxiety and parenting stress. Finally, parenting stress was also hypothesised to be related to anxiety for both groups (Rodriguez, 2011) but not correlated with tic severity for the TS group (Stewart et al., 2015).

5.2.2 Methods

Participants

Parents were recruited with the help of Tourette's Action and Tourette's Hero. Both organisations posted details of the study on their websites and shared information on their social media pages and mailing lists. Private TS and parenting Facebook groups that provided permission to advertise to their members were also used to recruit participants for the TS sample. The typically developing sample was recruited via social media and personal networks. A total of 64 parents completed surveys: 33 parents of YP without tics and 31 parents of YP with tics. Ten of the parents of YP without tics were excluded as their child was not considered to be typically developing (parents disclosed a neurodevelopmental diagnosis). Six of the parents of YP with tics were excluded because their child was diagnosed with a tic disorder, not TS, or awaiting diagnosis. Of the remaining samples, only 20 of the parents of YP with TS were able to be age and, where possible, gender matched with typically developing controls. A further 3 pairs (6 participants) were removed from the sample as responses were provided by

fathers. Therefore, the final sample consisted of 34 mothers (17 mothers of YP with TS and 17 mothers of typically developing YP).

Thirty-four mothers (aged 38-55 years; $M = 44.88$ years, $SD = 4.26$) reported information on their child. As outlined in Table 15, most mothers defined themselves as White. Mothers were also asked for their weight and height which was converted into a BMI score using the NHS BMI calculator. Nine mothers did not provide sufficient detail for their BMI to be calculated. The BMI for mothers of YP with TS ranged between 20.30 to 39.60 ($n = 13$, $M = 29.58$, $SD = 6.83$). The BMI for mothers of typically developing controls ranged from 18.90 to 30.70 ($n = 12$, $M = 25.48$, $SD = 4.16$). Mothers were also asked for their child's weight. Half of the mothers did not provide their child's weight. Of those who did, YP with TS weighed between 30kg to 74kg ($n = 9$, $M = 55.97$, $SD = 14.16$) and typically developing controls weighed between 57.70kg to 11.08kg ($n = 6$, $M = 57.70$ kg, $SD = 11.08$).

Seventeen YP with TS (13 male, 4 female; aged between 11 years and 1 month and 16 years 5 months; $M = 13.59$, $SD = 1.96$) were age-matched to a group of typically developing YP (11 males, 6 females aged between 11 years and 3 months and 16 years and 5 months; $M = 13.77$, $SD = 1.89$). An independent-samples t-test was run to determine if there were differences in age between YP with TS and without TS. There was no significant difference in the age of YP with TS ($M = 13.59$, $SD = 1.96$) and typically developing controls ($M = 13.77$, $SD = 1.89$), $t(32) = -.27$, $p = .79$, equal variance assumed.

Twelve YP with TS were also reported to have comorbidities: ADHD (n=4), anxiety (n=7), autism (n=2), depression (n=1), learning disability (n=2), OCD (n=4), sensory processing disorder (n=1). Mothers of YP with TS were asked to complete the Parent Tic Questionnaire (PTQ) (Chang et al., 2009) for assessment of their child's tic-severity. Total PTQ total scores ranged from 4 to 115 (M = 49.53 , SD = 30.59), with the minimum and maximum range being 0 to 224. High scores indicate higher tic severity. Three of the children in the TS sample were reported to be on medication. Medications that were taken were as follows: Adderall (n=1), Aripiprazole (n=1), Guanfacine (n=1), Omap (n=1) and Sertraline (n=1). A Mann-Whitney U test was used to determine if there were differences in eating behaviours and anxiety between YP with TS who were reported by mothers to be on medication, and those who were not. Results indicated that there was no significant difference ($p > .05$) between YP with TS on medication and those not on medication.

Table 15. Demographic information for participants

	Mothers		YP	
	TS (n=17)	Controls (n=17)	TS (n=17)	Controls (n=17)
Age				
Mean (SD)	42.59 (3.36)	47.18 (3.88)	13.59 (1.96)	13.77 (1.89)
Range (years)	38 - 49	40 - 55	11.10 - 16.53	11.27 - 16.51
Biological Sex				
Female	17 (100%)	17 (100%)	13 (76.5%)	11 (64.7%)
Male			4 (23.5%)	5 (35.3%)
Ethnicity				
White	17 (100%)	14 (82.4%)	14 (82.4%)	12 (70.6%)
Black	-	1 (5.9%)	2 (11.8%)	1 (5.9%)
Asian	-	1 (5.9%)	-	1 (5.9%)
Mixed/Multiple	-	1 (5.9%)	1 (5.9%)	2 (11.8%)
Other	-	-	-	1 (5.9%)

Procedure

All participants took part using the onlinesurveys.ac.uk platform and had the option to opt-in to a prize-draw. Once the survey closed, a winner was randomly selected and contacted to claim their £25 Amazon voucher. Participant information sheets (see **Appendix Q**) provided sufficient information about the study to allow parents to decide whether or not to take part. Resources were provided at the end of the survey for parents who may wish to seek further advice should their participation raise any concerns regarding their child's eating behaviours (see **Appendix V**). The survey took ~25 minutes to complete and was live for five months during the COVID-19 pandemic (10/2020 - 02/2021). There was no missing data for this dataset.

Measures

Participants from both groups completed the same demographic questions (see **Appendix W**), four questionnaires concerning their child's eating behaviours and anxiety levels. Participants also completed two self-report questionnaires concerning their family mealtime environment and parenting stress levels. Mothers of YP with TS also completed an additional questionnaire to assess their child's tic severity. Demographic information captured included age, gender, height, weight, ethnicity, diagnosis history, and family evening meal frequency and duration. Further detail for these measures are listed below.

Modified Adult Eating Behaviour Questionnaire (AEBQ) (Hunot-Alexander et al., 2019)

The AEBQ is a 35-item self-report questionnaire which assess eating behaviours across eight subscales. The AEBQ was originally designed for use in adult populations but was recently validated for use with adolescents aged 11 to 18 years (Hunot-Alexander et al., 2019). The AEBQ was modified into a parent-report measure for parents of adolescents aged 11-16 years by changing statements from 'I' into 'my child' (e.g., *I refuse new foods at first*' was adapted to *my child refuses new foods at first*). This was deemed more appropriate than using the Child Eating Behaviour Questionnaire (Wardle et al., 2001) as this was created to capture the eating behaviours of children as young as two years of age. The 'Food Fussiness' subscale from the AEBQ was used in this study to assess parental perceptions of food fussiness behaviour, also referred to as selective eating. This 5-item subscale assesses refusal of new and unfamiliar foods, food neophobia (e.g., *My child refuses new foods at first*) and limited diet variety, picky eating (e.g., *My child enjoys a wide variety of foods*', item reverse scored). Parents responded to items using a 5-point-Likert scale ranging from 1 to 5 (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree). Some items were reverse scored, as per the authors' instructions, before calculating the mean subscale score. Higher scores indicate higher levels of selective eating. To determine whether a child was a selective eater or not, their mean score for the food fussiness scale needed to be above 4, suggesting that their average response to items on the scale were agree or strongly agree. The selective eating subscale was internally valid as a self-report measure with YP ($\alpha = .78$ in Hunot-Alexander et al. (2019)). In this study, as a parent-report measure the Cronbach's alphas were excellent for the TS group ($\alpha = .93$) and controls ($\alpha = .91$).

Positive Mealtime Attribute Scale - Parent, PMAS-P (Items currently unpublished, extracted from the development of the Family Dinner Index, see Skeer et al., 2017)

The PMAS-P is a 5-item self-report measure which assesses positive mealtime attributes associated with family mealtimes based on a recently developed unpublished self-report parental questionnaire. The development of the measure was informed by interviews with American YP aged 6 to 16 years and their parents. They asked about family mealtimes and their context, namely: family meals, parent-child relationship and family practices (Skeer et al., 2017). The larger survey for parents included 15-items related to various mealtime attributes. Based on three major themes identified in the qualitative study by Skeer et al. (2017) (feelings about family meals, use of technology and communication) and literature (e.g., Dallacker et al., 2019) the following items were assessed: Expectations (*'How often is your child supposed to be at dinners with you?'*), Togetherness (*'During a typical week in the school year, how much do you think your child likes having dinner with you?'*); Enjoyment (*'How much do you enjoy family dinners in general [note: this does not include the food being served]?'*); Communication (*'In general, how much do people talk to each other during family dinners?'*); and Digital Distractions (*'How often do people talk, send messages, or watch something during family dinners using personal devices (for example, phones)?'*, reverse scored). Participants responded to items using a 6-point Likert scale from 0 to 5 (0 = n/a, 1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = always). The Digital Distractions item is reverse coded for a total score to be calculated and was included to assess a mealtime attribute that detracts from the commensality of mealtimes (e.g., Spence, Mancini & Huisman, 2019) and has been associated with negative child outcomes (e.g., Berge et al., 2014). To aid interpretation, Dr Skeer advised to rescale between 0 and

100, then median split at 70. Scores above 70 represent higher positive mealtime attributes and a warmer mealtime environment while scores under 70 represent lower positive attributes. As an unpublished measure, there are no reliability statistics that can be used for comparison. In this study the Cronbach's alpha for the PMAS-P was questionable for the TS group ($\alpha = .67$) and acceptable for controls ($\alpha = .72$).

Modified Spanish Child Neophobia Scale (M-SCFNS) (Maiz et al., 2016)

The SCFNS is an 8-item self-report questionnaire which measures child neophobia that modified the Food Neophobia Scale (Pliner & Hobden, 1992) to be acceptable to YP 8 to 16 years by Maiz et al. (2016). While the SCFNS was developed to be used with children in Spanish, the authors provided an English translation of the scale in their paper. The English version of their scale was used in this study, although it was adapted to be used as parent-report as opposed to self-report: 'I' statements were replaced with 'my child' (e.g., *'I am very particular about the foods I eat'* changed to *'my child is very particular about the foods they eat'*). Items include *'even if my child does not know what a food is, they will try it'* (reverse scored), *'if my child's friends eat something they have never eaten before, my child is motivated to try it'* (reverse scored) and *'my child is fussy when it comes to food'*. Participants responded to statements using a 5-point Likert scale, with options ranging from 1 to 5 (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = always). Some items were reverse scored, as per the authors' instructions, before calculating the sum score. Higher scores indicate higher levels of food neophobia. In Maiz et al. (2016) as a self-report measure, the Cronbach's alpha was good ($\alpha = .81$). In this study as a parent-report measure, the Cronbach's alpha was excellent for the TS group ($\alpha = .95$) and good for controls ($\alpha = .88$).

Parental Stress Scale (PSS) (Berry & Jones, 1995)

The PSS is a 18-item self-report questionnaire which examines parental stress, capturing both positive themes of parenthood (e.g., enrichment) and negative components of parenthood (e.g., restrictions). The measure has been validated for use with both mothers and fathers with children with and without clinical conditions. Participants are asked to consider each statement that describes a feeling or perception about parenthood and to respond based on how their relationship with their child typically is. Statements include *'I am happy in my role as a parent,' 'the major source of stress in my life is my child(ren)'* and *'I feel overwhelmed by the responsibility of being a parent'*. Participants responded to each statement using a 5-point Likert scale ranging from 1 to 5 (1 = strongly disagree, 2 = disagree, 3 = undecided, 4 = agree, 5 = strongly agree). Some items were reverse scored, as per the authors instructions, before summing all items for a total score. Higher scores indicate higher levels of parenting stress. In Berry and Jones (1995) was good ($\alpha = .83$). In this study the Cronbach's alphas for both samples were also good ($\alpha = .85$ for the TS group and $\alpha = .89$ for controls).

As data were collected during the COVID-19 pandemic, it was considered important to capture how participants perceived their parenting stress levels at the time of completion compared to their 'usual' stress levels. At the end of the PSS questionnaire, participants were asked to select which of the following three statements most applied to them: (1) I feel LESS stressed than I was before COVID-19 and lockdown, (2) I feel the SAME as before COVID-19 and lockdown, (3) I feel MORE stressed than I was before COVID-19 and lockdown. Mothers of YP with TS were more likely to be more stressed than

they were pre-pandemic than mothers of typically developing controls (64.7% vs 35.5%). Mothers of YP who were typically developing were more likely to feel the same (47.1%) or less stressed (17.6%) than mothers of YP with TS (same 23.3% and less 1.8%). It is important that the effect of the pandemic on parenting stress levels is taken into consideration when interpreting parenting stress.

Sensory Eating Problem Scale (SEPS) (Seiverling et al., 2019)

The SEPS is a recently published 22-item parental-report questionnaire which examines specific sensory eating problems, allowing for more detailed measurement of sensory eating problems than existing measures, such as Dunn's sensory profiles which explore sensory challenges across many domains (Seiverling et al., 2019). The measure assesses six sensory eating problems: Food-Touch Aversion (e.g., *'My child has a clear dislike for food touching his/her lips'*), Single-Food Focus (e.g., *'My child accepts only one flavour of a certain type of food [e.g., strawberry yogurt]'*), Gagging (e.g., *'My child gags when food touches his/her tongue'*), Temperature Sensitivity (e.g., *'My child will only eat foods that are warm'*), Expulsion (e.g., *'My child uses his/her fingers to take food out of his/her mouth'*), and Overstuffing (e.g., *'My child attempts to swallow bites of food without chewing'*). Participants responded to items using a 5-point Likert scale from 0 to 4 (0 = never, 1 = rarely, 2 = sometimes, 3 = often and 4 = always). A slight modification was made to make the measure more acceptable to a wider audience, which was to include a definition of 'expel' for question 10 (*'My child expels food or liquid'* in the original scale was changed to *'My child expels [definition: to force something out of the body] food or liquid'*). Each subscale was summed to create a score. Higher scores indicate that higher levels of the attribute. Reliability statistics for the SEPS subscales ranged between .70 and .85 (Seiverling et al., 2019). However, in this study Cronbach's

alphas for both samples varied across scales from unacceptable to good ($\alpha = .00$ to $.89$), see Table 17.

Screen for Anxiety Related Emotional Disorder (SCARED) (Birmaher et al., 1999)

The SCARED is a 41-item parent-report questionnaire which assesses which assess anxiety-related symptoms across 5 domains: Panic Disorder or Significant Somatic Symptoms (e.g., *'When my child gets frightened, he/she feels like throwing up'*); Generalized Anxiety Disorder (e.g., *'My child worries about being as good as other kids'*); Separation Anxiety (e.g., *'My child has nightmares about something bad happening to his/her parents'*); Social Anxiety (e.g., *'It is hard for my child to talk with people he/she doesn't know well'*); and Significant School Avoidance (e.g., *'My child gets stomach-aches at school'*). Participants are advised to consider the past 3 months and how true the statements are for their child using a 3-point Likert Scale from 0 to 2 (0 = not true or hardly ever true, 1 = somewhat true or sometimes true, 2 = very true or often true). The total score across all subscales was used to assess anxiety levels, with higher scores indicating higher levels of anxiety. Scores above 25 are considered diagnostic of an anxiety disorder. The scale has been validated for use with parents of children age 8 to 18 years in diverse clinical and community samples. Reliability statistics for the total score was excellent ($\alpha = .90$) (Birmaher et al., 1999). In this study, the Cronbach's alphas were also excellent for the TS group ($\alpha = .98$) and controls ($\alpha = .94$).

Data collection for both groups occurred during the COVID-19 pandemic, as such, it was considered to be important to capture how participants perceived their child's

anxiety levels at the time of completion to compare to their child's 'usual' anxiety levels. Similar to the study with YP (chapter four), at the end of the SCARED questionnaire, participants were asked to select which of the following three statements most applied to their child: (1) my child feels LESS anxious than he/she was before COVID-19 and lockdown, (2) my child feels the SAME as before COVID-19 and lockdown, (3) my child feels MORE anxious than he/she was before COVID-19 and lockdown. Almost half (47.1%) of YP with TS were described by their mothers to have the same anxiety levels at the time of participation as pre-pandemic. This number was higher for typically developing YP where over half (58.8%) were described by their mothers have the same anxiety levels. More YP with TS were described by their mothers as being more anxious than pre-pandemic than typically developing controls (41.2% vs 25.3%). It is important that the effect of the pandemic on anxiety levels is considered when interpreting anxiety levels for both groups.

Parent Tic Questionnaire (PTQ) (Chang et al., 2009)

While PUTS was used as a self-report measure to assess premonitory urge severity in the previous chapter, the PTQ was used in this study as a reliable parent-report measure to assess tic severity. Prior research has demonstrated a significant correlation between child self-report PUTS scores and parent-report PTQ scores (Raines et al., 2018). The PTQ is a questionnaire which assesses parent-perceived child tic severity by measuring the presence, frequency, and intensity of 14 common motor tics and 14 common vocal tics. Parents are asked to consider tics that occurred within the past week when completing the questionnaire. Parents rate the frequency of tics using a 4-point Likert scale from 1 to 4 (1 = weekly, 2 = daily, 3 = hourly, 4 = constantly) and the intensity using a 4-point Likert scale from 1 to 4 (1 = minor, 2 = obvious, 3 = very bad, 4 = extreme).

Instructions for intensity ratings were: *“Rate how intense you believe the tic felt to your child over the past week. For example, if it was very mild, like a weak twitch, that would be a 1. A much more forceful tic that would be very noticeable to others and may even be painful would be rated as a 3 or even higher. Any tic that would be obviously noticeable to others should be rated as at least a 2”*. Frequency and intensity are summed, yielding a score of 0 to 8 for each tic. Each tic score is then summed to create a total score for motor tics (range 0 to 112) and vocal tics (range 0 to 112). The motor and vocal tic scores are summed for the total tic severity score (range 0 to 224). Higher scores indicate higher tic severity. Reliability statistics for the total tic severity score was excellent ($\alpha = .90$) in Chang et al. (2009). In this study, the Cronbach’s alpha was also excellent for the TS group ($\alpha = .93$).

Analysis

All analyses were computed using the SPSS version 26. Mealtime characteristics were normally distributed, as such t-tests were used to assess differences between groups. However, all the measures of interest within this study were deemed to be not normally distributed based either on kurtosis, skewness, or Shapiro-Wilk (see **Appendix X**). As such, only non-parametric tests were used to assess differences between groups (Mann-Whitney U) and relationships (Spearman’s correlation).

Data was analysed to establish whether the age of mothers and YP, BMI scores, YP’s weight⁴ and gender were correlated with selective eating, parenting stress and positive

⁴ As with previous chapters, BMI-SDS were beyond the normative range suggesting errors with the data, therefore weight alone was used to see whether there was any relationship between a young person’s weight and factors of interest.

mealtime attributes for both groups. No significant correlations were found ($p > .05$), therefore none of these factors were controlled for in further analyses.

5.2.3 Results

Descriptive Results

As outlined in Table 16, most of the mothers who participated had one or more additional adults and children in the family home (not including themselves and the child of interest). Additionally, the results indicate that there was no significant difference in family evening meal frequency between families with and without a young person with TS, $t(32) = -1.74$, $p = .09$, equal variance assumed. The results indicate that there was no significant difference in family evening meal duration between families with and without a young person with TS, $t(25.92) = .57$, $p = .57$, equal variance not assumed. Most mothers reported having at least 4 family meals a week usually lasting 30 minutes or less.

Table 16. Household numbers, evening family meal frequency and duration for YP with TS and typically developing controls based on maternal reports

	TS (n=17)	Controls (n=17)
Additional Adults (≥ 18 years) in the household		
0	2 (11.8%)	2 (11.8%)
1	8 (47.1%)	13 (76.5%)
2	6 (35.3%)	2 (11.8%)
3	1 (5.9%)	-

Additional Children (< 18 years) the household		
0	3 (17.6%)	2 (11.8%)
1	8 (47.1%)	11 (64.7%)
2	5 (29.4%)	1 (5.9%)
3	1 (5.9%)	3 (17.6%)
Evening Family Meal frequency (per week)		
0	-	-
1	4 (23.5%)	1 (5.9%)
2	2 (11.8%)	-
3	-	-
4	4 (23.5%)	6 (35.3%)
5	2 (11.8%)	3 (17.6%)
6	2 (11.8%)	2 (11.8%)
7	3 (17.6%)	5 (29.4%)
Average Evening Family Meal Duration		
15 minutes or less	2 (11.8%)	6 (35.3%)
30 minutes	14 (82.4%)	8 (47.1%)
45 minutes	1 (5.9%)	3 (17.6%)
An hour or more	-	-

Means and standard deviations for the measures are presented in Tables 17 and 18. Higher mean scores indicate higher levels of the attribute were reported. Based on a cut-off selective eating mean score of 4, proportionally more YP with TS were classified as selective eaters (n=13, 17.6%) than typically developing YP (n=2, 11.8%). Similarly, proportionally more mothers of YP with TS were also classified as selective eaters (n=2, 11.8%) than mothers of typically developing YP (0%). The mean anxiety score for YP with TS is above the cut-off (≥ 25) suggesting there may be a presence of an anxiety disorder. A third (n= 6, 35%) of mothers of YP with TS had reported anxiety scores above the cut-off. The mean anxiety score for typically developing YP falls below the

cut-off, however, 11.8% (n=2) had anxiety scores above the cut-off. Positive mealtime attributes for both groups was also above the cut-off (≥ 70), suggesting mothers experienced high levels of positive mealtime attributes and a warm mealtime environment.

Differences Between Groups

A series of Mann-Whitney U tests were conducted to determine if YP with TS were reported to show higher levels of selective eating, neophobia, sensory eating behaviours and anxiety than typically developing controls. Distributions for most of the factors for both samples were not similar, as assessed by visual inspection. The factor that was similar was gagging. As such, medians were reported for gagging. The other factors have median rank reported due to dissimilar distribution.

As indicated in Table 17, there were significant differences in reported levels of food-touch aversion in YP with TS and typically developing controls using a sampling distribution for U (Dineen & Blakesley, 1973). Distribution for food-touch aversion were not similar across groups, as assessed by visual inspection. Mothers of YP with TS reported greater levels of food- touch aversion in their child (mean rank = 21.09) than mothers of typically developing controls (mean rank = 13.91), $U = 83.50$, $z = -2.72$, $p = .03$. Scores for all other measures were not significantly different. No other significant differences were found despite proportionally more YP with TS being classified as selective eaters (17.5% vs 11.8%) and anxious (35% vs 11.8%) than typically developing controls.

Table 17. Means, standard deviations and Mann-Whitney U results for all factors related to YP

Measures	Subscale	TS (n=17)					Controls (n=17)					Mann-Whitney U		
		Alpha	Mean	SD	Mean Rank	Median	Alpha	Mean	SD	Mean Rank	Median	U	<i>z</i>	<i>p</i>
AEBQ	Child Selective Eating	.93	3.04	1.06	20.09	-	.91	2.51	.85	14.91	-	100.50	-1.53	.13
M-CFNS	Neophobia	.95	23.94	7.45	18.88	-	.88	22.12	7.18	16.12	-	121.00	-.81	.43
SEPS	Temperature Sensitivity	.73	.59	.69	18.06	-	.43	.46	.51	16.94	-	135.00	-.35	.76
SEPS	Single-Food Focus	.65	.96	.88	20.38	-	.69	.47	.59	14.62	-	95.50	-1.73	.09
SEPS	Food-Touch Aversion	.50	.21	.30	21.09	-	.00*	.01	.06	13.91	-	83.50	-2.72	.03

SEPS	Gagging	.52	.38	.51	-	.00	.63	.18	.30	-	.00	112.50	-1.27	.27
SEPS	Expulsion	.86	.43	.64	19.68	-	.58	.16	.34	15.32	-	107.50	-1.50	.21
SEPS	Overstuffing	.82	.88	.95	18.65	-	.89	.73	1.08	16.35	-	125.00	-.71	.52
SCARED	Child Anxiety	.98	25.24	21.73	20.50	-	.94	13.47	12.53	14.50	-	93.50	-1.76	.08
PTQ	Tic Severity	.93	49.53	30.59	-	-	-	-	-	-	-	-	-	-

NOTE: Higher scores indicate higher levels of the attribute for all measures

* All participants responded the same, no standard deviation to calculate the Cronbach's alpha.

COLOUR KEY

Orange highlights indicate significance $p < .05$.

Yellow highlights indicates that the measure is above cut-off

Purple highlights suggest that the alpha is $< .60$.

A series of Mann-Whitney U tests were conducted to determine if mothers of YP with TS reported higher levels of maternal selective eating and parenting stress than mothers of typically developing controls. Mann-Whitney U tests were also conducted to determine if mothers of YP with TS reported fewer positive mealtime attributes than mothers of typically developing controls and if there were BMI differences between mothers. Distributions for all the factors for both samples were not similar, as assessed by visual inspection therefore median rank is reported. As indicated in Table 17. there were no significant differences in levels of selective eating, parenting stress and positive mealtime attributes between groups using a sampling distribution for U (Dineen & Blakesley, 1973).

Correlates of Selective Eating, Positive Mealtime Attributes and Parenting Stress

Two-tailed Spearman's correlations were used to explore the relationships between selective eating in YP and mothers, with YP's eating behaviours and anxiety levels. As indicated in Table 19, greater selective eating in mothers of typically developing controls was associated with greater levels of selective eating in their children, $r(15) = .60, p = .01$. The same relationship was not found in the TS group. Mother's reports of their child's eating behaviours (sensory eating behaviours and neophobia) and anxiety levels were not found to be correlated to maternal selective eating for either group.

Table 18. Means, standard deviations and Man-Whitney U results for all factors related to mothers

Measures	Subscales	TS			Controls			Mann-Whitney U		
		Mean	SD	Mean Rank	Mean	SD	Mean Rank	U	<i>z</i>	<i>p</i>
AEBQ	Mother Selective Eating	2.47	.94	18.62	2.08	.44	16.38	125.50	.50	.52
PSS	Parenting Stress	37.06	7.28	16.79	37.88	10.32	18.21	156.50	.41	.68
PMAS-P	Positive Mealtime Attributes	76.24	14.18	15.65	79.06	11.00	18.35	159.00	.50	.63
BMI		29.54	6.83	8.67	25.48	4.16	7.00	21.00	-.71	.53

NOTE: Higher scores indicate higher levels of the attribute for all measures

COLOUR KEY

Yellow highlights indicates that the measure is above cut-off.

Blue highlights indicate that the score is above 'healthy' BMI range

In the TS sample, greater maternal report of their child's selective eating was correlated with increased single-food focus, $r(15) = .50, p = .04$, temperature sensitivity, $r(15) = .72, p = .001$, and neophobia, $r(15) = .90, p < .001$. None of the other sensory eating behaviours or anxiety were significantly correlated with selective eating in YP with TS. For the control group, greater maternal report of their child's selective eating was correlated with lower levels of expulsion, $r(15) = -.52, p = .03$, and greater levels of neophobia, $r(15) = .78, p < .001$. None of the other sensory eating behaviours or anxiety were significantly correlated with selective eating in YP with TS.

Two-tailed Spearman's correlations were used to explore the correlates of positive mealtime attributes and parenting stress. As indicated in Table 20, greater parenting stress levels in mothers of typically developing controls were correlated with lower levels of maternal selective eating $r(15) = -.72, p = .001$, and greater levels of child anxiety, $r(15) = .63, p = .01$. None of the other factors were significantly correlated with parenting stress and no factors were positively correlated with positive mealtime attributes for either group.

Table 19. Child correlates of selective eating in YP and mothers

Measure	Subscale	Selective Eating in YP				Selective Eating in Mothers			
		TS		Controls		TS		Controls	
		<i>r</i>	<i>p</i>	<i>R</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
AEBQ	Selective Eating in YP	-	-	-	-	-.43	.09	.60	.01
SEPS	Food-Touch Aversion	.20	.44	-.24	.36	-.00	.99	-.08	.76
SEPS	Single-Food Focus	.50	.04	.39	.13	-.02	.95	.26	.31
SEPS	Gagging	.42	.10	-.27	.30	-.16	.55	-.26	.32
SEPS	Temperature Sensitivity	.72	.001	-.21	.42	-.39	.12	-.09	.73
SEPS	Expulsion	-.08	.76	-.52	.03	-.09	.74	-.30	.25
SEPS	Overstuffing	.19	.48	.21	.43	.14	.58	.05	.85
M-CFNS	Neophobia	.90	.000	.78	<.001	-.34	.18	.41	.11
SCARED	Anxiety	-.17	.51	-.27	.29	.11	.68	-.25	.34

COLOUR KEY
 Orange highlights indicate significance $p < .05$

Table 20. Correlates of positive mealtime attributes and parenting stress

Measure	Subscale	Positive Mealtime Attributes (PMAS-P)				Parenting Stress (PSS)			
		TS		Controls		TS		Controls	
		<i>R</i>	<i>p</i>	<i>R</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
AEBQ	Selective Eating in YP	.01	.98	-.04	.89	.26	.31	-.43	.09
AEBQ	Selective Eating in Mothers	-.20	.44	.16	.53	-.06	.83	-.72	.001
SEPS	Food-Touch Aversion	-.37	.15	.41	.10	.25	.34	-.05	.85
SEPS	Single-Food Focus	-.20	.44	.30	.25	.33	.20	.00	.99
SEPS	Gagging	-.26	.32	-.13	.62	.00	.99	.47	.06

SEPS	Temperature Sensitivity	-.40	.11	-.03	.90	.16	.54	.36	.15
SEPS	Expulsion	-.06	.81	-.11	.67	-.27	.30	.46	.07
SEPS	Overstuffing	-.47	.06	-.31	.22	-.47	.06	.40	.11
M-CFNS	Neophobia	.12	.65	-.02	.94	-.08	.76	-.29	.26
SCARED	Anxiety	-.26	.32	.14	.61	-.13	.61	.63	.01
PTQ	Tic Severity	.46	.06	-	-	.22	.39	-	-

COLOUR KEY

Orange highlights indicate significance $p < .05$

5.2.4 Summary

There were no differences found in mealtime frequency or duration. Mothers of YP with and without TS reported having at least 4 family meals a week that usually lasted 30 minutes or less. There were also no significant differences in reported positive mealtime attributes, with both groups having a mean above the cut-off which suggests mealtime environments were warm and positive.

Proportionately there were more selective eaters in the TS group, both YP and mothers, than in the control group. However, the difference in selective eating for both YP and mothers were not significant. The only significant difference between the reported eating behaviours of YP with TS and typically developing controls was for food-touch aversion. Mothers of YP with TS reported their child to have greater levels of food-touch aversion than controls. Neophobia and none of the other sensory eating behaviours significantly differed between groups.

Additionally, while there was no significant difference in maternal selective eating between groups, maternal selective eating in the typically developing group was significantly correlated with their child's selective eating. This suggests that factors other than modelling may influence selective eating in neurodiverse samples. Greater reports of selective eating in YP with TS was associated with greater single-food focus, temperature sensitivity and neophobia. While neophobia was also associated with selective eating in typically developing YP, single-food focus and temperature sensitivity were not. Greater selective eating in typically developing YP was associated with lower levels of expulsion. Despite proportionally more YP with TS having a reported anxiety score above the cut-off than typically developing controls (35.3% vs 11.8%), the

difference between groups was not significant. This may be due to the varying impact of the pandemic on anxiety levels for YP with TS and typically developing controls; some YP were reported to experience an increase in anxiety levels (41% for TS group, 35.3% for controls), others experience a decrease (11.8% for TS group, 5.9% for controls).

Similarly, there was not a significant difference in parenting stress between groups and parents reported varying effects of the pandemic on their stress levels; some mothers reported less parenting stress during the pandemic (11.8% for TS group, 17.6% for controls), while some reported more (64.7% for TS group, 35% for controls). Nevertheless, correlates of parenting stress differed between groups, with greater parenting stress in mothers of typically developing YP being associated with greater child anxiety and lower levels of maternal selective eating. There were no correlates of parenting stress for mothers of YP with TS, including tic severity.

Taken together, these results suggest that there are differences in correlates of selective eating and parenting stress for mothers of YP with TS and mothers of typically developing controls. Yet despite these differences, they experience similar mealtime duration, frequency, and positive mealtime attributes. How mothers of YP with TS perceive their child's eating behaviours and the nature of their mealtime experiences remain unanswered and are aimed to be addressed in the qualitative study that follows.

5.3 Phenomenological Examination of the Mealtime Experience for Mothers of Young People With TS

5.3.1 Aims and Research Questions

The previous chapter provided the first qualitative study to capture how YP with TS conceptualised their symptomology to influence their eating behaviours and mealtime experiences. The perspective of mothers of YP with TS who are often the main food provider and share mealtimes with them has yet to be explored. This study sought to fill this gap by phenomenologically exploring the mealtime experiences of mothers of YP with TS or a Persistent Tic Disorder (PTD), and understanding how mothers conceptualise their child's symptomology to influence their child's eating behaviours and the subsequent effect this has on themselves and their family mealtime experiences. Mothers are able to shed light on how symptoms of their child's tic disorder (both TS and PTD) and associated comorbid conditions interplay to make mealtimes complex.

Family mealtimes were explored within multiple social contexts to provide a rich understanding of the contextual nature of mealtimes. Namely exploring mealtimes at home, eating out of home at relatives' houses, or visiting dining establishments such as restaurants and cafes. The research questions addressed in this study are as follows:

1. What family mealtime challenges, if any, do mothers of YP with TS face?
 - a. How, if at all, do tics shape family mealtime experiences?
 - b. How, if at all, do mothers perceive sensory sensitivity to shape their child's eating behaviours and their family's mealtime experiences?
 - c. How, if at all, do mothers perceive rigidity to shape their child's eating behaviours and family's mealtime experiences?

2. What is the impact of these eating and mealtime challenges on mothers?
3. How do mothers navigate these challenges?

5.3.2 Method

Design

This phenomenological study explored the mealtime experiences of 17 mothers of YP with TS or PTD, capturing both richness and diversity of accounts. As detailed in chapter two (Methodology), IPA was embraced as the methodological framework for this study because it centres around the lived experiences of mothers and the meaning they attribute to their experiences.

Recruitment

Tourette's Action helped disseminate information about the study among their network of people with TS and tic disorders. Participants were also recruited through social media networks such as Facebook, Twitter and Redditt. Mothers who were interested in the study were advised to contact the researcher for more information. Mothers who wanted to participate were sent an information sheet (see **Appendix Q**) that detailed the study's aims and objectives and how data would be used and protected. Once a date, time, and location (virtual or in-person) were agreed upon, mothers were sent an overview of the interview schedule to know what type of questions to expect.

All participants provided written and verbal consent (see **Appendix H**) 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.

Participants

Seventeen mothers with children diagnosed with TS or a PTD took part (six also had children who participated in the qualitative study presented in chapter four). Mothers were eligible for inclusion if they had a child aged under 16-years with TS or PTD diagnosis. Most of the YP were diagnosed with TS (n=15), two of the youngest children were diagnosed with PTD. Almost all of the participants were reported to be diagnosed with more than one comorbidity, see Table 21. The comorbidities reported were: OCD (n=9), anxiety (n=9), ADHD (n=8), sensory processing disorder (n=5), learning disability (n=5), ASD (n=3) and low self-esteem (n=1). Several mothers also reported that their child was awaiting further diagnoses: ASD (n=4), ADHD (n=1) and anxiety (n=1). Mothers also reported traits in their children that were not diagnosed nor awaiting diagnoses: sensory processing disorder traits (n=5), OCD (n=1), ASD (n=2). This sample is thought to reflect the spectrum of presentations within this population; with TS being a multifaceted condition with complex clinical presentation due to high comorbidity rates. Mothers can shed light on how symptoms of their child's TS and comorbid conditions interplay to make mealtimes complex. Half (n=8) of mothers also reported that their child was taking medication. Mothers were predominantly employed, either full-time (n=7) or part-time (n=4), and most mothers lived with their partner (n=16) and had other children living in the household (n=13). Four mothers also reported that someone else in their household has a tic disorder. All participating mothers and their children were white.

Table 21. Parent, child, and family characteristics

Participant Characteristics			Child Characteristics				Household Characteristics	
Pseudonym	Mother's paid employment status	Partner's paid employment status	Pseudonym	Age	Diagnoses ¹	Medication ¹	Immediate relative with TS/PTD	Other children in the home
Amy	Full-time employment	Full-time employment	Talia*	13yo	TS plus 2 diagnoses	None	No	No
Caroline	Not in paid employment	Full-time employment	Adam	3yo	PTD plus 1 diagnosis	None	Partner with TS, youngest suspected PTD	Yes
Charlotte	Not in paid employment	Not in paid employment	Thomas*	14yo	TS plus 3 diagnoses	Takes antidepressant, antipsychotic, and antihistamine	No	Yes

Ciara	Not in paid employment	Full-time employment	Justin	11yo	TS plus 1 diagnosis and 1 trait	None	No	Yes
Harriet	Not in paid employment	Full-time employment	Max	8yo	TS plus 1 diagnosis and 1 trait	None	No	Yes
Jackie	Full-time employment	Part-time employment	Ivy*	14yo	TS plus 2 diagnoses and awaiting 1 more	None	No	No
Jessica	Part-time employment	Full-time employment	Warren*	11yo	TS plus 3 diagnoses	Takes antidepressant and melatonin	No	Yes
Lauren	Full-time employment	Full-time employment	Finley	13yo	TS plus 2 diagnoses, awaiting 1 more and 1 trait	Takes stimulant	No	Yes

Marisa	Full-time employment	Full-time employment	Lottie	4yo	PTD	None	Has TS	No
Naomi	Not in paid employment	Full-time employment	Oscar	8yo	TS plus 4 diagnoses	None	No	Yes
Polly	Full-time employment	N/A ²	Zack*	14yo	TS plus 2 diagnoses	None	No	Yes
Rebecca	Part-Time employment	Full-time employment	Ryan	13yo	TS plus 2 diagnoses and awaiting 2 more diagnoses	Takes antidepressant	No	Yes

Rita	Not in paid employment	Full-time employment	Effy	13yo	TS and 3 diagnoses and 1 trait	Takes alpha-agonist hypotensive agent and melatonin	No	Yes
Serena	Part-time employment	Full-time employment	Felix	11yo	TS plus 3 diagnoses and 2 traits	Takes stimulant antipsychotic, antidepressant, antidiuretic, and melatonin	Younger child, possible PTD	Yes
Sophie	Part-time employment	Full-time employment	Jack	10yo	TS plus 2 diagnoses and awaiting 2 more diagnoses and has 1 trait	Takes lpha _{2A} -adrenergic receptor agonist	No	Yes

Susan	Full-time employment	Full-time employment	Annabelle*	13yo	TS plus 6 diagnoses	Takes antipsychotic	No	Yes
Yasmin	Full-time employment	Full-time employment	Isaac	12yo	TS plus three diagnoses and 1 trait	None	Partner has tics	No

NOTES:

1. The specific diagnoses of YP and list of medications that they take have not been listed within the table in order to preserve confidentiality.
2. Polly's ex-husband lives separately, so no other caregiver was living in the family household.

* highlights YP who also participated in this doctoral study, findings presented in chapter four

ABBREVIATIONS: N/A = not applicable, yo = years old

DISCLAIMER: Columns two and three

focus on paid employment status; therefore, those who work within the family home as homemakers and carers are classified as “not in paid employment.” This does not serve to discredit the value of their invisible domestic labour and is only used to provide context for caregiver work patterns and to classify

whether a family is a single- or dual-earner household as both are important factors worth considering when exploring family mealtimes (Brannen et al., 2013; O'Connell & Brannen, 2016).

Data Collection

Almost all semi-structured interviews were conducted virtually, using platforms such as Skype and Zoom. Three interviews were held face-to-face at the participant's home at their request (pre-COVID-19 pandemic). Interviews ranged from 49-182 minutes and took place between October 2018 and August 2020. Most of the interviews took place before the COVID-19 pandemic and national lockdowns. Only Jackie and Susan were interviewed during the pandemic. All interviews were recorded for transcription purposes and transcribed verbatim by the researcher.

Empirical literature and anecdotal evidence guided the creation of the interview schedule (see **Appendix Y**). The supervisory team also reviewed the schedule. The first part of the schedule captured contextual information about participants, their child, and their household. Notably, parental occupation and work pattern; target child's age, gender, and diagnosis; and family structure. The second part of the schedule focused more specifically on mealtimes, asking 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 types of food and drink does your child like or dislike?
3. How, if at all, does your child's TS/tics influence your mealtime experiences or their eating behaviour?
4. Does your child take any medication? If so, have you noticed any changes to their appetite and weight? If yes, can you talk to me about that?
5. When was the last time you ate out as a family? Can you describe it to me?
6. Do you have any future concerns about your child's mealtimes?

Interviews were conducted in-line with Smith and Osborn (2003) recommendations for IPA research, as detailed in chapter four.

Data Analysis

As previously discussed in chapters two and four, IPA guidelines by Smith et al. (2009) were used to analyse transcripts. For this study, there was a total of 152 nodes created on NVIVO. All aspects of data analysis were carried out as previously described.

5.3.3 Themes

The following themes address the research questions for this study by detailing the mealtime challenges mothers of YP with TS and PTD raised during their interviews; how mothers conceptualised these challenges, what behavioural trait or characteristic associated with their child's tic disorder and comorbidities interplay with mealtimes to create challenges; the perceived impact of these challenges; and how mothers navigate said challenges. Analysis of 17 semi-structured interviews resulted in seven subthemes which were grouped under three superordinate themes: (1) tics as a barrier to positive mealtime experiences, (2) eating behaviours and mealtime challenges, (3) table tension, see Table 22. These themes captured mothers' thoughts and feelings surrounding their family mealtime experiences and their child's eating behaviours. Some of the words mothers used to describe mealtimes were *stressful*, *uncomfortable*, *chaotic*, *messy*, and *fragmented*. Each theme articulates these descriptors more fully while situating them within the context of distinct behaviours and characteristics associated with TS and comorbidities.

Table 22. Theme structure for mothers of young people with TS

Superordinate themes	Subthemes
	Functional challenges
Tics as a barrier to positive mealtime experiences	Disruptive tics and fragmented mealtimes Self-consciousness and anxiety when dining out
Eating behaviours and mealtime challenges	Food preferences and feeding practices Mealtime rigidity
Table tension	Barriers to positive mealtime communication Conflicting mealtime expectations

Tics as a Barrier to Positive Mealtime Experiences

Mothers described their child experiencing an assortment of tics, all of which were portrayed to have varying effects on mealtimes. Tics were described as having three effects on mealtimes; each is detailed in a subtheme: (1) functional challenges, (2) disruptive tics and fragmented mealtimes, and (3) self-consciousness and anxiety when dining out.

Functional Challenges

On a functional level, mothers reported that tics impaired their child's ability to eat and drink uninterrupted. In most instances, these functional challenges were more impactful on their child's behaviour than the mealtime experience. For example, Amy and Jackie

noted that their daughters sometimes had head and neck tics that made it hard for them to eat. The interruptions caused by these tics were described as a source of frustration for their daughters.

“[...] because of the neck jerking, it’ll interrupt her from her eating pattern.” (Jackie)

Similarly to head and neck tics, oral tics and hand tics were also described to interfere with a child’s ability to eat, although they could often eat around them.

“When, when she was doing the lip rolling umm, sometimes she would find it difficult eating and the jaw slamming. Umm sometimes like she’ll bite her tongue or the inside of her cheek. [...] she would find those difficult at times.” (Amy)

“[...]he had, he had one for a while that was like (demonstrates mouth wide open tic) the whole time (demonstrates mouth wide open and eyes closed tic) like this, opening his mouth. But he still ate. It was just that he would chew his food and then (mouth open tic) in between” (Polly)

“[...] he would shake his hand before he would pick the cutlery up. Umm but it wouldn’t necessary affect him. It wouldn’t necessarily cause him an inability to eat. It’s just that there would be an action before he would eat.” (Polly)

While Polly did not feel that Zack needed help to manage his tics during mealtimes, Amy expressed that she would help Talia when she appeared to be struggling by diverting her attention away from tics. As with this example, maternal empathy appeared to influence how mothers navigated tics that presented challenges for their child during mealtimes. Another example of this from Amy related to tic spillages caused by limb tics. Amy described her efforts to minimise embarrassment or frustration that Talia felt if she spilled her drink.

“[...] it’s just been a case of you know ‘just grab the towel and mop it up, it’s like you know your clothes wash, you wash so where’s the problem?’ [...] It’s not like she’s doing things on purpose or anything [...] so, there’s got to be that relaxed type of attitude towards it because if you get stressed or when you’re frustrated as well then, she gets more and the more frustrated and stressed that she gets the worse the tics are. [...].”(Amy)

Amy’s approach was not unique, and mothers never reported spillages to be problematic. Mothers were often more preoccupied with the emotional impact on their child than the mess created by the spillage, often led by empathy. Despite mothers feeling unable to stop tics, they did feel able to help minimise their child’s emotional reactivity by reducing the mess, and resulting frustration, caused by tics.

“[...] she has had tics where she’s tipped food over, spilled food, dropped food umm, and she’s really conscious of that [...] Now she just uses a water bottle with a sports cap. It might spill a little, but it doesn’t go everywhere like it has in the past.” (Rita)

A final tic that was described to impair a child’s ability to eat and enjoy mealtimes were throat tics. Jessica described how Warren’s throat tic sometimes made it difficult for him to finish his meal and left him *“panicked.”*

“He’s choked before because umm... it went to the back of his throat and he tried to clear his throat but it... got stuck so he choked. It scared him a bit. But then because he panicked, his tic heightened so he was doing it constantly so he couldn’t eat, he couldn’t finish his tea basically. So he had to wait until he calmed back down then he could do it... He’s done that quite a few times.” (Jessica)

Understandably, mothers were more concerned about the emotional impact they perceived these tics to have on their child than they were about the functional challenges.

As such, mothers often navigated these mealtime challenges with empathy as they attempted to minimise their child's emotional distress, where possible.

Disruptive Tics and Fragmented Mealtimes

Tics were also described as disruptive to family mealtimes, although the disruption level depended on tic severity and type. Tic severity was cited as disrupting mealtimes in two ways, requiring mealtimes to be delayed until tics waned and perpetual movement during meals, as children struggled to sit still. Other tics that mothers described as disruptive to the family's ability to enjoy mealtimes were expulsive tics and tics that harmed others.

A few mothers described their child's tics as influencing the timing of their family meals. These mothers believed that their child could not sit down for dinner shortly after returning from school due to tic rebounds (tic rebounds refer to a perceived increased tic frequency and/or severity thought to occur after a period of tic suppression). Mothers rationalised that it was more effective to delay dinner than to try and force their child to sit at the table. For example, Lauren described this scenario in a way that highlights how much empathy for their child's struggles influenced how mothers navigated tic-related challenges.

“He'll hold them in and try and suppress them as much as he can [...] but eventually when he gets home, it's like taking a lid off a pressure cooker, and all of those tics have to get out. So at the time he's coming home, umm when you think actually we should be sitting down and we should be having dinner, uh we can't do that because he needs at least 2-hours just to go into his room, have that space on his own, not really have any interaction. Just so he can feel comfortable in his own skin. Just to be

able to shout and scream and run around and not have an audience. And that's really sad." (Lauren)

Lauren's use of "*really sad*" demonstrated empathy and provided insight into the meaning she attributed to her observations. Lauren appeared to believe that being alone was the only way Finley could release some of the pressure he felt, both physically (e.g., tics, premonitory urges, need for movement) and psychologically (self-consciousness, with Lauren describing Finley as not feeling, "*comfortable in his own skin*" and needing to "*not have an audience*"). Viewing Finley as being unable to freely be himself and needing to escape the gaze of others made Lauren sad, not simply being alone or needing to delay mealtimes. Arguably, Lauren's attunement to his need and discomfort moved beyond empathy, demonstrating an emotional sensing of his needs, being metaphorically in his skin (and discomfort) and providing a reciprocal affect of her own emotional discomfort.

While mealtimes were often delayed preventing tics from disrupting the mealtime, the delay itself was a disruption to the family routine; the family ate later than they otherwise would. While mothers, such as Lauren, were able to accommodate tic rebounds by pushing mealtimes back, this only resolved the challenge of getting their child seated at the table. Many mothers also noted that it was a struggle to keep them there.

"Umm.. it's just utter chaos, it's... he don't sit down at the table, he walks around, he gets upset... uh... I don't know. And then we get/ everybody gets stressed" (Jessica).

Interestingly, despite finding their child's inability to remain seated disruptive, mothers accepted that movement was non-negotiable due to their child's movement disorder. Mothers described being acutely aware of their child's need for movement and often came to understand that movement was a necessity for their child that should not, and could not, be policed. As such, mothers often made concessions for their child with TS, allowing them to move around as needed, but maintained an expectation that their other children stay seated throughout the meal.

"Like, he, he's always found it hard to sit still, and he's never been able to sit at the table, but I sort of knew that as a mum and just let him bounce around a lot if he needed to [...]" (Ciara)

"[...] he wants to move around [...] it tends to be 3 of us sitting at the table with Oscar bobbing about. Umm... and... I guess... it's sort of the things that goes with the Tourette's I suppose. [...] obviously, if he gets up and down, we accept that [...] he's got to go and tic [...]" (Naomi)

Mothers also reported that it was more disruptive to the mealtime to keep their child seated than to allow them to move about while the rest of the family continued with their meal. Movement during mealtimes was perceived as disruptive, but not necessarily a barrier to enjoyable family mealtimes. Tics that were, at times, barriers to positive mealtime experiences were expulsive tics. Although, how impactful expulsive tics were on mealtimes appeared to be entirely dependent on each family member's ability to tolerate the tic. For example, Ciara described Justin's spitting tic as not impacting her family's ability to enjoy their meal whereas Rebecca described her family mealtimes as being negatively impacted by Ryan's spitting tic. Rebecca explained that it was

particularly challenging for her younger son with ASD, Josh, to ignore Ryan's tics, but that she was also unable to ask Ryan to stop spitting.

"It's very difficult to get your head around if you are not used to being spat at (laughs). It's very difficult to uh... well it's vile [...] you can't really tell them off, you're not supposed to do that with the tics, so it's just a matter of coping with it and just carrying on. That's easier for an adult to do, although hard but almost impossible for a child to do. And so Josh, Josh's got a lot of anxiety around umm sitting at the table where he's likely to be spat at [...] he feels sometimes not safe at the table, he didn't feel like he was comfortable eating, so we kind of made a decision that uh he was better off eating and not, not associating fear with food and not eating at all."
(Rebecca)

Rebecca explained that the only way she was able to meet her sons' varying needs was to have both of them eating in separate parts of the house. Rebecca willingly sacrificed the family meal in favour of her children's long-term wellbeing and future mealtime enjoyment, stating: *"I just hope that one day they'll come back to the table and we can eat together because they are not anxious about food (laughs)."* This fragmentation of the family meal was also noted by Marisa, and in both cases, one child ate alone, separate to the rest of the family unit. In Rebecca's case, Josh ate alone, while in Marisa's case Lottie did. Marisa explained that she preferred Lottie to eat alone as this shielded Lottie from being reprimanded by her dad for her expulsive tic. Marisa described Lottie's expulsive tic as driving her dad *"nuts."* Marisa felt it was important that Lottie could tic freely without feeling *"like she's bothering her dad."* This was particularly important to Marisa due to her own childhood experiences growing up with tics. Rebecca and Marisa's parallel yet distinct experiences as mothers highlight the role family dynamics played in shaping how tics impacted mealtimes and how mothers navigated these challenges.

While expulsive tics were bothersome to some, they were not harmful. However, tics that were described as being disruptive and harmful to others were stabbing, hitting, and kicking tics. At times, mothers described these tics as being painful and having a negative effect on mealtime enjoyment. For example, Ciara described herself as being *“traumatised”* by Justin’s tics and made it difficult for her to enjoy mealtimes.

“Just this week, again, I’ve been starting getting kicked under the table and having to stop that because you just don’t want that when you’re eating. [...] It’s, it’s hard to say how difficult that is. You know, I think I’ve actually been quite traumatised over the years from the amount of being jumped on and touched and umm I say kicked, but it’s not aggressive, it’s just overly boisterous [...]” (Ciara)

While Ciara understood that Justin did not intentionally want to hurt her, she nonetheless felt unsafe. Ciara explained that she felt one of the reasons why she *“got ill”* was due to *“the constant bracing yourself because you never know when you’re going to be bundled into”* because of Justin’s tics and that mealtimes were *“easier because we’ve got him [Justin] there in-between the table and the wall.”* She described the table as a barrier, maintaining distance between herself and Justin, however his growth spurt meant that the seating arrangements no longer served Ciara well, it no longer protected her from being kicked. Therefore, not only did Justin’s tics disrupt Ciara’s ability to enjoy mealtimes, but it also took away what appeared to be her only safe space. Fortunately for Susan, her table was able to maintain distance between her and Annabelle, which meant that being hit during mealtimes was no longer a challenge.

“We’ve got enough space. We’re lucky enough to have six seats at the table. So, we leave a gap in the middle. I used to sit next to Annabelle, but I got stabbed and hit.

One, one mealtime, I got hit on the head with a spoon over 30 times. And it really does hurt.” (Susan)

Susan demonstrated her dedication to persevere through the mealtime, being hit and hurt “*over 30 times*”, highlighting not only the impact of the tics on others (e.g., “*and it really does hurt*”) but the lengths taken by mothers to ensure everyone’s needs were considered at mealtimes and that changes were made to accommodate tics as opposed to centring attention on tics and their impact.

Overall, there appeared to be several tics that mothers felt were disruptive to their mealtimes, although the level of disruption varied. Some mothers described their child as struggling to sit still during mealtimes, and some felt the need to delay mealtimes to a time in the day when their child’s tic frequency and intensity was relatively low; this would reduce the level of disruption that tics had on the mealtime experience. More problematic were tics that were expulsive and tics that caused harm to other family members.

Self-Consciousness and Anxiety When Dining Out

Most mothers felt that their child’s mealtimes were characterised by self-consciousness and anxiety when dining out. The effect self-consciousness and anxiety had on family meals when dining out varied, depending on tic severity and their child and family unit’s resilience. Many reported their child’s desire not to have attention drawn to them would influence every aspect of dining-out, from the frequency to the location and time of eating causing stress for all members of the family.

“[...] eating out at a restaurant, depending on his mood and where, what his tics are like can vary massively [...] some days it’s literally like having a bull in a china shop. Trying to get him to sit down, sit still, he’s ticking, not throwing his salad bowl across the table umm... but we try to avoid those places to be honest because it’s not nice for anyone. [...] if Felix is screeching and bouncing off the walls, then everyone’s just a little more stressed out.” (Serena)

However, mothers whose children were not overwhelmed by noisy environments tended to opt for child-friendly establishments where their child could assimilate by blending into the background. For example, Serena highlighted how the general chaos found in child-friendly establishments allowed for more laid-back dining out experiences.

People get more anxious if people are looking. Umm... and that’s not, I feel like, why would I put him in that situation? Because he knows what’s happening, he knows that people are looking and he knows that we as a family might be feeling a little bit more vulnerable if he’s launched his salad plate across the restaurant and stuff. So we just avoid those places. Umm we go to a family place, you know like Carveries and things like that because they’re darker, they’re loud anyway, they’re busy, so you just blend in.” (Serena)

Like Serena, several mothers noted how self-consciousness could permeate through the family unit, making the experience unpleasant for all. Therefore, selecting environments more conducive to a positive mealtime experience was often a preferred way of minimising self-consciousness. Another way mothers tried to minimise self-consciousness was to request quiet tables and inform the staff and fellow diners of their child’s condition. This was perceived by mothers to help to ease their child’s anxiety and minimise staring. Mothers also reported seating preferences. For example, Amy explained that Talia would sit at a corner table with her back towards the rest of the

restaurant. Amy believed this made the experience feel more intimate for Talia and helped her be less conscious of onlookers.

“If we, if we go out to eat, I tell them before we book in advance/ [...] We have to book in advance and ask for special tables, and then all the waiters have to know. [...] Annabelle likes me to tell everybody and people on the tables around us. [...] It makes her feel more comfortable that they unders/ they have some understanding. Most people have always been lovely about it.” (Susan)

“She just prefers to be in the corner looking in to the table [...]she feels like she’s just in this little/ that it’s really just me her and Patrick that’s there.” (Amy)

Mothers’ mealtime enjoyment appeared to be entwined with their child’s enjoyment and comfort levels. Those who were able to find ways to decrease their child’s self-consciousness did report that they could create some positive experiences when dining out. In addition to controlling the environment to create less pressurised experiences, mothers also noted that their child would suppress tics to limit the attention tics attract. The challenge with this was that mealtimes would need to end abruptly when their child was no longer able to cope and suppress tics or that they would be unable to go out for a meal if their child was having a bad tic day.

“[...] there will be times where he will say ‘mummy can we go home now?’ or you know ‘I’m getting a headache’ or umm he’ll say or ‘I’ve got a tummy ache’ and that I know that he can’t, he needs to release it. And if we’re halfway through the meal then I’ll say to him ‘come on, do you want to come with me to the toilet’ and him and me will go off separately, and then he’ll just be able to do his own little thing. Tic away and no one else is watching him, and then he feels comfortable to go back to the table. [...] there’s certain times when if he does feel uncomfortable and he’ll say to me, ‘mummy I want to go home, I’ve got a headache, I need to go home’ and that’s

when I know, ok, we need to look at cutting it short, he's not going to be able to manage for much longer." (Sophie)

While tic-related self-consciousness was raised as a barrier to dining out by most mothers, most still dined-out as a family, albeit not as frequently or as enjoyably as they liked. Charlotte and Lauren were the only mothers whose sons refused to dine out with their family once they were old enough to stay home alone. While Lauren and Charlotte appreciated that it was easier for their sons to stay home, they often felt uncomfortable about leaving them and were concerned about their sons' social withdrawal.

"[...] the older that he's got, he's more aware of them. Umm, it's difficult to eat out because he doesn't like attention being brought to him. And umm he'll wear a hoodie and have it over his head umm because that's some type of protection for him that, you know, he's kind of hiding behind. [...] if we do go out, we don't tend to take Finley with us. And he's 13, and he can make that decision. It is not enjoyable for him, which is really/ it's a shame [...]" (Lauren)

"In fact, I can't think of the last time that [he] came out with us for something to eat. [...] I don't like leaving him at home on his own." (Charlotte)

Sometimes mothers could take their child somewhere private for tics to be released, and sometimes they had to leave early. Empathy appeared to shape how many mothers navigated dining out, often trying to find ways to make dining out more comfortable, where possible.

Based on mothers' accounts, self-consciousness appeared to be perceived as part of dining out due to the attention that tics can attract. As such, many mothers preferred

environments where their child's tics could blend in as these felt like less pressurised environments and allowed for a more positive experience. Some mothers also reported having to undertake additional steps to help their child feel more comfortable. Mothers also mentioned that their mealtime experience was also impacted by their child's ability to tolerate tic suppression.

Eating Behaviours and Mealtime Challenges

This superordinate theme discusses how mothers viewed their child's eating behaviours and the role sensory sensitivity and rigidity played in making mealtimes stressful and conflictual. This superordinate theme consists of two subthemes: (1) food preferences and feeding practices, and (2) mealtime rigidity.

Food Preferences and Feeding Practices

Several mothers described their child's food preferences as a source of stress, as they felt that their child's food preferences were limited, albeit to varying degrees. Mothers who described their child as a selective eater or having pronounced food preferences tended to attribute their child's dietary range to sensory aversions. For example:

"He seems to have heightened sense of smell, like he finds certain textures really uncomfortable umm and then he just/ he just tastes things, he only likes really bland things." (Harriet)

"She, she'll say if it smells wrong or looks wrong, it feels wrong, and there's like an invisible force field, and she just can't do it [...]" (Rita)

Conceptualising their child's eating behaviours as sensory based appeared to be something that happened over time. Mothers often described instances where it became apparent to them that their child was genuinely struggling with particular sensory properties and that their refusal was more than merely behavioural. Rita captured how coming from a place of understanding shifted the way she responded to Effy.

"[...] it's always been a pretty volatile relationship. So, she's always had quite extreme responses if she didn't want to eat it. Umm and like I say, she's found ways of managing better now, she's a lot better because I think I understand more now, I don't argue with her about it. Whereas before I'd put pressure 'you've got to eat, you'll be starving hungry later. You've got to eat.' Now I just kind of have food there that I know she can eat. Umm... if she hasn't had a hot dinner, I try not to worry about it. I try and think 'well I'll just give her something later.' [...] I remember like, 'you turn everything into a big deal, why does it have to be this drama, so much?' and then I don't know, there/ at some point (sighs) and I can't really tell you the moment, but at some point, I started to think umm 'actually, she's really struggling here. She's not actually doing this to spite me or give me a hard time. She's really struggling with this.' And umm I started having a bit more empathy for her and thinking 'what ways can I help her?' rather than battle with her because it was like a constant battle to get her to do anything." (Rita)

Rita's example demonstrated a perspective shift many mothers also experienced; they found that conceptualising their child's food refusal as being rooted in their child's sensory aversions as opposed to being behavioural made it easier for them to accept their child's preferences and not take food refusal personally. Additionally, while Rita provided insight into her overall perspective shift concerning Effy's sensory challenges, she demonstrated how mealtimes could become less conflictual when mothers work with, rather than against, their child and their sensory aversions. Rita evidenced her perspective shift by giving voice to her internal dialogue in these moments (e.g., "*she's*

not actually doing this to spit me” and “what ways can I help her?”). By adjusting her meaning-making, Rita was able to have more empathy for Effy.

Mothers typically struggled initially to understand their child’s reactions to certain foods, but they began to accept that their child was struggling, with time. Harriet demonstrated this:

“For instance, and he’s a good boy, and he tries his hardest, but he tried to eat a piece of sweetcorn, and it took him 15 minutes. And it was 15 minutes of crying, you know, at the noise in his ear of crunching it, you know, so (sighs) that’s what we’re facing.”
(Harriet)

Over time, mothers accepted that controlling feeding practices were counterproductive and appeared to feel powerless and defeated. Harriet articulated this sentiment as she detailed her various efforts to improve Max’s diet over the years, explaining that she *“tried all the self-help at home”* strategies but that nothing worked. Harriet was certain that help was needed, although she was unsure who needed the help, saying *“we feel we need, or he needs help, or we need help, or you know something.”* This highlights her feelings of confusion about what they need but also her awareness that it is a dynamic challenge and not simply a ‘Max’ challenge.

“I used to be quite rigid in terms of saying ‘no, you absolutely have to try that and if you don’t then that’s just it and I’m not leaving this table until you do’ but we could have been half an hour of him screaming that he wasn’t even going to try putting something in his mouth back then so, that kind of that rigidity on my part kind of has fallen away.” (Harriet)

Harriet also demonstrated disbelief that despite all her attempts, Max's diet remained relatively unchanged and that *"eight years later he's still counting out the peas (laughs)"* despite her attempts to increase his exposure to non-preferred foods. While there were mothers who felt defeated and helpless at changing their child's diets, Serena felt able to. Serena stressed the importance of knowing what was realistically achievable and working with her son's preferences when increasing acceptance of otherwise refused foods.

"[...] he hates things with two textures. Like you cannot give him yoghurt with fruit in. Or bits in, that's a no, no. [...] I learnt from a very young age when he was little that that's just not something I'm going to force him to have. Umm but if it's something that I know, like because he really likes mince like for spaghetti bolognese and he really likes mashed potato but really struggled with having shepherd's pie. So having the two together [no]. But we worked through that, and now he's fine." (Serena)

Serena's approach appeared to be more successful than most mothers attempts as she tailored her approach to work with Felix's preferences. Whether successful or not, what was apparent was that all mothers felt they were responsible for their child's diet and ensuring that it was nutritionally adequate. Mothers who did not feel this burden were less likely to perceive their child's dietary preferences as a challenge and were less likely to encounter mealtime battles. For example, Marisa, Caroline and Polly all described their children as selective eaters, yet this did not appear to be a challenge nor source of stress. Seemingly, Marisa and Caroline were able to alleviate concerns about nutritional deficiencies; while Caroline was able to rely on breastfeeding to fill dietary gaps, Marisa could rely on nutritious preschool meals on weekdays.

"Adam was much more on the sensory side that he wants uhh smooth textures, one food, nothing mixed in together, you know kind of stuff. Much more sensory kid. He didn't get emotional, he just refused. He'd just not eat. [...] With Adam what he's

done, is he's withdrawn and continued breastfeeding. So that's how he's... you know, adapted to it, which our family dynamics have allowed. And so, that's how the sensory hasn't been that big of an issue for us." (Caroline)

"[...] she eats breakfast and lunch and snacks at school so... uhh she/ I know that she's having very varied meals there [...] so I'm not going to worry about her too much about what she's eating for dinner." (Marisa)

Polly on the other hand could not rely on alternative sources of nutrition, yet still appeared unaffected by Zack's selective eating. Polly described Zack as being "*quiet fussy*" because "*there's only certain things he likes*", however, this was not a challenge as he still ate a wide variety of foods and was a "*really good eater*". Upon closer inspection, it dawned on Polly that Zack had pronounced food preferences, predominantly eating chicken and meat, with minimal consumption of carbohydrates. However, this was not a problem to her because he was not rigid (he did not only eat one type of food or have food "*fetishes*").

"[...] he's chicken mad isn't he? (laughs). I never realized how much bloody chicken he had until I've spoken to you (laughs)." (Polly)

"[...] he's not quirky, he's not like umm, like umm, what's the word I'm looking for?... Umm like some children have particular umm... fetishes, you know. Where he's not, he's not particularly umm... he's not particularly umm wanting to stick to one type of food, no he's not like that[...]" (Polly)

Polly's case highlights that pronounced food preferences are not necessarily a source of stress for mothers. It appears as though hyperawareness of their child's eating behaviours and maternal dissatisfaction with their child's food preferences resulted in maternal stress.

Interestingly, a couple of mothers also noted that the burden to nourish their child felt heavier due to their child's diagnosis. A notable example is Ciara, whose preoccupation with getting Justin to eat healthily created feeding battles despite Justin eating a varied diet.

"[...] when your child has a chronic condition, and there's no cure and... there's precious little help from the health service, you have to work it out for yourself [...] I am giving him as healthy a meal as possible, and I hope that is at least helping things not get worse." (Ciara)

Ciara's desire for Justin to have a healthier diet than he would like often led to mealtime conflict, stating that *"it just feels like a battle all the time"*. Ciara additionally noted that she added minerals such as magnesium to their drinking water, which Justin disliked.

"[...] they did notice it at first and (laughs) and Justin was saying "ah I've got a vitamin mummy, why are you always trying to make us have vitamins?" (laughs)." (Ciara)

In the end, mothers often described themselves as feeding their children their preferred foods, to avoid them missing a meal. For example, Harriet described having to find a balance between *"starving your child"* and making sure they are *"getting proper nourishment"* as being *"extremely stressful."* Even when mothers tried their best to accommodate their child's preferences, they could not always ensure their child would eat the meal as some children's preferences were unpredictable. This was disheartening for mothers like Jackie, who felt that even despite their best efforts to make a meal their child would enjoy, they were still unable to 'get it right.'

“[...] it's the predicting of, you know, you're not wanting to waste food, predicting what I can cook that she's going to like? And it can be a bit disheartening after you've spent an hour or more cooking and then doesn't like that, can't eat it. And I couldn't have predicted that outcome.” (Jackie)

In addition to preparing most of the family meals, mothers also noted that they had to accommodate their child's food preferences. The levels of accommodation varied, as did the impact of this additional labour on mothers' stress levels. A few mothers prepared separate meals for their child with TS. Although, in the case of Lauren, she prepared individual meals for the whole family due to lack of taste synchronicity. Lauren likened her household to a *“café where everyone has a different meal.”* While she first cited this as a source of stress, she later recanted and explained that while it *“sounds like it would be stress city [...] it does become the norm.”* While Lauren had acclimatised to making several meals, the idea of cooking multiple meals was stressful for others. In such cases, mothers opted for meals that could easily be modified to meet everyone's needs.

“[...] say I was doing a Chana masala or something, a chickpea curry, Max would have the chickpeas and the rice but no sauce so it's not really our dinner at all, but that's, that's what he'd eat.” (Harriet)

“I give them an option, and we try and come at one we all agree at because I was cooking different meals for everybody. [...] I'll do something where Annabelle could have say, chicken in a wrap and Ella will eat a Caesar salad.” (Susan)

Overall, child food preferences appeared to be a source of stress and discontentment for many mothers. While mothers appeared to understand that sensory sensitivities often underpinned their child's food preferences, they nonetheless desired their child

to have a broader diet. When mothers used controlling feeding practices, mealtimes were described to be stressful and conflictual. Mothers' feeding practices also naturally shifted as they gained a more empathetic perspective regarding their child's eating behaviours and food refusal. Mothers who were able to see their child as struggling due to sensory sensitivity tended to accommodate their child's food preferences.

Mealtime Rigidity

Mealtime rigidity was another challenge several mothers had to contend with; often alongside selective eating. In most cases, mothers were responsible for foodwork and found accommodating their child's additional mealtime demands a source of stress. Mothers reported that their selective eaters often required their meal to be served in a particular way, commonly with each meal component separate on the plate. In most instances, mothers felt this was a sensory preference as children disliked the mixing of textures. For example, a few mothers described their child as being particular about how their baked beans were served, often needing the beans to not touch other components of the meal, and in two cases requiring the beans to be separated from the tomato sauce.

“Beans can't touch his food [...] so jacket potato and beans, umm they have to go in a cup [...] (Serena)

“[...] he doesn't really like bean juice. So you have to drain the bean juice up the beans so it's not as wet. And he likes the beans separate to the chips.” (Lauren)

Interestingly, mothers appeared to become accustomed to their child's preferences, sometimes not realising just how specific their child's requirements were until they had to describe them in the interview. Serena commented: *“when you actually talk about*

this you realise how many little quirks he has". Most mothers reported that it was easier to ask their children how they preferred their meal to be served than to risk getting it wrong and having to undertake additional foodwork to create another meal. Usually, mothers who felt the need to be explicit with their child regularly reported that their child's preferences were not predictable.

"[...] we tend to dish up or... you know, plate up the dinner with her there saying what she wants with what or on two plates or however she wants it because it's really not worth the drama or the battle if I plate it all up and leave it there for her and that's not how she wanted it then she would... she might be able to manage it some days but, most days it would just cause an argument and, it's just not worth it. It doesn't matter if it's in a bowl does it or on a plate or whatever. It's not the end of the world."
(Rita)

While some children were reported to refuse meals that were not to their requirements, other children were more flexible. For example, Amy explained that Talia would *"push everything back, she'll separate everything,"* if she was served something touching. Mothers who did report their child having a 'meltdown' if food was served touching, tended to refer to past instances when their children were younger.

"It's not so bad that she's screaming her head off any more or that she's having meltdowns over it, but she would just leave it if not. You know if it was touched or mixed or you know she wasn't particularly/ wasn't comfortable with that it would just be left on the plate, not eaten..." (Rita)

Several mothers also noted that their child's preferences extended to brands, with children refusing to eat items that were not their preferred brand.

“[...] he likes porridge, and I got a different porridge oats, and he knew. There’s no tricking him [...] he won’t eat it, won’t eat it. And then it’s... he’ll have this thing like ‘well why didn’t you go and get me the right one?’, ‘why haven’t you gone and gotten me the right one?’, ‘why didn’t you do it today?’, ‘what were you doing today?’, ‘why didn’t you get that?’. You know? And it’s like (sighs) I don’t know, like ‘I made a mistake, I got the wrong porridge’ (grimaces). He’s not happy.” (Naomi)

Naomi depicted Oscar as interrogating her when she bought the wrong brand. She also noted feeling as though *“there’s no acceptance that someone might make a mistake”* and that Oscar would constantly remind her of the mistakes she has made in the past. This made Naomi feel guilty and anxious about making mistakes as she anticipated being chastised by Oscar.

Brand loyalty was particularly challenging when mothers were unable to purchase the preferred brand or when the brand adjusted the recipe. While most mothers noted that they tried to buy the brand their child liked, Ciara would purposely buy different brands as she enjoyed experimenting despite this usually resulting in arguments. This may have been an act of resistance, with Ciara asserting her authority over foodwork. However, it was unclear what purpose this would serve as Ciara said she was *“pretty firm”* in ensuring that she bought her *“own stuff”* for dinner that she was *“happy with”* (often organic, gluten and dairy free). So why she would purposefully buy different brands of the food items her sons ate was unclear.

“[...] he does notice if I change the brand and sometimes won’t have something then.[...] they’ll both be quite vocal about it. [...] we do have arguments about that because I, I suppose I do like trying different things, so I do buy different brands to do that.” (Ciara)

The mother who appeared to be most impacted by their child's brand loyalty was Rita. Rita resorted to hoarding branded foods that both her children considered 'safe' to avoid "*meltdowns*." Rita recalled feeling "*dread*" when she had run out of ingredients in the past.

"I go through some weeks of buying umm in the past eight cans of baked beans or eight cans of tuna or for my son chicken nuggets is a big thing for him, so I try to make sure I always have chicken nuggets in the freezer for when it's really stressful, and he won't eat anything else. So umm... I kind of have those. I dread running out of them (laughs) put it that way. And I know a lot of other families, ASD families are like 'oh my God I ran out of a certain brand of something' and they knew that it wasn't/ the difference and it's really umm an extreme reaction when that food isn't there. Especially when they're tired and they're hungry, and they're stressed, and you've got no food to offer them, that is their safe food if you like, that escalates the situation."
(Rita)

A food jag is when an accepted food is eaten, sometimes exclusively, for a sustained period before suddenly being refused. Effy's food jags left Rita with cupboards full of no longer accepted items. As a result, Rita was stressed about not having safe foods in the house and about money wastage when safe foods shift unexpectedly.

More broadly, food jaggling was challenging for mothers due to the lack of predictability of their child's accepted foods. In the case of Lauren and Rita, food jags were particularly stressful due to their child's limited diets. Both mothers found food jags to be a source of anxiety as they anticipated needing to find another 'safe food' that their child would accept once they tired from their currently accepted food.

“So it's really tough. So it's a massive journey. We're still learning every day. I may change what we do next week. So if he just doesn't want to eat, to eat at all then... I don't know. I'd try anything. I mean, I'm baking a cake every three days. Umm, that's new. But I know what'll happen. In a month's time, he'll hate cake because he's had too much of it. It's like anything else. I'm going to have to come up with something else, and I don't know what that will be [...]” (Lauren)

Another form of rigidity that mothers noted was their child having cookware preferences. Several mothers noted that their child was particularly attached to a set of cutlery, cups, or plates. In most of these cases, children would still accept non-preferred cookware with some complaint, but minimal resistance. In a few instances, children would refuse their meals altogether. Serena noted that Felix was particularly attached to cookware as a toddler.

“[...] when he was little, oh my God, it was this plate, this cutlery, this colour end of. There was no negotiation at all. [...] So I ended up having to buy, going to IKEA and buy 5 of these sets just to get out that colour, that cup, and that cutlery and I always had to take some with me. This was when he was little, and then I was like actually, no this is getting controlling, and I stopped it, and I threw them all in the bin.” (Serena)

Serena noted that Felix used to “*scream*” and refuse to eat if he wasn't served with the right cookware. She became displeased with the power dynamic, feeling that he had too much control. Serena managed to break Felix's rigidity by refusing to give in to his preferences. The other mothers with children with cookware preferences were less impacted, and as such, did not feel the need to try and effect changes.

Mealtime rigidity also presented itself in children's need to know what to expect and struggling with deviations from their expectations. A few mothers felt that their child was heavily reliant on knowing what they would be served and when.

"[...] he knows approximately what time it's going to be, between 5 and 6. Because, he sort of has to prepare for things, Warren. He has to umm know when he is having his tea. If he is having his tea late, why he is having his tea late. He, he struggles to sort of umm..." (Jessica)

Jessica expanded, stating that "*it's just basically sticking to a routine,*" a routine that is detailed down to the cookware he uses. Mothers' descriptions of their child's need for routine and a low tolerance for changes appeared to be underpinned by anxiety. Mothers felt their child could manage their anxiety levels by knowing what to expect; this often allowed them to feel prepared. While this made sense for children who were selective eaters who may have experienced anxiety surrounding what would be served, Sophie's son Jack was said to also engage in this behaviour. For Jack, it was more about predictability than about the food itself.

"[...] when we have dinner, he always wants to know what's going to be for dinner. And Simon turned around and said to him 'oh it's going to be a surprise' he wouldn't like that. He'll say 'no, no, no, tell me what we've got for dinner, tell me what we've got for dinner,' and then he'll say 'mummy, what have we got for dinner? I need to know what we are eating.' You know he needs to know. He's happy to have more or less anything, as long as he knows what it's going to be." (Sophie)

Awareness of the distress that not knowing has on their child and conceptualising their child's need to know what to expect appeared to make it easier for mothers to comply. In essence, mothers tried to provide structure and comfort for their child through mealtime structure by ensuring their child knew when mealtimes were and what would be served. Although, this became challenging if things changed as children were described as struggling to adapt.

"[...] he sort of has to prepare for things, Warren. He has to umm know when he is having his tea. If he is having his tea late, why he is having his tea late. He, he struggles to sort of umm...cope with change." (Jessica)

A final form of rigidity that mothers noted related to their child's eating behaviours was their child engaging in specific eating practices, often eating one meal component before the other. Some also had a particular order to how they ate. Eating practices were noticed by mothers but were not viewed as challenging; possibly because it did not require anything from them in the way other rigidities did. Jackie captured this acceptance:

"I think there are certain ways that she looks at the food on the plate and she might eat them in a certain way. But we haven't really talked about it too much. I haven't drawn too much attention to it. I've just left, left her to it." (Jackie)

Overall, mealtime rigidity did appear to impact mothers, as mothers found their child's requests stressful and at times, a source of anxiety. Stress was linked to mothers having to undertake additional foodwork to satisfy their child's preferences. This ranged from purchasing certain brands to the way food was plated and what it was served on. Anxiety was more prominent for mothers whose child's preferences were less predictable or harder to satisfy. In addition to rigid preferences, some mothers also noted that their child needed to know what to expect at mealtimes. These children were described as struggling to adapt when their expectations were not met, or things changed.

Table Tension

Mealtimes were sometimes described by mothers as tense affairs, either experiencing tension at the dinner table as a result of their child's behaviours or experiencing tension that results from conflicting mealtime expectations. These experiences are discussed within the following two subthemes: (1) barriers to positive mealtime communication and (2) conflicting mealtime expectations.

Barriers to Positive Mealtime Conversations

Mothers noted that their child's continuous interruptions and age-inappropriate feeding skills were disruptive to mealtimes and, at times, a source of tension. While a young person's interruptions made it challenging for the family to have an enjoyable mealtime conversation, YP's eating behaviours were also cited as dominating mealtime conversations. How mothers felt about these challenges varied according to their expectations and how disruptive mothers perceived their child's behaviour to be.

Ciara and Sophie both noted that their sons would interrupt the flow of conversation during mealtimes. Both mothers were unsure which of their sons' diagnoses to attribute this behaviour to. In the case of Ciara, she and her husband were unable to have a conversation over dinner without Justin interrupting. Although, she did note that she also struggled with Josh interrupting too, so this could be a normative family experience.

“[...] (sighs) you know it has been I suppose hard over the years for me and Nick to have a conversation together at the dinner table because... Justin particularly interrupts, you know, it's part of the autism, isn't it? But maybe it's part of the Tourette's syndrome as well (laughs) you can't divide it out. He likes talking about what he likes talking about, and sometimes we have to get him to stop doing that.”
(Ciara)

In the case of Sophie, she was able to have an enjoyable conversation with her husband and daughter, so long as Jack did not join them. Sophie explained that Jack would eat alone for most weekday dinners. While she attributed this to his need for a longer bedtime routine, it also allowed the rest of the family to have a more positive experience. Sophie explained that mealtimes with Jack were stressful, in part, due to his interruptions and inability to follow a conversation.

“[...] once he’s in bed, later on, then, then myself, my husband and my daughter will sit down and eat, together it’s just, it’s just relaxed. We can have more conversations. We can just sit in a much more relaxed environment. I think it’s also because of the ADHD that Jack is constantly talking [...] he is interrupting the conversation, or he wants to know what’s going on. [...] he gets very confused, and so the whole mealtime then starts to revolve around us saying to him, ‘no sit quietly’ or ‘be quiet, we’re trying to talk about this’ or ‘in a minute Jack’ or ‘no, just calm down’ [...]” (Sophie)

While Ciara and her husband tried to set boundaries around their children’s interruptions during mealtimes, Sophie and her family appeared to fragment mealtimes to preserve mealtime enjoyability. Sophie felt that she could spend quality time with Jack during his bedtime routine; therefore, she did not feel guilty about excluding him from the family dinner. Despite this, she did note that *“he’d rather sit down with all of us”* because *“he enjoys family mealtimes.”*

“It was, it was easier when he was younger, and we could say ‘no, it’s because you’ve got to get to bed’ and things like that. And now he is getting older he’s like ‘well why can’t we eat together?’, ‘why can’t I eat later?’” (Sophie)

Considering Sophie’s concern that an earlier bedtime would no longer serve as a rationale for fragmented mealtimes, it seems reasonable to suggest that mealtimes were

fragmented for conviviality instead of logistical purposes. Another factor that influenced Sophie's family's decision to eat without Jack was his age-inappropriate feeding skills. Age-inappropriate feeding skills refers to a failure to develop, or utilise, feeding skills that would otherwise be expected for a young person of a particular age. Within the context of this research, an example of age-inappropriate feeding skills is an adolescent not appropriately using cutlery or not feeding themselves.

A few mothers noted that their children engaged in age-inappropriate feeding skills, with the main issue being lack of cutlery use. Ciara, Sophie, and Naomi all described their sons' feeding skills as being a challenge, albeit to varying degrees. Despite their sons all being over the age of seven, they were described as struggling to use their fork and knife appropriately; often relying on their parents to cut their food for them.

“[...] he'll ask us to cut his food up and given that he's 8, we do cut his food up for him... which I've never really thought about before.” (Naomi)

The way that Naomi juxtaposed Oscar's age with his reliance on his parents to cut his food for him indicates that she believes that his cutlery usage as age inappropriate. Sophie described Jack as eating with his hands, which often resulted in messy mealtimes.

“He really struggles holding a knife and fork. So he ends up with food absolutely everywhere. He ends up eating with his fingers all the time and things like that. Or he is talking constantly and doing things so mealtimes can be a dragged out and quite stressful.” (Sophie)

Each of their mothers expressed some level of concern about their child's lack of autonomy with their eating skills. Some mothers who described themselves as being

raised by strict parents also appeared to be disappointed by their child's poor table manners. For example, Ciara described Justin's eating in an animalistic way stating that *"he'll just put his fork in a hunk of meat and gnaw off the fork."* Both Sophie and Ciara noted that their husbands and the child's grandparents struggled to accept their child's age-inappropriate feeding skills and would prompt their children to eat in a manner they deemed appropriate. When dining-out, there was an expectation that their sons would attempt to use their cutlery appropriately. While Ciara described she and her husband *"gradually"* came to terms with Justin's cutlery use, it was still something that they were hyperaware of due to them being raised with *"strict middle-class table manners."* Similarly, Sophie believed that Jack's father struggled with Jack's feeding skills because *"it was always inbred into him from his dad, to eat properly."*

While Sophie and Ciara preferred their sons to practice 'good' table manners, they both felt the need to come to terms with the fact that their sons may never eat the way they wanted them to. Joint mealtimes were still a challenge as Jack's dad and paternal grandfather both struggled to refrain from commenting on Jack eating with his hands. Sophie felt that their commentary was more impactful on the mealtime than Jack's feeding skills.

"It really bothers them that he's quite a messy eater and that he uses his hands so often they will tell him to use his fork, or they will try and correct him. It's them trying to correct him that causes him more stress and anxiety than the way he actually eats himself." (Sophie)

While the most common feeding skill challenge related to cutlery use, in the case of Yasmin, the issue was less surrounding Isaac's ability to eat independently and more related to his distractibility during mealtimes.

“I have to feed him, not because he's incapable of feeding himself, but because he'll just sit there and be distracted, maybe because he's thinking if he puts the fork in his mouth, he'll, he'll tic. I don't know. And I haven't asked him, and I sense he wouldn't really be comfortable talking about that to me because he is very sensitive about it.”
(Yasmin)

Overall, mothers appeared to view their child's interruptions and communication surrounding age-inappropriate feeding skills as sources of mealtime tension. It was also stressful for them to try and manage their child's interruptions at mealtimes. As for age-inappropriate feeding skills, some mothers described themselves and family members as feeling uncomfortable with the way their child ate. How challenging mothers found this depended on their views of what was appropriate and their ability to accept their child's eating behaviour. Mealtimes appeared to be dominated by directive communication to manage their child's behaviour which was described as stressful both for mothers and their child.

Conflicting Mealtime Expectations

Expectations surrounding family mealtimes appeared to be a notable factor influencing how satisfied mothers were with their family mealtime experiences. Mothers noted two main conflicts, conflict within themselves between what they want and what their reality was, and conflict between their expectations and that of their partners.

Several mothers appeared unsatisfied with their family mealtime experiences and hyperaware of the discrepancy between their reality and what they had hoped family mealtimes would be like. The intensity of their dissatisfaction depended on how tightly they held onto their expectations and how much they were able to embrace their reality. Even when some mothers were able to accept their mealtime experiences, those who still held onto their ideals struggled. A key example of this was Naomi and Caroline. Naomi held onto her childhood mealtime experiences and felt that Oscar was the main barrier to achieving ‘Waltons’⁵-like mealtimes. Caroline held onto an expectation that her family mealtimes could improve but also recognised that despite all her best efforts thus far, mealtimes were still “crazy.” Both mothers held strongly onto their expectations, although in Caroline's case, her “micromanaging” of mealtimes was described as a source of stress for her family.

“[...] we used to have them as kids, it should be like a social time where everyone is happy, and you’re catching up with the day or/ but it’s not because Oscar will want to get up or ‘that’s not right,’ ‘that’s not right.’ I think, maybe I sort of sit there and think, ‘oh, they’re gonna’/ oh I don’t know, not like the Waltons but you know be like ‘this is lovely, you’ve worked so hard, this is delicious’ (laughs). But it rarely ever is [...] it’s like a battleground really to sit down as a family [...].” (Naomi)

“Like the number of times that we’ve been successful at that is so rare that that’s really creating stress for my family because I just keep plugging away at it. Like I keep expecting that we’ll be able to [...] every day, all day, like our lives revolve around the kitchen. That we’re making food, we’re cleaning food, we’re eating food, like they’re just like so over it. Like that we haven’t figured this out yet (laughs) you know like we’re not going to.” (Caroline)

⁵ This is a reference to an American historical drama series about a family, set during the Great Depression and World War II. This show originally aired from 1972 to 1981 and provided a portrayal of family unity and togetherness.

Naomi's quote captured the discrepancy between what she felt mealtimes should be, a wholesome family activity, versus what they were, a "*battleground*." There was also a sense that everyone, apart from Oscar, was playing their role. Naomi described herself as playing her part by making healthy homemade meals. Naomi described Isobel and Jeremy playing their role by showing appreciation for her efforts and complimenting the meal.

"I'll probably end up saying something like 'I spent ages cooking this' then Jeremy will say to him 'your mum spent ages cooking this' (laughs) umm Isobel will probably twig onto that and say umm 'this is lovely' and then he'll, you know, he is quite blunt with what he thinks of it. So it's not like relaxing, we all sit there you know... it's quite tiring." (Naomi)

Oscar not playing his part appeared to be a common theme of the interview and Naomi's mothering identity appeared to be entangled with this. Naomi commented that even when Oscar was a baby, he refused homemade baby food which meant she could not be the "*smug mummy*" she wanted to be. Her motivation to undertake extensive foodwork appeared to be embedded in her desire to derive joy from the pleasure her family experienced when they ate her meals. Similarly, other mothers noted this challenge as they felt their foodwork was not enjoyed, nor appreciated, as they had hoped.

"I think it's, it's a challenge trying to predict sometimes whether she's going to like what I'm cooking. That can be really frustrating, and that could become a challenge if I allowed it. [...]it can be a bit disheartening after you've spent an hour or more cooking and then doesn't like that, can't eat it. And I couldn't have predicted that outcome." (Jackie)

“I want food to be joyful. I want it to be something that can be social, and I [can’t] figure out how to do that when other people won’t cooperate (laughs).” (Caroline)

For Harriet, not only was she not able to derive joy from her family’s enjoyment of her foodwork, she was also unable to enjoy the meal that she had tirelessly prepared. Harriet explained that Max’s food refusal and ‘meltdowns’ created a stressful mealtime atmosphere that made it difficult for her to be able to enjoy the moment and savour her meal.

“[...] there has been times when I have just picked up my plate, because I’ve had a knot in my stomach from the screaming, picked up my plate and had to go to a different room to eat my meal because I might have just spent/ because I work really hard at (laughs) trying to make sure there’s a balanced diet in the family all week and I might have made something that took me an hour, an hour and a half, and I can’t even taste it because my child is screaming because the smell from his plate or even having to do it. Umm, so it can be very stressful.” (Harriet)

Whether related to tics or their child’s food preferences, mothers noted a common challenge was an inability to predict the outcome of a mealtime. The more a mother tried to anticipate and mitigate against a stressful mealtime experience, the more they appeared to be affected by mealtime challenges that occurred nonetheless. Notably, maternal identity was heavily tied to what their child ate and as such, it was challenging for mothers to let go of mealtime expectations entirely. Jackie captured this sentiment as she expressed guilt and disappointment tied to Ivy’s eating behaviour.

“I mean, for me as a mum, I think it's umm I have to not be too disappointed if, you know, I can spend quite a lot of time cooking and preparing and think it's going to be fine. And then if she says ‘I can’t eat it,’ I’ve then got the guilt of ‘well do I have to go

back into the kitchen and cook another meal?’ and I might not want to. I might be too tired, you know, I might be exhausted. I might just want to go and sit. I've done my job. The cafe is closed. I don't want to go back and cook another meal... so I might get exasperated and then hopefully sometimes Eric will jump in and do something or I'd just say ‘it's going to have to be boiled egg. I'm not doing another meal,’ and then I feel guilty because it's just boiled egg now.” (Jackie)

Jackie accepted that disappointment was part of this experience, but she had to manage her level of disappointment so as not to make the mealtime more stressful than it needed to be. On the one hand, Jackie felt tired and felt as though she had done her job by cooking, but on the other, she also worried about what Ivy ate and felt the need to provide what she deemed to be an adequate alternative to what was originally served.

The very few mothers who accepted that they had no control and released all expectations about mealtimes appeared to be the most content. Rebecca and Lauren captured this best. Rebecca accepted her fragmented mealtimes, while Lauren accepted the need for multiple meals. Despite these mothers preferring one family mealtime and meal, they accepted that it was simply not possible for their family.

“It would be nice to just cook one meal, and everybody eat it [but] we're not that family. So you've got to adapt. And we're all happy, relatively. And, you know, there are days where I get absolutely fed up, and I just say ‘I can't do this anymore.’ Well, it's not because I've had to cook three meals (laughs) [...] And then you reset because the day starts and, you know, it's, it's just it's tough. It is. And I think people on the outside think, ‘gosh, I don't know how you do it,’ umm but you do because that's what your kids need.” (Lauren)

Rebecca also recognised that while she *“would like everyone to be in the same place”* that this simply was not possible due to her sons’ conflicting needs. For Rebecca and Lauren, mealtimes were simply for getting everyone fed.

All the above examples describe internal challenges mothers faced between their expectations and reality. Another challenge mothers noted was between their expectations and those of their partners. Most of the mothers reported that there were notable differences in mealtime expectations and level of understanding or empathy towards their child. In most cases, mothers reported their partner to be stricter or less understanding than they were. Both expectations and parenting style were noted to have intergenerational influences. In the example below, Jessica described why she believed she was stricter than her husband, Jim.

“We were brought up differently. Jim didn’t [...] sit and eat with his parents, it were always, you know, you ... you can sit and eat in there. [...] she (Jim’s mother) made meals separately for everyone. So if he didn’t want something, he could have something else. Whereas my sort of upbringing were completely different. I, we had a set meal at a set time.” (Jessica)

In cases where mothers believed themselves to be less strict and more understanding than their partners, they also felt the need to advocate on their child’s behalf. Like Rita, some of these mothers felt caught in the middle as they empathised with both their partner and their child. Rita articulated this well when discussing her husband’s reaction to Effy going out with friends the day after she had a *“meltdown and just absconded and went to the car”* during a family meal.

“He struggles, he struggles with it more than I do. He/ even now so like she had this meltdown in Pizza Hut. I encouraged her the next day, and she went to drama, and he’s upset because we rarely go out for family meals or do stuff anymore because of her issues. [...] he thought ‘well if she can go out to drama, why can’t she go out for a meal with us?’ ‘ If she can do what she wants to do, why can’t she do what we want

to do as a family?.' And how sort of sad it is and I totally understand where he's coming from because I felt like that in the past, and even now I do. I feel sad, and I see other families having a lovely time, and I'm like '(sighs) ah I wish we could just do that,' but he struggles to understand it to the degree that I have. [...] he doesn't really get it so much." (Rita)

Some mothers also felt they were better able to understand their children because they had similar challenges. Marisa, Susan, and Lauren all related to their child and had negative experiences with their parents' reaction to their own behaviour. Mothers noted that this influenced the way they tried to respond to their child's challenges. For Marisa, it was her father's reaction to her tics when she was a child.

"I'm much more sensitive and ahh... Umm... reactive to her tics in a way that I'm like, you know, I know she can't help it and I know <clears throat> whatever she is doing is temporary and is probably going to turn into another tic in a couple of days. Umm and he gets much more annoyed with them, and I have to tell him, like 'take a step back' you know like, sometimes he'll say, tell her to stop doing or making certain sounds, and I have to pull him aside, and I'm like 'dude, come on that's not, like she can't help it. She doesn't know she's doing it' and also I'm having flashbacks to my own childhood, like don't be that dad, you know. And he says 'I can't help the way I feel about it' and I'm like 'but you can help the way you react to it' you know. So, there's a little bit of tension there, umm some of the tics bother him more than others." (Marisa)

For Susan and Lauren, they related to their child's eating behaviours as they also described themselves as selective eaters.

"I didn't have a good relationship with food. And my mom and dad were very strict. [...] Umm so I was very mindful that I didn't want my children to feel that way because I still that carried that with me, that God, I can't believe they made me sick. What were we trying to win here? There was no sense to it and just a lot of upset." (Lauren)

Overall, mothers struggled to reconcile the differences between their desired experiences and their reality, or differing expectations between them and their partners. Ideas surrounding mothering and feeding were a source of stress for mothers as they often struggled to recreate experiences they strived for. Those who strongly internalised notions of good mothering were more impacted by their mealtime challenges. For these mothers, mealtimes appeared to be associated with dissatisfaction with their mealtime experiences, grief for what cannot be (e.g., Walton's-like mealtimes), guilt for not being able to recreate the mealtimes they had hoped for, and sadness.

5.3.4 Summary

This qualitative study aimed to investigate the mealtime experiences of families with a child with TS from the perspective of mothers. The 'tics as a barrier to positive mealtime experiences' superordinate theme noted mealtime challenges mothers attributed to their child's tics. Mothers described their child's tics as being a functional barrier to mealtimes as well as being disruptive. Mothers also noted that tics made dining out a stressful experience characterised by self-consciousness.

The 'eating behaviours and mealtime challenges' superordinate theme detailed how mothers perceived their child's eating behaviours shaped mealtimes. Mothers described how their child's food preferences and mealtime rigidity could create stressful mealtime experiences, as well as being stressful due to the additional foodwork mothers had to undertake to accommodate their child's preferences and rigidity. Food preferences were described as being influenced by sensitivity to taste, smell and/or texture. Mealtime rigidity included both cognitive and behavioural rigidity, although mothers also felt that

sensory sensitivity underlined some of their child's preferences. How mothers perceived their child's eating behaviours informed their feeding practices, which in turn influenced how impactful their child's eating behaviour was on their family mealtime experiences. In most cases, mothers accommodated their child's requests to keep the peace as they learned through experience that controlling feeding practices were counterproductive.

The table tension superordinate theme described sources of mealtime tension. Child-related factors were interruptions to mealtime conversations and age-inappropriate feeding skills. Both these behaviours were described as creating tension at mealtimes and as barriers to positive mealtime conversations; conversations became more directive than facilitative of bonding. Another source of mealtime tension was parental expectations. Mothers described two conflictual expectations, an internal conflict between the mealtime experiences they desired and their reality, and a conflict between their expectations and those of their husbands. Struggles to reconcile these differences created stress for mothers as well as feelings of guilt, grief, and disappointment. Notions of good mothering also appeared to underlie how impactful an inability to recreate desired mealtimes were for some mothers.

This was the first study to extensively document how tics and mealtime rigidity characterise mealtimes in distinctive ways for this clinical group from the perspective of mothers. At times, the tics themselves were challenging, acting as barriers that prevented YP from engaging with mealtimes, and other times they affected conviviality. Mothers also noted dissatisfaction with their family mealtimes although the extent of the dissatisfaction varied depending on the meaning they attributed to their experiences.

This highlights the importance of exploring maternal narratives and the perceived impact this has on their ability to achieve fulfilling mealtime experiences.

5.4 Discussion

Parenting a young person with TS can be a challenge as parents can face several daily obstacles as they struggle to manage their child's tics and establish routines (Ludlow et al., 2018). While literature does recognise that tics can be problematic to everyday activities, no attention has been given to mealtimes. Arguably, an important family activity closely related to family quality of life (Evans & Rodger, 2008; Fiese & Schwartz, 2008). This chapter is centred around the perspective of mothers and had two overarching aims. Firstly, to explore maternal reports on the eating behaviours of YP with TS, their family mealtime environments, parenting stress levels and how they compare to typically developing controls. Secondly, to identify mealtime challenges mothers report they and their families face as a result of their child's TS or comorbidities, and to understand the impact of these challenges and how they are navigated by mothers. The proceeding paragraphs will discuss the findings, first focusing on eating behaviours (predominantly quantitative findings), then turning to mealtime challenges (predominantly qualitative findings).

5.4.1 Eating Behaviour

In the quantitative study, proportionally more YP with TS were classified as selective eaters than typically developing controls, based on maternal report. However, there was no significant difference in reported mean selective eating scores (or neophobia), which contradicts the findings of Smith et al. (2019). While the current study and the study by

Smith and colleagues utilised different versions of the same measure (Adult Eating Behaviour Questionnaire; Child Eating Behaviour Questionnaire), the differences between the measures may account for the contradictory results. The Adult Eating Behaviour Questionnaire was validated by Hunot-Alexander et al. (2019) for use as a self-report measure with YP aged 11 to 18 years. In this study, the measure was transformed from self-report to parent-report by adapting the wording of statements (e.g., 'I' statements changed to 'my 'child' statements). This was deemed a more age-appropriate way to assess YP's eating behaviours due to the age of this study's sample (aged 12 to 16 years).

The selective eating scale within this study also demonstrated good internal reliability suggesting that transforming it to parent-report did not affect the reliability of the measure. Whereas the internal reliability of the Child Eating Behaviour Questionnaire (Wardle et al., 2001) selective eating subscale in Smith et al. (2019) was questionable with their sample of YP aged 6 to 16 years; the measure was originally designed to assess the eating behaviours of young children (aged 2 to 9 years). Hunot-Alexander et al. (2019) suggest that the adult version of the Eating Behaviour Questionnaire is more valid with adolescents than the child version due to the considerable physiological and psychological differences between adolescents and young children. Considering that there were proportionally more selective eaters in the TS group than the control group, future research should continue to explore selective eating in YP with TS and what impact selective eating has on their health, wellbeing, and mealtimes.

In addition to assessing selective eating, the quantitative study also utilised the Sensory Eating Problem Scale (Seiverling et al., 2019) to assess specific sensory-based eating

behaviours. There were no significant differences found between the reports of mothers of YP with TS and mothers of typically developing controls for almost all of the sensory eating behaviours. Mothers of YP with TS reported their child to display greater food-touch aversion than controls. The food-touch aversion items suggest that YP with TS have a greater dislike of food and drinks touching their lips, teeth, and fingers than their typically developing peers. However, it is important to note that the internal reliability for this measure was poor. Most of the mothers of YP with TS (80%) responded ‘never’ to all 4 items, compared to almost all of the control group (98.75%). The combined scale demonstrated good internal reliability. However, the purpose of the scale is to assess specific eating behaviours, therefore it is important that each subscale is reliable. One of the possible reasons for such low alphas for the food-touch aversion scale with the typically developing sample may be due to the specificity of the measure. The floor effect suggests that it may be inappropriate to use with normative samples without sensory challenges or feeding challenges. More research is needed to validate the use of the Sensory Eating Problem Scale with parents of older children without identified feeding ‘problems’.

Interestingly, while there was no significant difference in maternal selective eating between groups, maternal selective eating in the typically developing group was significantly correlated with their child’s selective eating. This suggests that factors other than modelling may influence selective eating in neurodiverse samples. Greater maternal reports of selective eating in YP with TS were associated with greater levels of single-food focus, temperature sensitivity and neophobia. While neophobia was also associated with selective eating in typically developing YP, single-food focus and temperature sensitivity were not. It is possible that single-food focus may be a rigidity-based eating behaviour and that temperature sensitivity may be linked to sensory

sensitivity (however, this was not measured in this study). This may explain why YP with TS had a proportionately higher rate of selective eaters than typically developing controls and why their selective eating levels were not associated with maternal selective eating (Zickgraf et al., 2020).

Greater maternal reports of selective eating in typically developing YP was associated with lower levels of expulsion. It is possible that disgust may play a role in selective eating for typically developing YP. Rozin and Fallon (1987) suggested the expulsion of ‘inappropriate’ foods is associated with nausea, a physiological correlate of disgust. Harris et al. (2019) also found that disgust was strongly associated with severe levels of selective eating in typically developing adults. More research is needed to understand the relationship between the sensory basis of different eating behaviours and how this relates to persistent selective eating in both typically developing and neurodiverse samples.

Despite proportionally more YP with TS having a reported anxiety score above the cut-off than typically developing controls the difference between groups was not significant. Similarly, there were no significant differences in parenting stress levels between groups. Mothers reported that the pandemic had varying effects on their child’s anxiety and their parenting stress levels. This is important to note because a recent study by Gonzalez and Ventura (2021) highlighted the relationship between perceived increases in parenting stress during the pandemic, parental feeding practices and selective eating in YP. Parents who were more stressed reported more frequent use of counterproductive feeding practices (using food as a reward, for emotional regulation, pressure-to-eat). High levels of parenting stress were also associated with greater selective eating, suggesting the

important impact that stress can have on selective eating in YP. Similarly, Mosli et al. (2021) found that maternal concern about their child's diet and selective eating was associated with greater levels of feeding stress during mealtimes. As maternal feeding stress was associated with use of pressure-to-eat, Mosli et al. (2021) proposed that interventions should seek to reduce maternal stress as this may promote more favourable feeding interactions and mealtime experiences as pressure-to-eat is a counterproductive feeding practice (Jansen et al., 2017). For example, pressure-to-eat has been associated with the following: lower food enjoyment (Galloway et al., 2006), lower child BMI (Jansen et al., 2012) and disordered eating in adulthood (Ellis et al., 2016). Within the qualitative study, selective eating was cited by mothers as a source of stress and their concern also motivated mothers to use controlling feeding practices in the past. Therefore, mothers of YP with TS who are selective eaters may also benefit from feeding practice guidance.

Finally, in the quantitative study, no correlates of parenting stress for mothers of YP with TS were found; including child tic severity which was hypothesised not to be a correlate based on the findings of Stewart et al. (2015). However, an increase in the perceived parenting stress levels for mothers of typically developing YP was associated with lower levels of maternal selective eating and greater levels of child anxiety. The relationship between parenting stress and child anxiety was anticipated due to previous studies finding a relationship between the two (Rodriguez, 2011). The relationship between parenting stress and maternal selective eating, however, was unexpected. Research by Koumoutzis and Cichy (2020) suggests that female caregivers may comfort eat to cope with family strain; this could explain the relationship between selective eating, however it is unclear why this relationship was not found for mothers of YP with TS. Further

research is needed to explore why there is a negative correlation between parenting stress and maternal selective eating.

5.4.2 Mealtime Challenges

In the quantitative study, mothers of YP with TS reported similar weekly family dinner frequency (average of 4 or more times a week), duration (average of 30 minutes or less) and positive mealtime attributes as mothers of typically developing controls. Despite the quantitative study suggesting no difference in meal frequency, the qualitative findings suggest that some families had less frequent family meals due to their child's behaviour. While ASD literature suggests that YP might prefer eating alone (Adams et al., 2020; Elnajjar, 2021), this might not be the case for YP with TS who may desire social interaction; as was the case for Jack who was described by his mother as enjoying the togetherness of mealtimes and who wanted to be allowed to eat dinner with his family more frequently. This highlights the inclusion/exclusion dichotomy that exists within commensality; commensality can nourish social relationships and produce belonging, but it can also be exclusive to those not permitted to participate (Fiese et al., 2006; Fischler, 2011). While family mealtimes have been associated with a sense of belonging and family cohesion in typically developing families (Spagnola & Fiese, 2007), this may not be the case for family members who eat separately to the rest of their family. It is also possible that YP who are involuntarily excluded⁶ from family mealtimes may feel marginalised and internalise this as familial rejection. More research is needed to

⁶ YP who wish to not eat with their family are voluntarily eating alone, thus are not likely to be adversely affected by the rest of their family eating together. This could include YP with ASD who prefer to eat alone (Adams et al., 2020) and more generally adolescents who are less inclined to want to eat with their family regularly (Neumark-Sztainer et al., 2000).

explore how YP perceive fragmented mealtimes and what effect, if any, it has on familial outcomes and a young person's psychosocial development.

As previously discussed, what matters most about family mealtimes is the quality of the experience, not simply the frequency (Dallacker et al., 2019). Yet little is known about the mealtime experiences of families with a young person with TS. The qualitative study captured maternal accounts of the nature of their family mealtime experiences, namely, the challenges they faced and how they responded to them. Mothers in this qualitative study noted similar mealtime challenges as documented in the ASD literature due to shared neurodevelopmental traits (Ausderau & Juarez, 2013; Lazaro & Ponde, 2017; Rogers et al., 2012; Suarez et al., 2014). However, mothers in this study also reported tic-related mealtime challenges. Tic-related challenges are discussed first before turning to mealtime challenges that relate to their child's eating behaviour.

Mothers depicted an array of tics that impacted their child's ability to eat, be seated, stay seated and other family members' mealtime experiences (e.g., throwing tics). Mothers described tics as a source of frustration for their child and disruptive to others' mealtime enjoyment. While Suarez et al. (2014) were surprised to find that an inability to remain seated was a primary frustration for mothers, it is to be expected within this population. TS is a movement disorder; thus, it was not surprising that mothers had trouble getting their child to be and remain seated during mealtimes.

Interestingly, a few mothers felt that their child's tics intensified when they returned home from school as a result of tic suppression during the day. As such, they needed to delay mealtimes to accommodate the perceived increase in tic severity. While it is

common for parents to perceive tic rebounds, experimental research does not support the assertion that tics intensify as a result of suppression (Himle & Woods, 2005; Specht et al., 2013; Verdellen, Hoogduin & Keijsers, 2007). Himle and Woods (2005) compared tic frequency for YP (n=7, aged 8 to 12 years) during baseline, pre- and post-suppression. They found that tic frequency returned to baseline post-suppression for all but one participant. Similarly, Specht et al. (2013) found that tic frequency for YP (n=12, aged 10-17 years) returned to baseline after prolonged periods of suppression. Regardless of whether tic severity objectively increased as a result of tic suppression at school, it appeared that tic severity was disruptive as mothers felt the need to delay mealtimes to accommodate tics; something which was also mentioned in Ludlow et al. (2018). While this was disruptive to the family's routine, it was often less disruptive than the presence of certain tics during the meal.

While tics that presented practical challenges were frustrating for YP, they were rarely described as having a negative effect on the broader mealtime experience beyond maternal empathy for their child's struggles. However, a notable qualitative finding was that mothers described emotional arousal, such as anxiety and frustration, as tics intensified, which in turn increased tic severity and the level of disruption tics had on the mealtime. This maternal observation of a feedback loop between anxiety/stress and tic severity is supported by research (Caurín et al., 2014; Godar & Bortolato, 2017). However, in the quantitative study, no relationship was found between maternal report of their child's anxiety and tic severity in YP with TS. The lack of relationship in the quantitative study may be due to there being no relationship between overall anxiety levels and overall tic severity. This suggests that the relationship between anxiety and tic

severity is temporary; increased anxiety can trigger tics, which accounts for the increased severity, however this is a fluctuation that returns to baseline (Godar & Bortolato, 2017).

Considering that a child's tics are beyond a mother's direct control, which mothers reported left them feeling helpless, they often searched for ways that they could help their children. A few mothers cited the tic-anxiety/stress feedback loop as a reason for accommodating their child's preferences; mothers did not want to trigger emotional distress as this could make the mealtime spiral out of control as their child's tic increase. Future research should explore the effect of mealtime accommodations on YP's tic expression and dietary quality as mothers may unintentionally reinforce tics and selective eating due to the 'positive' outcomes associated with tic expression during mealtimes (e.g., mothers making exceptions for their child with TS, so they receive 'special' treatment in comparison to their typically developing sibling or mothers only serving preferred foods) (Essoe et al., 2021).

Lazaro and Ponde (2017) also found that mothers of YP with ASD may unintentionally reinforce their child's selective eating and mealtime behaviour due to them conceptualising their child's behaviour as ingrained in their ASD. While YP with additional needs may require some accommodating, it may be challenging for mothers to discern what is necessary and helpful, as opposed to what reinforces behaviours and may be counterproductive (Himle et al., 2018). Clinical professionals would be best suited to provide parenting support, however reports suggest that little support is currently available for these challenges (Bhikram et al., 2021; Lazaro & Ponde, 2017).

In addition to the practical challenges tics presented, mothers described experiential and emotional challenges. These included affecting the ability of others at the table to relax, and enjoy their meal, and self-consciousness when dining-out. Outside of the family home, tics were often an issue, drawing unwanted attention to the family. Most families avoided dining-out regularly due to several challenges, the main one being maternal perceptions of how other diners would view their child's tics and behaviour. This was particularly true for socially unacceptable behaviour which could easily be viewed as bad behaviour and bad parenting (e.g., swearing tics (Eddy & Cavanna, 2013)). Avoidance of social activities such as dining out, due to fear of being stared at, is a common challenge faced by families with a young person with TS (Cutler et al, 2009).

Families who dined out tended to opt for environments they felt would be more accepting of their child's tics and behaviours; usually family-friendly restaurants where they could blend into the background. While the need for family-friendly environments was also mentioned by mothers of YP with ASD in Suarez and colleagues' study, what was deemed suitable varied depending on each child's needs (Suarez et al., 2014). Mothers in the current qualitative study preferred louder venues where their child's tics could blend in, whereas mothers in Suarez and colleagues' study required quieter venues to accommodate their child's sensory sensitivity. This finding highlights the varying needs of neurodiverse populations and how environments that might meet the needs of some families may be problematic to others. Therefore, the more diverse establishments are, the more likely families are to find environments that meet their needs.

It is not customary practice, however, for restaurants to display environmental information that could support families to find venues that meet their needs. Restaurants can make themselves more accessible to families by providing clear information online that allows parents to assess whether the environment is optimal for their family's needs. Researchers could play a role in supporting the design of a standardised system to assess restaurant environments. This would benefit many families, as parents with typically developing children also consider their child's eating behaviours, mealtime behaviour and attention span when selecting a restaurant to visit; often opting for child-friendly fast-food venues with a quick service time (McGuffin et al., 2015).

Contrary to the quantitative finding, mothers in the qualitative study found their child's eating behaviours to be a source of mealtime stress. Food related challenges included selective eating, food jags, food refusal based on sensory sensitivity (taste, texture, and smell) and mealtime behaviour challenges (meltdowns). These eating behaviours were described as creating stressed and strained mealtime interactions, often leading to conflict and additional foodwork. Some mothers frequently used combative language to describe their mealtime interactions with their children, often describing it as a 'battle.' These mothers tended to be concerned by their child's eating behaviour, which motivated them to assert control over their child's food choices; a well-documented drive for controlling feeding practices (Callie L Brown et al., 2016; Costa et al., 2021). Mothers described their attempts to control their child's eating behaviours as leading to a battle of wills, which ultimately ended in a 'meltdown' and mothers conceding to keep the peace. The repetition of these experiences exhausted mothers and often led to them feeling defeated, similarly to mothers of children with ASD (Ausderau & Juarez, 2013; Lazaro & Ponde, 2017; Rogers et al., 2012; Suarez et al., 2014).

Mothers viewing their child's expression of food autonomy as a problem was itself problematic. Viewing YP's expression of autonomy as non-compliance is a parent-centred unidirectional perspective. Walton et al. (2017) highlight the importance of viewing feeding interactions as bidirectional, particularly in preventing a battle of wills which can occur when parents exert control over their child's food choices, evoking child resistance. Instead, an approach that values both parties' desires and seeks to find a compromise is more productive in trying to create harmonious mealtime experiences and supporting YP to develop a healthy relationship with food. While mothers may think that controlling feeding practices will improve their child's selective eating (Costa et al., 2021), they unwittingly further entrench selective eating and create negative associations with food (for review, see Ruzicka et al., 2021). This was supported by the experiences of mothers who had conflictual mealtimes as they often described conflicts as being an issue of the past. Mothers often learned the hard way that controlling feeding practices were counterproductive as they only made mealtimes more stressful. While some mothers in this study felt defeated, others were able to transform their perspective as they tried to work with their child's food preferences rather than against them.

Alongside food preferences, mothers also described mealtime rigidity as a challenge. Mealtime rigidity expressed itself in several ways; children were described as having preparation and plating preferences, including cookware preferences, and being brand loyal. Mothers said that these additional demands placed them under pressure and increased the amount of foodwork they had to undertake; this included cognitive and emotional labour. Although some of this was underpinned by sensory challenges, others were more linked to cognitive rigidity and the need for things to be and feel 'just right.'

These traits have long been documented as a feature of TS (Leckman et al., 1994). It might also be worth considering whether obsessive-compulsive symptoms underlie mealtime rigidity and engagement in specific eating practices due to the overlap between tics and compulsions (Palumbo & Kurlan, 2007).

The cumulative nature of stressful mealtime experiences and having to accommodate preferences took a toll on mothers in the qualitative study; some felt hopeless with no other choice but to give up despite not wanting to, while others surrendered to their reality, opting to give in to keep the peace. Research by Thullen and Bonsall (2017) found that disruptive mealtime behaviour, food refusal and mealtime rigidity were all positively correlated with stress in parents of children with ASD. Considering many of the mothers in this study detailed all three behaviours as mealtime challenges, mothers of YP with TS may benefit from interventions to reduce mealtime-related stress. It is also believed that this is the first study to document mealtime rigidity in this clinical group. Future research should consider adapting the Brief Autism Mealtime Behavioural Inventory (BAMBI) (Lukens & Linscheid, 2008) for use with children with TS to explore the relationship between mealtime behaviour problems and parental stress. Clinical professionals who work with YP with TS could use BAMBI to identify families that may benefit from interventions to address selective eating and mealtime stress.

A final noteworthy qualitative finding related to how mothers felt about their family mealtimes and their inability to recreate their desired experiences; this was also noted in ASD literature (Ausderau & Juarez, 2013; Suarez et al., 2014) and typically developing literature (Thompson et al., 2021). The incongruency between what mothers

desired and their reality, and failure to accept their reality, appeared to be the source of dissatisfaction in this study. Some mothers grasped onto their ideals, while others could modify their expectations and create more fulfilling experiences. Although, a modification of expectations and acceptance of their reality did not necessarily mean that mothers did not have moments where they grieved for what could not be. The role grief plays in the lives of mothers of children with chronic conditions has been well documented (Coughlin & Sethares, 2017). Mothers in this study who internalised notions of good mothering (e.g., the provision of nutritious home-cooked meals, see Ristovski-Slijepcevic et al., 2010), were particularly affected as it challenged their identity. This is unsurprising as parents of YP with chronic conditions tend to have a heightened sense of responsibility for their children (Cousino & Hazen, 2013; Tabatabai, 2020). Considering the politicisation of feeding and how central it is to maternal identity, mothers who are dissatisfied with their family mealtime experiences may benefit from tailored interventions.

While the qualitative study highlights the challenges mothers and their families faced, it does not seek to imply that these experiences are representative of all families with a young person with TS and that all mealtime experiences are stressful and challenging. There were some positive experiences shared. The resilience of these mothers and their commitment to their children and families was palpable. The results shared seek to shine a light on some of the hidden challenges these mothers faced, and that other mothers may also face. The hope is that by highlighting the barriers to harmonious and enjoyable mealtimes, practitioners who work with these families may be able to provide mealtime-specific support. Families may benefit from support that can help them create meaningful experiences, be it adjusted mealtimes to accommodate for their challenges or finding alternative bonding activities. While mothers had to contend with the same

common barriers as families with typically developing children (time poverty, lack of synchronicity, picky eating, and high stress (Middleton et al., 2020)), these challenges were often amplified by their child's conditions and, in some cases, the conditions of other family members. The cumulative effect of stressful mealtimes on familial wellbeing and resilience within this clinical population is worthy of attention and support. Additionally, screening for mealtime challenges in YP with TS could lead to early identification of challenges that can negatively impact quality of life.

5.5 Chapter Summary

This was the first mixed-method study to explore the eating behaviours of YP with TS and the mealtime experiences of their mothers. The results from the quantitative study found differences in correlates of selective eating and parenting stress between the TS group and typically developing controls. Yet despite these differences, they experience similar mealtime duration, frequency, and positive mealtime attributes. While the quantitative study suggests that traits and characteristics associated with TS (anxiety and tic severity) did not shape eating behaviours, mealtime environments nor parenting stress, the qualitative findings suggested otherwise. Mothers of YP with TS reported their mealtimes were shaped by their child's eating and mealtime behaviours, similar to research on ASD samples, namely affected by sensory sensitivity and rigidity. This usually resulted in mothers having to undertake additional foodwork to accommodate their child's requests.

This was the first study to document how tics and mealtime rigidity characterise mealtimes for this clinical population. At times, the tics themselves were challenging, acting as barriers that prevented children from engaging with mealtimes, and other times they affected conviviality. Mothers also noted dissatisfaction with their family mealtimes although the extent of the dissatisfaction varied depending on the meaning they

attributed to their experiences. This highlights the importance of exploring maternal narratives and the perceived impact this has on their ability to achieve fulfilling mealtimes experiences. The next chapter contributes to the dissertation by providing the perspectives of clinical professionals.

Chapter Six: Phenomenological Examination of the Eating Behaviours and Mealtime Experience of Young People with TS and their Families from the Perspective of Clinical Professionals

6.1 Introduction

While the mealtime experiences of YP with TS and their families were previously undocumented from the vantage of academic literature, there is thought to be a wealth of knowledge garnered through comprehensive assessment of, and experience working with, YP with TS and their families (Martino & Pringsheim, 2018). A variety of clinical professionals including, but not limited to, psychologists, psychiatrists and neurologists work closely with families and YP with TS due to the multifaceted nature of TS and comorbidities (Bhikram et al., 2021). Families normally interact with clinical professionals when they need support with challenges they face, therefore professionals are well placed to report on challenges families experience.

Research has shown YP with TS tend to report lower quality of life (Eddy, Cavanna, et al., 2011; Eddy, Rizzo, et al., 2011) and psychosocial functioning (Gutierrez-Colina et al., 2015) compared to the general population. Furthermore, Bitsko et al. (2013) found that health care needs increased as tic severity increased. However, it was noted that YP with TS and comorbidities required services the most; including mental, emotional, and behavioural support. For example, the authors highlighted that YP with TS and a

comorbid diagnosis of ADHD were particularly more likely to require more access to mental health services. Research suggests that as many as 80% of people with TS have an ADHD and/or comorbid OCD diagnosis (Kumar et al., 2016), and that symmetry/exactness, aggressive urges, fear-of-harm, and hoarding are transdiagnostic traits shared by people with TS, OCD and ADHD, possibly due to shared genetic susceptibility (Hirschtritt et al., 2018). Considering the high comorbidity rates and the increased service needs of YP with TS and an ADHD comorbidity, clinical professionals are likely to have had more clinical contact with this subsection of the TS population. As such, their experiences are likely grounded in the entwined manifestation of TS-ADHD.

More specific to eating behaviours and mealtimes, ADHD is also a comorbidity that can present with its own mealtime challenges (Ghanizadeh, 2013; Ptacek et al., 2014). Therefore, it is likely that ADHD-related eating behaviours and mealtime challenges will form a notable part of professionals eating behaviour knowledge and clinical experience. For example, Ghanizadeh (2013) found that YP (aged 3 to 15 years) with ADHD and higher levels of oppositional behaviours were more likely than YP with ADHD and low oppositional behaviours to be selective eaters, food neophobic and have a limited dietary range. Due to shared neurodevelopmental traits, these eating behaviours are also experienced by neurodiverse YP (e.g., ASD and TS). Additionally, YP (age 6 to 10 years) with ADHD were found to eat more sporadically than typically developing controls; being more likely to skip meals and engage in irregular and or impulsive eating (Ptacek et al., 2014). Their eating patterns could be linked to whether or not they were on medication, as stimulant medications often suppress appetite (Wigal et al., 2006). Research by Waring and Lapane (2008) found that YP (aged 5 to 17 years)

with ADHD on stimulant medication had a 60% greater risk of being underweight when compared to healthy controls; those not on ADHD medication had a 50% greater risk of being overweight when compared to healthy controls. These studies highlight that there are a range of atypical eating behaviours within the ADHD population, and that medication can influence eating patterns and behaviours.

As noted in chapter one, YP with TS and ADHD comorbidity are more likely to be prescribed medication for their ADHD and tics than YP with a sole TS diagnosis (Jewers et al., 2013). Also, in most cases ADHD medications were more often prescribed than medications for tics. Therefore, the effect of ADHD medications on appetite and eating behaviours is important to consider when exploring the eating behaviours and mealtime experiences of YP with TS and their families.

While one of the key clinical responsibilities listed in the NICE (2018) guidelines for ADHD is the physical monitoring of YP prescribed ADHD medication (which includes monitoring weight and height to assess weight fluctuations; see guideline 1.85), it is unclear whether the same practice is followed for YP with TS and ADHD comorbidity, although this is presumed since NICE guidelines do not exist for TS. The Canadian Alliance for Monitoring Effectiveness and Safety of Antipsychotics in Children guidelines advise professionals to monitor weight gain and growth, however it is also unclear which professionals do (Pringsheim et al., 2011). There is a well-defined need for more longitudinal studies, not only addressing medication-induced weight fluctuations, but also studies that control for dietary effects in TS (Ludlow & Rogers, 2018).

In the UK, NICE (2018) guidelines (see guidelines 1.8.6 and 1.8.7) and best practice reviews provide guidance on managing appetite suppression side effects of medication for YP with ADHD (Cortese et al., 2013; Graham et al., 2011). This overall guidance includes: (1) taking medication with or before meals, (2) eating additional meals or snacks before or after appetite suppression, (3) consuming calorie dense and nutrient rich foods, (4) getting dietary advice, (5) taking planned medication breaks, and (6) switching medication. The emphasis of this advice is on increasing calorie intake and managing appetite suppression, as opposed to managing mealtime challenges that may arise as a result of appetite suppression or parental efforts to enact the guidance above. It is presumed that the parent-child feeding dynamic is intensified due to the contrast between YP's decreased desire to eat and parental desire to increase their child's consumption. Nevertheless, this has yet to be empirically explored.

Considering that there are no NICE guidelines for TS, best practice is often unclear; this can be detrimental to patient care due to lack of general TS awareness among non-specialist clinicians (Bitsko et al., 2013). While clinical professionals are anticipated to utilise the ADHD guidelines when prescribing ADHD medication to YP with TS and ADHD comorbidity, it is unclear how clinical professionals feel about managing mealtime challenges, and how they manage them if they arise.

In addition to medication-related mealtime challenges, selective eating is also an anticipated challenge that may arise. As discussed in the previous chapters, selective eating is a challenge that exists in the TS population, at similar levels to the ASD population, that has only recently been empirically explored (Smith et al., 2019, 2020). It is unclear whether selective eating is a challenge that clinical professionals who work

with YP with TS and their families are aware of and/or treat. Whether eating behaviours and mealtime challenges are raised in practice with professionals, and how professionals manage these challenges, also remains undocumented.

The purpose of this qualitative study was to gain insight into the eating behaviours and mealtime challenges of YP with TS and their families from the perspectives of clinical professionals. Professionals working with a diverse range of families are well-placed to act as informers, voice the experiences of the families they work alongside, and provide valuable practice-based knowledge. Clinical professionals can help scope the range of eating and mealtime difficulties that exist within the TS community while framing them within the context of clinical knowledge and expertise. This information will raise awareness of potential challenges to mealtimes, an integral part of daily life, for YP with TS and their families. While it is important to address challenges directly related to tics, it is also important to support healthy lifestyles, quality of life and social relationships for those with chronic disorders and their families (Eapen et al., 2016).

6.2 Research Questions

This study aims to understand how TS traits and characteristics might influence mealtime experiences and shape eating behaviours from the perspective of clinical professionals who work with YP with TS. The research questions addressed in this chapter are as follows:

1. What mealtime challenges, if any, do patients and their parents raise with clinicians?
 - a. How do clinicians make sense of these challenges?
 - i. How, if at all, do clinicians perceive tics to shape mealtime experiences?
 - ii. How, if at all, do clinicians perceive sensory sensitivity to shape a child's eating behaviours and their family mealtime experiences?
 - iii. How, if at all, do clinicians perceive rigidity to shape a child's eating behaviours and family mealtime experiences?
 - iv. How, if at all, do clinicians perceive medication to influence a child's eating behaviours and family mealtime experiences?
2. What is the impact of these eating and mealtime challenges?
3. How do clinicians approach these challenges?
4. How do these challenges fit into the wider context of their work with this population?

6.3 Method

6.3.1 Design

This phenomenological study captured the clinical experiences of seven diverse clinical professionals who work with YP with TS and their families, capturing both richness and diversity of accounts. As detailed in chapter two (Methodology), interpretative phenomenology was embraced as the methodological framework for this study because it centres around the lived experiences of participants and the meaning they attribute to their experiences.

6.3.2 Recruitment

Tourette's Action helped disseminate information about the study to clinicians on their database and through their social media accounts. Clinicians interested in participating were advised to email the researcher. They were then sent an information sheet (see **Appendix Q**) which detailed aims and objectives of the study; how their data would be used and protected; and their right to withdraw. Participants were also sent a copy of the interview schedule, so they knew the line of inquiry before consenting to take part. Clinicians were advised that they might find it helpful to review their clinical notes and reflect on their experiences prior to the interview, as this might help them to answer some of the questions.

All participants provided informed consent (see **Appendix H**) and were assured of their anonymity and right to withdraw at any stage. Participants also provided consent for their interviews to be recorded for the purpose of transcription.

6.3.3 Participants

Seven clinical professionals took part in this study. Although the sample size was small, it remained within the bounds of an acceptable sample size for an IPA study (Smith et al., 2009). Clinicians were eligible for inclusion if they had experience working with YP with TS, with no restrictions placed on their job title, service type (i.e., National Health Service (NHS) or private), level of experience or geographical location. The aim was to have a heterogeneous sample to allow for a range of experiences relevant to the phenomenon of interest. This enabled greater insight from as many vantages as possible which was thought to be important due to the varying professionals who work YP with TS and their families (Bhikram et al., 2021). Characteristics of the seven participants are listed in Table 23. Most of the clinicians were based in the UK; two of whom were based in specialist tic services. In addition to providing their clinical perspective, three had direct lived experience as either the parent of a young person with TS or as an adult with TS; although the focus of this study was on their professional perspective

Table 23. Table of participant pseudonyms, clinical roles, and experience

Pseudonym	Sector	Clinical Base	Job Role	Lived Experience	Case Sample
Andrea	Private	UK	Psychologist	Yes	Approx. 30-35 cases over 5 years
Lisa	Private	UK	Psychotherapist	None	Approx. 15-20 cases over 2 years
Melissa	Private	AUS	Psychologist	Yes	15 cases over 5 years
Morgan	NHS	UK	Psychologist	None	Approx. 200 cases over 2.5 years
Theo	NHS	UK	Prescribing Professional	Yes	Approx. 2,000 cases over 10 years
Harry	NHS and Private	UK	Paediatrician	None	Approx. 360 cases over 18 years

Kieran

Private

UK

Psychiatrist

None

Approx. 30 cases over 22 years

6.3.4 Data collection

All semi-structured interviews were conducted virtually, using platforms such as Skype, Zoom and FaceTime. Interviews ranged from 30 minutes to 60 minutes, although Theo was interviewed twice to capture his considerable experience. Interviews took place between May 2019 and August 2020. Only Harry and Kieran were interviewed during the COVID-19 pandemic. All interviews were digitally recorded and transcribed verbatim by the researcher.

Empirical literature, anecdotal evidence, and insight from TS clinical consultation sessions guided the creation of the semi-structured interview schedule (see **Appendix Z**). The schedule was also reviewed by the supervisory team. The first part of the schedule captured participants background information and their experience of working with YP with TS. The second part focused on their knowledge of eating and or mealtime challenges with the following core questions:

1. Can you describe any eating difficulties you have encountered within your patients with TS throughout your clinical career?
2. Can you talk to me about medication prescribed to YP with TS and possible side effects?
3. Can you talk to me about fluctuations in the weight of your patients with TS, if any?
4. Can you talk to me a little bit about sensory processing difficulties or heightened sensations in your patients with TS?

5. Anecdotal evidence suggests that tics can get in the way of eating, influence the social element of the meal, or present a risk during mealtimes. Can you tell me about any tics that may have been raised in relation to eating or mealtimes?

Similarly to the other qualitative studies presented in this dissertation, interviews were conducted in-line with Smith and Osborn (2003) recommendations for IPA research. However, in this study interviews were also designed to simulate reflective practice sessions so clinicians could feel comfortable contextualising their experience within this new frame of reference. This was deemed to be particularly important as most clinicians had not previously reflected on the eating and mealtime experiences of their patients. This is also why some of the questions were kept purposefully broad. Prompts were used to capture eating behaviour and mealtime specific experiences.

6.3.5 Analysis

As detailed in chapters two and four IPA guidelines by Smith et al. (2009) were used to analyse transcripts, though case summary templates were not used. Instead, a reflective narrative was written for each case before moving onto the next case. Patterns across all cases were subsequently explored to create the superordinate and subordinate themes related to the eating and mealtime experiences of YP with TS and their families.

6.4 Themes

The following themes address the research questions for this chapter by detailing the mealtime challenges YP with TS and their parents raise with clinicians; how clinicians conceptualise these challenges i.e., what behavioural traits or characteristics associated with TS and comorbidities interplay with mealtimes to create challenges; the impact of

these challenges for YP with TS and their parents; and how clinicians manage these challenges in practice. All clinicians communicated primarily with the mothers as they usually attended sessions with their child, although there were rare occasions when fathers would also attend. Lack of engagement by fathers in their child's appointments and treatment is a known phenomenon and has previously been studied (Phares et al., 2010; Walters et al., 2001). Due to lack of differentiation between findings that relate specifically to the experiences of mothers or fathers, reference is made to parents. However, it is important to keep in mind that clinical professionals' understanding of parents' experiences is primarily rooted in maternal accounts (Phares et al., 2010; Walters et al., 2001). Therefore, some of the parent findings may not relate to the experiences of fathers.

Analysis of the seven semi-structured interviews resulted in five subthemes which were grouped under two superordinate themes: (1) how tics shape YP's mealtime experiences and (2) parental mealtime challenges and factors that shape family mealtime experiences, see Table 24. These themes captured clinicians' thoughts surrounding, and the meaning they attributed to, the mealtime challenges their patients and their parents faced.

Table 24. Theme structure for clinicians

Superordinate themes	Subthemes
How tics shape YP's mealtime experiences	Disruptive tics
	Tic visibility and self-consciousness
Parental mealtime challenges and factors that shape their mealtime experiences	Won't eat: selective eating and parental feeding practices
	Can't eat: appetite suppression and parental concern
	Won't stop moving: tics, ADHD, and stereotypes

Some of the words clinicians used to describe the mealtime experiences of YP with TS and their parents were *noisy, chaotic, distracted, stressful, pressurised, embarrassing, isolating, anxiety-provoking, frustrating* and *conflict*. Each theme articulates these descriptors more fully while situating them within the context of distinct behaviours and characteristics associated with TS and comorbidities. By virtue of clinicians' work, non-problematic experiences were rarely discussed in practice; meaning that they were often not able to comment on positive aspects of mealtimes or more generally on the overall mealtime experience. As such, the findings present a picture of challenging mealtimes, not necessarily the 'typical' mealtime experiences of YP with TS and their parents.

6.4.1 How Tics Shape Young People's Mealtime Experiences

This superordinate theme delves into the challenges that YP with TS raised with clinicians; detailing how tics impacted a young person's ability to engage with mealtimes and wellbeing. It is important to note that while this section describes mealtime challenges, clinicians noted that mealtime challenges were rare to see in practice, especially challenges explicitly raised by YP. In most cases, mealtime challenges would be revealed when discussing a young person's tics and the broader impact it has on the young person's life.

Clinicians reported that mealtime challenges would usually only surface in relation to broader discussions on the impact of tics on daily life and functioning; with sessions often focused on 'tic hassles.' In most cases, functional challenges were temporary as tics would wax and wane, whereas the socio-emotional consequences of tics tended to be more enduring. This superordinate theme touches on these two challenges: (1) disruptive tics and (2) tic visibility and self-consciousness. These themes help develop an idea of how clinicians perceive the mealtime experiences of YP with TS to be shaped by their tics and the clinical relevance clinicians attribute to said experiences.

Disruptive Tics

All clinicians recognised that tics could be problematic during mealtimes, although not all had worked with patients who had specific mealtime challenges. Nevertheless, they were all theoretically aware of the mealtime implications of particular tics. Clinicians noted a multitude of tics that had the potential to disrupt mealtimes. The tics in

themselves were not necessarily problematic, but within the context of mealtimes they could prove to be a challenge, acting as a barrier to eating, drinking, or staying seated.

"[...] the vocal [oral] ones like, you know, the swallowing and, you know, gulping that might interfere with their eating and drinking. The physical tics, you know, things like the, the head and neck movements, and shoulder movements and limb movement. Movement of the arms and legs." (Harry)

"[...] you've got the actual tics themselves. So, you can have tics of your arm which flick your food, you can have tics that stab your fork into your eye, you can have tics that are vocal which mean you can't chew or speak while you're eating, it all gets messed up together. You can have head tics that stop you from eating, mouth tics, eye, nose tics, finger tics. Anything that gets in the way of the process of shovelling food into your gob is a barrier and that could even be simply sitting down on a chair."
(Theo)

All clinicians noted tic severity varied widely across their cases and, in most cases, tics were rarely disruptive in the aforementioned ways. YP who had milder tics were able to manage their tics and work around them which allowed for minimal disruption to their mealtimes. Those who were reported to have more severe tics or clusters of tics tended to be more likely to report mealtime disturbances. There was a sense that this was understandable, as tics tended to have a more disruptive effect on all areas of life for those on the severe end of the spectrum; mealtimes were no exception.

The functional challenges presented by tics during mealtimes were reported to be managed on a practical level, with mealtimes being delayed to allow the tics to settle or mitigate their effect. For example, using aids such as a cup with a lid to reduce drink spillage.

"I think he had quite a violent head jerk [...] so it was very difficult for him but I think mum overcame that by buying him one of these cups, you know with a lid [...]" (Lisa)

Lisa explained that the head jerking tic eventually went away and so it was no longer a challenge the family had to work around. This could be why mealtime challenges such as these are rarely mentioned to clinicians, as they resolve themselves with time. While it was possible to manage the impact of a tic on a functional level, it was notably harder to manage the impact of a tic on a child's life. Kieran placed mealtime challenges in context of wider challenges that stem from tics, noting how tics can 'derail' a young person's mealtime and life.

"Totally just derailed the meal completely. Umm you couldn't, you know, couldn't carry on, he had sort of almost like a five-minute kind of body tensing where he had to keep doing it to kind of try to get rid of this horrible hot and cold water feeling over him.[...] the main focus wasn't meals, the main focus was just this was totally derailing his life. Umm it would be happening four or five times a day and it was just a right mess." (Kieran)

In such cases, the focus was placed on the tic and not the context as there appeared to be more far-reaching consequences. Mealtimes were a situational challenge for this particular tic, but there were other contexts where the tic was also problematic. The cumulative effect of the tic on day-to-day life required significant clinical attention. Another clinician, Lisa, also noted how a repeated experience can affect self-esteem. Lisa described how one child's tic-induced clumsiness warped his sense of self and the world.

"[...] so, it was more with kind of like spilling drinks and things. Umm but he came very, very anxious and you know with a very kind of like self-damning kind of very negative umm perspective of the world" (Lisa)

There was an overall sense that disruptive tics in themselves were not problematic in relation to mealtimes, as practical solutions could usually be employed to mitigate their effects. Nevertheless, the repetitive nature of mealtimes means that these experiences that might start as a source of frustration could develop into more serious challenges effecting a young person's wellbeing and quality of life. The extent to which tics disrupted mealtimes was hard to determine as most clinicians did not ask specifically about tics in the context of mealtimes. Although, there was a sense among clinicians that such issues would be raised by YP and parents if they were truly becoming problematic, whether or not they were asked about. What was unanimous was that tics did have the potential to disrupt daily life, mealtimes included.

Tic Visibility and Self-Consciousness

A more common challenge that YP raised to clinicians in relation to tics and mealtimes was the increased visibility of tics and the self-consciousness that often ensued. In the spirit of this sentiment, Theo described TS as a "*socially conscious movement disorder*" thus self-consciousness was deemed to be part-and-parcel of life with TS. In general, all clinicians noted self-consciousness as a challenge that many YP with TS faced. Mealtimes were described by a few clinicians as a pressurised environment. Andrea described how mealtimes were pressurised by explaining that having to sit "*directly facing someone*" makes tics "*much more visible*". Theo built upon this, adding the dimension of "*unspoken rules*" associated with mealtimes as an additional source of pressure. Typical mealtime etiquette, such as sitting still, engaging in appropriate dinnertime

conversation, being relatively quiet, and eating with one's mouth closed could all be challenging if children had discordant tics.

YP with TS were noted to complain about mealtimes both within and outside of the family home; although, more commonly about mealtimes around non-immediate family and members of the public. Additionally, these types of challenges were more prevalent in older adolescents than younger children, as adolescents tended to be more aware of social norms and their differences. This made them more attuned to people noticing their tics which often left them feeling embarrassed.

"[...] especially teenagers, they often have an insight, they are aware of their tics. So, they are worried about other people watching them." (Harry)

Lisa provided an example where tics were not only visible due to the seating arrangement, but also due to the way the table was laid. Her patient's mother would drape a cloth over the table when entertaining guests. This presented a challenge as the tablecloth would move when her patient experienced a leg tic. This would draw attention to his tic which heightened his anxiety and left him feeling embarrassed.

"[...] mum did lots of entertaining at the weekend. Family came around and umm you know the/ I guess it was traditionally that she put a cloth on the table, and you know he felt, I think he felt under a lot of pressure because there had been a time when, when the table cloth/ as he moved, the table cloth would move and everything would move. And umm I don't think he was so fussed if it was just family but sometimes they'd have family friends and I think that he found that really quite embarrassing."
(Lisa)

As with other practical challenges caused by tics, Lisa worked with the mother to find a solution to prevent the tablecloth from moving. Lisa described having to balance respecting the mother's traditions while trying to help her to make mealtimes less stressful for her son.

“So it was almost a conflict between almost, kind of, umm... what was seen to be right, in terms of table etiquette was, you know, the placement and setting of the table, but that was conducive to him having a positive experience because he ticked.”

(Lisa)

While they managed to resolve the issue of the tablecloth moving, it did not resolve his self-consciousness as he was left with anticipatory anxiety and worried that it might happen again.

Additionally, some clinicians saw self-consciousness as a barrier to mealtime enjoyment. Some patients reported that they avoided mealtimes altogether, while others felt unable to be present in the moment as they directed their attention towards tic suppression.

"You may be suppressing your tics which means you're holding yourself back which a lot of kids struggle with because if you're giving sort of, if you're holding yourself from doing something you're not engaging as much." (Theo)

Theo added to this conceptualisation noting how anticipatory anxiety can reinforce tics by heightening neural speed and thus tic severity. Such self-consciousness and anxiety around tics can create a self-fulfilling prophecy by increasing the chances of ticking during the meal.

"The difficulty with Tourette's is the more anxious you feel, the more self-conscious you feel, the more you think about your tics, the more you're embarrassed, it raises your neural speed. You know? You're adding layers of complication. It's like plate spinning. You're adding layers all the time and the more plates you add, the more tics you have which creates more plates. So, the vicious cycle of anxiety and worry is not that it causes tics but it ramps them up and that makes you more conscious which ramps it up, which makes the problem worse. Which ramps it up. And you just go back and forth between the two things. So, if you're someone that's prone to having say self-consciousness at dinner, you worry before you even get in there." (Theo)

Several other clinicians also noted this feedback loop between tics and anxiety, although not specifically in relation to mealtimes. Eating out of home was noted to be particularly challenging due to concerns about reactions from the public. Harry drew attention to the possible knock-on effect avoidance of social activities, such as eating out, could have on a young person's social life. He recalled a case where a young person struggled to eat out with her friends.

"I had one girl, she had severe tics and she, she finds it hard to go to her friends and also going to a restaurant or places like that to eat out [...]" (Harry)

Harry noted that this patient was particularly distressed by her tics and that she wanted to know when she would be able to have "*a normal life*" again. Harry suggested that being unable to go out with friends for meals negatively affected her quality of life. The role meal avoidance plays in social isolation for YP with TS was not definitive among clinicians, although Harry's example does suggest it could be socially disabling as it further reduces their scope of social interactions.

Meal avoidance was also noted by Theo to potentially effect family bonds as patients missed shared family experiences. Although, he did say that this was typically less of a concern for YP who tended to become more 'reclusive' in their teenage years.

"[...] if that's the only time when your family bonds and sits down to talk to each other, you miss out on those interactions and you become the one that's in the living room again." (Theo)

Interestingly, Andrea mentioned the importance of "*normalising*" mealtime experiences. Although she did not clarify on why, it could be because familiarisation with the experience could eventually reduce anxiety and self-consciousness when eating out. Parents were also advised by all clinicians to normalise tics by not drawing unnecessary attention to them. This could serve to make mealtimes less pressurised which would also decrease self-consciousness.

"I definitely direct parents to, down the line of trying to ignore the tics as much as possible which then has the knock-on effect of releasing the anxiety which then tends to lessen them. "[...] you want a half reasonable family mealtime that everybody enjoys and that is as relaxed as possible." (Andrea)

Andrea explained how creating a mealtime environment that was accommodating to tics could relieve some of the anxiety a young person may feel surrounding their tics being "*on display*." As she described the "*knock-on effect*" she was effectively detailing how the anxiety-tic feedback loop could be utilised to deescalate; reducing pressure to reduce anxiety and tics.

This superordinate theme covered two of the most common mealtime challenges brought to the attention of clinicians by YP with TS. These experiences highlighted how tics can shape their mealtime experiences by either presenting a practical obstacle that they needed to manoeuvre or effecting their ability to relax and enjoy the mealtime; leaving them feeling self-conscious and at times isolating them as they avoided eating out of home.

6.4.2 Parental Mealtime Challenges and Factors That Shape Their Mealtime Experiences

This superordinate theme discusses mealtime challenges raised by parents. While tics during mealtimes were either a temporary inconvenience for YP or a source of self-consciousness and anxiety, parents tended to raise both tic and non-tic challenges. Similar to accounts of the YP with TS, parental mealtime challenges were rarely the main presenting problem. Instead, they often arose out of discussions about tics or comorbidities such as ADHD, OCD and ASD. These mealtime challenges have been divided into three sub-themes: (1) won't eat: picky eating and feeding practices, (2) can't eat: appetite suppression and parental worry and (3) won't stop moving: tics, ADHD, and stereotypies. These challenges were also seen by clinicians as preventing parents from creating the mealtime experiences they desired. As such, clinicians tended to work more with managing parental expectations rather than focusing on what parents perceived to be the problem. Clinicians only intervened in cases where YP also felt something was a problem.

Won't Eat: Selective Eating and Parental Feeding Practices

Clinicians noted that parents of YP who experienced sensory sensitivity usually described their child as a selective eater. Although, perspectives on the prevalence of selective eating within the TS population were polarised. A couple of clinicians viewed selective eating as being "*fairly prevalent*" (Harry) with comparable prevalence as in the ASD population, whereas the majority felt it was "*rare*" (Lisa) to see in practice when working with patients with TS (unless patients had a comorbid diagnosis of ASD). Clinicians who rarely saw selective eating in clinic questioned whether this was the case because selective eating was not routinely asked about during sessions, or because YP and their parents did not feel it was an issue. Nevertheless, there was a sense that things that were truly problematic for families would always come to the surface eventually.

"[...] and it may be that, you know, I just haven't asked the right questions or it's not been around, it's been around, but it has not been, you know, the focus of attention"
(Andrea)

"Well, to be honest, usually parents are very forthcoming about sensory issues."
(Kieran)

Almost all clinicians reported only asking about sensory sensitivity when they suspected ASD. Although Theo argued that sensory sensitivity was in fact a neurodevelopmental trait, despite being regularly misconceived as an ASD trait. Therefore, in his mind and experience, sensory-based selective eating and associated problems were just as prevalent in YP with TS as YP with ASD.

"[...] you get the same difficulties as you get with Autism basically. People think that they're Autistic traits but they're not, they're Neurodevelopmental traits. So, kids with Tourette's have got equal amounts of "I [don't] like food touching", "this one's too

hot", "this one is gritty", "that one is slimy", "that one I don't like the look of", "that one I don't like the feel of". You get lots of textural sensitivity." (Theo)

Reflections from other clinicians provided support for Theo's views on fellow clinicians' misconceptions about sensory sensitivity and selective eating being 'autistic traits.' Kieran noted that he *was "not necessarily pairing the sensory sensitivity with the tics"* as he had not *"mentally made much of a connection"* so he would typically explore an ASD diagnosis. Melissa also suggested that her training and the diagnostic criteria for ASD informed her formulations. Therefore, despite seeing similar challenges in YP with TS, she would usually consider an ASD comorbidity to help contextualise their sensory and eating challenges.

"[...] I suppose because I have such a focus and training in Autism and I know that is one of the diagnostic criteria so I suppose I put that under the Autism umbrella of the sensory difficulties [...]" (Melissa)

"If you've got ASD and tics, you've got 'I can only have beige food and orange food and it mustn't touch on my plate'. [...] I kinda put that in the ASD camp rather than the tics camp." (Kieran)

Regardless of how clinicians conceptualised selective eating in their TS patients, many had experience working with YP with TS who were described by their parents as selective eaters. Additionally, some were able to tie selective eating to features associated with TS such as rigidity and particularity. In most cases these issues were rarely the main presenting challenge.

"Actually, a lot, quite a few of our children are reported to be fussy eaters or to have restrictive eating linked to things like texture of food or possibly rigidity around only wanting to eat certain things. Because I suppose in the broader context of tics there are [...] features like rigidity, so food, restricted eating or fussy eating related to sensory sensitivities and rigidity would be one thing that does crop up from time to time." (Morgan)

"[...] I haven't had anyone where that was specifically the issue. I've worked with lots of people with eating issues and food issues but no-one where that's been their exact presentation." (Melissa)

Theo and Melissa reported the most experience working with selective eating challenges. They explained that these challenges were not unique to families of YP with TS, often presenting with the same mealtime battles faced by parents of selective eaters, typically developing and ASD alike. Theo noted that the main difference was the intensity. He felt that, due to the temperament of YP with TS, the feeding dynamic intensified as YP with TS can be more defiant. In general, he described YP with TS as being *"more"* in all aspects explaining that *"they're not abnormal but the intensity is more"*.

"[...] you see the same in Autism that they'll only eat certain foods or textures of foods. There tends to be, again, the same kind of problems that everyone has, like not liking veg. But they tend to be more extreme in their emotional reaction so it's harder to get them to eat it. They fight it more. They're more upset or their more argumentative or they're more oppositional with it." (Theo)

Melissa and Theo described how selective eating can influence parental wellbeing. Noting how the pressure parents feel to feed their children can encourage them to continue to use coercive feeding practices which only served to escalate tension within

the feeding dynamic and mealtime. Melissa and Theo felt that parents were pressured by societal expectations of what their child should eat and how their family mealtimes should be. Their inability to meet these perceived expectations often left parents feeling disappointed. Theo commented that this disappointment stemmed from a wider bereavement parents of children with disabilities face, as they come to terms with the reality of their lives and how it differs from their expectations.

"[...] if you add layers of the parents' mental health on top of that, 'you've got to eat your veg because I have to be a good parent that gives you it'. 'You've got to clean your plate' [...]. There's so many opportunities for it to kind of go (explosion sound effects) [...]" (Theo)

"[...] I've talked to this mum particularly about the, the lack of ability to nourish your child. It is fundamental. Like you're not able to provide the foundations of what your child needs. You're not able to that. We're not able to nourish this little guy. Like it's kind of soul destroying for them (laughs). It's really hard and I find the dads get particularly frustrated and that makes them be more forceful" (Melissa)

Melissa and Theo would support parents in managing their expectations and response to their child's eating to create a more pleasant mealtime experience. Despite training parents to use less coercive feeding practices, Melissa explained that they would often revert to using pressure to eat; saying: *'I've done all this training, they'll still go 'eat your carrots, eat your carrots, eat your carrots''*. There was a sense of frustration in seeing them revert to counterproductive practices, although this was followed by an understanding why parents revert.

Can't Eat: Appetite Suppression and Parental Concern

TS is highly comorbid with ADHD, a notable proportion of YP with TS were reported to be on ADHD medication. It was common knowledge among most clinicians, prescribers, and non-prescribers alike, that ADHD medication was *"crap for appetite"* (Theo). Of those who did see YP who were on ADHD medication, this was often a common parental challenge and source of concern. Parents would often worry about whether their child was eating enough, with some of them resorting to using pressure to get their child to eat more. This often created the same mealtime battles as found in families with selective eaters.

"[...] often kid's parents are coming in saying 'oh, they're not eating, so what can I do? I've got to make them eat?'" (Melissa)

Melissa also shared that there were teachers who sometimes found themselves stuck in feeding battles as YP would often refuse to eat at school, which highlights how feeding battles can strain any relationship.

"What comes to mind is this teacher's experience the other day that said umm they were having troubles with the child, mine was just to talk about the behavioural issues and then they said 'you know, he's just terrible in the afternoons blah blah blah and umm... so I bring him in at morning tea and make him eat his banana first' and I'm like (laughs) 'he's not going to eat the banana first. He's had medication 15 minutes before. He's in no way going to be eating anything, let alone a banana which for him was so sensory, so it smells, so awful (laughs).' And so I think it was really impacting on her relationship. She was having/ my words to her was 'you're being set up to fail'. That's terrible (laughs) you know. So the relationship for the rest of the day was completely downhill." (Melissa)

Theo noted that medication often intensified the feeding dynamic as parents felt under *"pressure to get the calories in them"* to maintain their child's weight in fear that doctors would stop medication to prevent further weight loss. So, not only would YP be resistant to eating because they lacked an appetite, but parents would be more forceful with trying to make their children eat. Unfortunately, high parent and child control heightened the tension at mealtimes. Parental fears surrounding medication being stopped appeared to be founded as prescribing clinicians did note that they would stop medication if they felt a young person was losing too much weight, although this would be the last resort.

"Occasionally, we have to stop, stop the medication. That's always a shame, especially if you've had a great response." (Kieran)

Having to stop medication that appeared to be helping a young person because of weight-loss seemed to also be disappointing for clinicians. To avoid having to stop medication, most clinicians noted that they would give parents meal planning advice. All their advice echoed the same message:

"If they're given ADHD medication there's advice given; information around eating a full breakfast before you take the medication in the morning and then making sure you have a decent meal at the end of the day when the medication has worn off a bit." (Morgan)

Generally, clinicians found that meal planning around a young person's appetite fluctuations worked well. Although Theo noted that this was not usually the case for younger children who tended to sleep before their appetite rebounded, thus *"missing a meal a day"*. In these cases, parents were more likely to resort to using pressure to make their child eat which usually led to *"fights"* (Theo). In cases where missed meals were not

able to be replaced after the medication waned, alternative medications were considered. As a non-prescriber, Melissa refers her patients back to their prescriber to change their medications, although she usually took it upon herself to provide in-depth advice on which medications would work best to support their needs. Melissa saw herself as an *"in-between"*, able to spend more time explaining things to parents than medical professionals were typically afforded. This approach differed to other non-prescribers who tended to see such conversations as beyond the scope of their role. Theo also noted that some parents were resistant to pushing meals back so would also benefit from medication swaps.

"If you get home and you're expected to eat at half 4 and you're on Concerta and it don't wear off until 6 o'clock I'll swap you [...] parents say 'I've got 3 kids to feed and that's the time, oh you want me to feed them separately, so I've got to make 2 meals now, have I?'" (Theo)

Theo explained that while some parents were resistant to delaying meals as they preferred to maintain synchronicity among the family, others were resistant due to their own rigidity.

Interestingly, Melissa noted that swapping longer acting medications for shorter ones sometimes had the added benefit of improving selective eating as children's hunger would make them *"more open to food"*.

"[...] I find the actual short dose actually helps their eating because they're forced not to just graze and graze and snack all the time. They're forced to actually get hungry and when that medication wears off they're starving and they will eat." (Melissa)

Melissa expressed caution, stating that this was just an observation based on her experience and that she was not aware of any evidence to support this claim. Kieran shared an additional strategy to mitigate weight loss; he would advise parents to use medication intermittently, allowing for appetite and weight regulation.

"I say 'take it every day until we work out the right dose and whether it's working for you. But then let's say it is working and we go, listen, holidays. You don't need to take it necessarily... at weekends, you don't necessarily need to take it depends on your homework and that kind of thing'. So, we'll have you know, you can have a proportion of the time when they're not on the medication with something like methylphenidate. and then appetite comes back." (Kieran)

It appeared that most of the challenges families faced when prescribed appetite suppressing medications could be managed with careful meal planning and taking mealtimes into account when deciding which medication to prescribe younger children. Notably, being aware of the possible effect long-acting medications could have on a young person's ability to consume enough calories. Additionally, forcing YP to eat during times of appetite suppression only seemed to lead to mealtime battles so parents and teachers were advised against this as, in the words of Melissa, they would be *"set up to fail"* if they tried to enter a feeding battle with a young person without an appetite.

Won't Stop Moving: Tics, ADHD, and Stereotypies

An expected mealtime challenge for this population was an inability to stay seated or still during a meal. By virtue of having a movement disorder, sitting still was a challenge. Although, in addition to tics and the general restlessness of having a movement disorder, clinicians also noted two other factors that made it hard for YP to stay seated and still;

ADHD and stereotypies (repetitive movements or sounds). This theme touches on how all three of these sources of movement were described to be disruptive to mealtimes and a source of parental stress. Additionally, highlighting how parental expectation of relative stillness and their responses to movement were usually viewed by clinicians as the 'problem' that required addressing as opposed to the movement itself. Theo and Andrea explained that there were a variety of ways that parents would respond to tic-based mealtime movement.

"[...] parents take that to a number of places, they either take it to a 'let's ignore it and they can do the best they can' kind of place or they end up being more emotional, more snappy, 'just sit still' because that's the only way you know how to try and help it. [...] Some parents get frustrated, some parents get angry, some parents go 'you hold it in all day at school, why can't you hold it in for the meal I just spent three hours cooking?', you get all manner of comments." (Theo)

"[...] you kind of [get] the full range of responses from being quiet punitive quiet "try to stop ticking", "stop ticking", "come on, we're having a meal", you know, "just for 10 minutes, calm/" you know, quiet directive. Through to other parents who umm kind of are able to have a meal and not acknowledge it at all. I definitely direct parents to, down the line of trying to ignore the tics as much as possible which then has the knock-on effect of releasing the anxiety which then tends to lessen them [...]" (Andrea)

Expectations of stillness made mealtimes a pressurised environment for YP with tics, which, only served to make their tics worse and mealtimes more stressful for all. To resolve these clinicians focused on managing parental expectations. Theo often told parents that their children were *"going to over-move, that's non-negotiable"*. He felt the issue was not the child's inability to sit still but a parents' unrealistic expectation. If parents could accept that their children would move then they would rid themselves

from the stress caused by trying to make their child sit still while also alleviating stress for their child.

"[...] you're not wanting to kind of say 'he's not normal, so why have you got normal expectations of him?' but you end up doing that in a way and saying 'your expectations are based on a child without Tourette's, they have got Tourette's so why are you expecting them to sit for an hour on Sunday while Grandma talks about being in the war for an hour' (laughs) [...]" (Theo)

Besides tics, YP with an ADHD comorbidity also struggled to stay seated during meals. Similarly, this was something that parents needed to accept, working with movement rather than against it. Melissa highlighted the double-edge sword of ADHD medication as it usually helped YP stay focused, and seated, during the meal while also bringing its own complication of appetite suppression. She noted that in cases like this where movement during meals was a challenge, medications such as Guanfacine could help as it reduced hyperactivity without suppressing appetite. Melissa explained that Guanfacine *“operates in the background which means at breakfast time they can sit, they can stop, they can focus. At dinnertime they can stop and actually eat.”*

Theo and Kieran explained that in most cases ADHD would be more challenging during mealtimes than the tics themselves. Kieran described the nature of mealtimes for YP with ADHD as chaotic, drawing upon a humorous animalistic comparison to jest about the lack of civility to the occasion.

"They're up and down, they're interrupting, sometimes there's conflict. [...] You call them for tea, they're distracted. Umm it's very, variable. Sometimes they just wolf their food, get up and leave. Yeah, I think ADHD mealtimes are kind of pretty rushed, chaotic, noisy, distracted 'chimps tea party' type of fare, you know?" (Kieran)

The perpetual motion of a young person with ADHD seemed to heavily shape their mealtime experiences and was often noted as a common challenge for parents. Another challenge that was raised by Morgan was stereotypies, which she described as *"rhythmic repetitive movement"*. Stereotypic movements can vary from simple body-rocking and finger-tapping to more complex movements such as hand-flapping and pacing. While not unique to TS, stereotypies were said to be more common in YP with tics than for YP without tics. Morgan explained that parents of YP with stereotypies usually complained about their children being distracted during meals. This was particularly challenging for a small population of YP who had *"intensive imagery movements"* (Morgan). In these cases, a young person's conscious engagement with their imagination was simultaneously accompanied by stereotypic movements that they usually had limited awareness and control of. Such YP could become engrossed in these movements and their imagination which further distracted them from their meal. Morgan described YP as imagining *"really lovely vivid things"* and gaining pleasure from these experiences. A young person's enjoyment was noted to make it harder for parents to get their child to disengage. This served to prolong mealtime experiences and often left parents feeling frustrated. While intensive imagery movements were not very prevalent, when they were present mealtimes were almost always affected.

"[...] tics can be annoying. Whereas we see stereotypies interfering a lot more with mealtimes than tics because the children are doing their stereotypies and enjoying them and they're distracting them from their dinner (laughs). So they're spending a long time doing their movements and not eating when they should be [...]" (Morgan)

Morgan commented that it was common for mealtimes to span over an hour which was not an issue but because of the repetition of prolonged mealtimes, could become a

source of stress and conflict. Parents could experience similar mealtime battles as those with children who refuse to eat either due to selective eating or appetite suppression. Morgan also noted how long mealtimes could also increase a young person's desire to escape the mealtime by engaging in their stereotypies.

"[...] it becomes, can become a bit of a battle. Not only is it taking longer but it's frustrating for parents and frustrating for the child as well [...] so, it just becomes a bit of a sort of negative experience but it's difficult because it's something that has to happen at least once a day[...] and then if it's hot food then it's cold and then it's even less appealing and they get into a vicious cycle." (Morgan)

Morgan explained that YP may engage in stereotypies during mealtimes because they *"can be quite boring for children"*, so they would use their stereotypies to create entertainment for themselves. Morgan's team would provide mealtime support when working with families to manage stereotypies so they do not impair daily life and functioning. Recommendations would usually include setting time limits to mealtimes and encouraging gentle redirections when YP become engrossed in their stereotypies. This superordinate theme detailed three of the main challenges' parents raised with clinicians in relation to mealtime challenges. Each of these challenges were rooted in YP not behaving in accordance with parental desire, be it not eating what or when parents wanted or not sitting still and remaining focused for the entirety of the meal.

6.5 Discussion

This chapter captured the experiences and understanding of a group of clinical professionals working with YP with TS and their families, focusing specifically on eating and mealtime challenges encountered in practice. IPA of accounts from different clinical perspectives illuminated a range of mealtime challenges linked to distinct

behavioural traits or characteristics associated with TS and common comorbidities; an area and perspective that has yet to be qualitatively explored. The eating and mealtime challenges presented were functional challenges that arose as a result of disruptive tics; anxiety and self-consciousness due to increased tic visibility at mealtimes; and mealtime ‘battles’ as parents tried to make their selective eater or child on stimulant medication eat and stay seated, despite having a movement disorder and ADHD. This study draws attention to these distinct barriers to mealtimes that families of YP with TS may have to contend with, and how these challenges add a layer of complexity to their mealtime experiences.

It is believed that this is the first study to document how tics can present as a challenge during mealtimes from the perspective of clinical professionals. Similar to anecdotal evidence that has been reported on online forums, clinicians noted a multitude of tics that have the potential to disrupt a meal, acting as a barrier to eating, drinking, staying seated or disrupting the mealtime experience as a whole. Clinicians noted that YP tended to come to them primarily to work with their tics, therefore the focus of assessment and treatment was primarily on the tics themselves. This was particularly pertinent for those who worked in private practice as clinicians were usually hired by parents to work with YP to specifically address their tics. Despite a focus on tics, clinicians did note that they had limited experience working directly with mealtime tic hassles; although on a theoretical level they were fully aware of the numerous challenges tics could pose. They accounted for the discrepancy between how common these challenges could be and how unlikely they were to be raised in practice by noting the transitory nature of such challenges.

Clinicians explained that as tics waned, so too did these challenges. As such, they felt that these types of tic hassles often fell towards the bottom of patients 'list' of things to address in sessions. Additionally, parents were reported to find practical solutions to alleviate the distress caused by some tics, for example using cups with lids to prevent drink spillage which could lead to embarrassment and self-damning thoughts, thus not warranting clinical intervention. Clinicians noted that tics that were problematic for YP during mealtimes would be managed in the same way as other tic hassles, by using behavioural interventions (Verdellen et al., 2011). Unfortunately, many YP with TS struggle to access tic interventions (~ less than 20% have access) due to lack of availability and/or financial constraints despite behavioural interventions being recommended as first-line interventions for YP due to comparable efficacy to pharmacological treatments and less associated adverse effects (Cuenca et al., 2015; Whittington et al., 2016). It is widely acknowledged that more access is needed to behavioural tic therapies, such therapies would help to minimise tic-related impairments in all domains of life, mealtimes included.

Another challenge clinicians noted was meal avoidance, a form of social withdrawal, employed by YP prone to self-consciousness at mealtimes. Several clinicians believed that misconceptions about TS and lack of awareness by the public added to dining out at restaurants being anxiety-provoking for YP with tics. Those who were severely self-conscious about their tics were said to avoid eating out. While this might shield them from feeling judged by strangers it also prevents them from important socialising which could have a diminishing effect on their social life and relationships. For example, research on adults with TS has noted loneliness to be a common experience, as adults avoided social situations to evade social judgement and rejection (Malli et al., 2019). A

reasonable approach to tackle this issue could be to help people with TS normalise their mealtime experiences, especially outside of the home, thus allowing them an opportunity to benefit from the socialisation and strengthening of interpersonal relationships that can occur during mealtimes (Neely et al., 2014). However, it is likely that work would also need to be done with the public and dining establishments to make them more accommodating of differences, as public perception plays a vital role in how people with TS feel in social settings (Cox et al., 2019; Davis et al., 2004).

Clinicians mentioned two mealtime behaviours that parents reported to be challenging: their child's refusal to eat, be it due to selective eating or appetite suppression as a result of medication, and a young person's inability to remain seated during mealtimes due to TS, ADHD, or stereotypies. In most of these cases, clinicians worked with parents to manage their expectations and find productive ways of working with their child's behaviour as opposed to working against it. Supporting parents to manage their expectations has been noted to be a useful intervention to create more positive mealtime interactions and experiences. For example, a recent study by Curtiss and Ebata (2021) found that parents of selective eaters with ASD who struggled to align their expectations with their child's needs struggled to provide the right type of support for their children and had mealtime interactions that were conflictual. The strained interactions affected the conviviality of the mealtime, therefore parents could benefit from learning to balance their expectations with their child's needs so they can create warm and supportive mealtime environments and interactions.

A novel finding among clinicians was how they conceptualised sensory sensitivity and selective eating. While a majority viewed these characteristics as being related to ASD,

recent research supports Theo's assertion that sensory processing is a neurodevelopmental trait (Galiana-Simal et al., 2020) as is selective eating (Smith et al., 2020). The fact that several clinicians still formulated sensory sensitivity and selective eating as ASD-related suggest that work needs to be done to increase awareness among clinicians of neurodevelopmental traits. Notably, the importance of asking about sensory sensitivity and selective eating when assessing neurodiverse patients, as opposed to only assessing those presenting with, or suspected of, ASD.

Alongside sensory sensitivity, clinicians also noted a relationship between selective eating and rigidity which was harmonious with recent findings from Zickgraf et al. (2020) who found that selective eating was maintained and characterised by rigidity. Clinicians described families of YP with TS as having similar mealtime challenges to other families with selective eaters (i.e., mealtime battles, parental stress, and additional parental labour). However, the intensity of these challenges was heightened by rigidity and oppositional dispositions. In essence, selective eating was entrenched; thus, YP were less receptive to parental efforts to change their behaviour which usually resulted in a strained and conflictual feeding dynamic. This was noted as a source of stress and dissatisfaction for parents in the same way as documented in the ASD (Ausderau & Juarez, 2013; Suarez et al., 2014) and typically developing literature (Middleton et al., 2020; Thompson et al., 2021). Such experiences have the potential to diminish family quality of life, cohesion, wellbeing, and functioning. Therefore, families with these challenges would benefit from tailored mealtime support. While it is important that clinicians work with parents to manage their expectations and teach them helpful feeding practices, clinicians may also need to work with YP to address selective eating. Zickgraf et al. (2020) recommends that interventions take a two-pronged approach, with

professionals addressing both rigidity and sensory sensitivity as they both play a role in maintaining selective eating.

The mealtime experiences of families with a young person on stimulant medication were described to be similar to that of families with a selective eater. It appears most research on ADHD medication and appetite suppression focuses on weight and growth complication as opposed to noting the impact to the family mealtime and feeding dynamic (Ahmed et al., 2017; Ptacek et al., 2014; Wigal et al., 2006). Based on the findings from this study, the mealtimes of families with a young person on stimulant medication would be a useful avenue for future research. Clinicians working with YP on stimulant medications should be aware of the effect that appetite suppression could have on mealtimes and the family unit. Prescribers within this study (and Melissa, a non-prescriber) appeared to be aware of best practice guidance for managing appetite suppression side effects for YP with ADHD (Cortese et al., 2013; Graham et al., 2011). Alongside considerations on the effect stimulants could have on a child's weight, prescribers should also consider the effect that it can have on their family mealtime experiences. Non-prescribers would also benefit from screening for mealtime challenges that result from stimulant medications as they may be able to provide general guidance to help parents work with their child's appetite in a way that is more conducive to positive mealtime experiences. They would also be able to redirect families back to prescribers to discuss alternative medications that could be less impactful on the family meal.

Clinicians described parents reported their child struggled to sit still during mealtimes was both an expected and unexpected finding from this study. As TS is a movement disorder, it was conceivable that remaining seated and relatively still through a meal

would be a challenge. What was unexpected was the role that stereotypies played in making mealtimes challenging. Interestingly, the mealtime experiences of families with a young person distracted by their stereotypies were described by clinicians as being similar to those of families with a selective eater. Mealtimes were prolonged and mealtime communication was dominated by parents redirecting their child to eat. Research on stereotypies note that the compulsive nature of these movements can interfere with daily functioning (Martino & Hedderly, 2019). However, no detail is given to explain which daily activities are particularly affected and how they are affected. Based on the experience of Morgan and her accounts of her team's experience, mealtimes were common daily activities affected by stereotypies. Future research should qualitatively explore how stereotypies affect mealtimes and the prevalence of these challenges. Such research would also benefit from exploring the effect of stereotypies on the parent-child feeding dynamic. Clinicians may be able to support parents to manage their expectations, as movement is inherent in their children.

6.6 Chapter Summary

This study was the first to begin exploring the nature of mealtime challenges within this population, providing clinicians' accounts of the reality of their patients' lived experiences and factors that made mealtimes challenging for YP and their parents. Clinicians reported several ways that the mealtimes of YP with TS and their families were adversely affected by TS or comorbid behaviours/disorders. Clinicians described YP as being affected by their tics and resulting self-consciousness, and parents as being affected by their child's eating behaviours (selective eating and appetite suppression), and inability to stay seated. Clinicians appeared to work more with parents on managing their expectations of their children than needing to work with YP to change their

behaviours. The next chapter draws this doctoral study to a close by discussing key findings from all empirical chapters, highlighting the significant contribution to knowledge this dissertation provides.

Chapter Seven: General Discussion

The primary aim of this doctoral study was to explore the eating behaviours and mealtime experiences of YP with TS and their families. This was achieved by using mixed-methods and drawing upon multiple perspectives of those involved. This chapter brings together the empirical findings and provides an analytical discussion in the context of previous research and the theoretical framework. As described in chapter two, the theoretical framework for this dissertation combines Ecological Systems Theory (Bronfenbrenner, 1979, 2001) and the Dialectical Model of Feeding Interactions (Satter, 1995, 2007, 2012) to understand mealtime experiences and interactions. Where appropriate, findings are discussed in relation to the theoretical framework.

In this chapter, there is an emphasis on the family food environment and mealtime experiences, as this emerged as the foodscape with the richest data from all participant groups. However, other foodscapes will also be addressed. The contextual nature of mealtime challenges is vital as this allows challenges to be situated within particular food contexts, spaces, relations and practices. This appreciation for the social complexities surrounding food and varying social dynamics supports pragmatic recommendations for research and practice. The conclusions have relevance for YP with TS, their families, clinicians and researchers alike, particularly emphasising the social importance of mealtime experiences. To aid narrative flow, subheadings are used throughout the discussion.

7.1 Measuring the Family Meal

Prior research on family mealtimes has predominantly used meal frequency as a proxy for the processes that unfold during family meals and has been associated with an array of positive outcomes in typically developing families (for reviews, see Dallacker et al., 2019; Middleton et al., 2020; Robson et al., 2020). The quantitative studies in this dissertation found no significant differences in family meal frequency; families with and without TS reported an average of four or more family meals a week. Although this dissertation was the first to explore family meal frequency in families with YP with TS, Lee et al. (2008) also found no significant difference in family meal frequency for YP (aged 3 to 17 years) with ASD, ADHD, and typically developing controls. Participants in Lee and colleagues' study also reported an average of four or more family meals a week. Nevertheless, despite comparable family meal frequency, little is known about the outcomes associated with frequent family meals for neurodiverse YP and their families (Curtiss & Ebata, 2021).

Further assessment is needed to establish whether there are measurable differences in the processes that unfolded during family meals (e.g., mealtime interactions, communication and enjoyment) as research suggests that what occurs during the meal is crucial to the outcomes that families accrue, not merely frequency (Dallacker et al., 2019; Skeer et al., 2017). The Family Dinner Index (Skeer et al., 2017) assessed positive mealtime attributes, which may facilitate positive outcomes. While no significant differences were found between the TS groups and typically developing controls, there was one notable difference in the relationship between the use of technology during mealtimes (digital distractions) and the other positive mealtime attributes. As discussed in chapter four, this finding suggests that being allowed to use technology during mealtimes may improve the mealtime experience of YP with TS. Despite a lack of mean

difference between groups, the relationship between ‘positive’ mealtime attributes differed, suggesting that the mechanisms of health-promoting mealtimes may also differ.

The qualitative studies suggest that TS and comorbid behaviours indeed characterise the mealtime experiences of YP with TS and their families. Thus, reaffirming the benefit of mixed-methods research and data triangulation. The quantitative findings provided novel general insights into the mealtime experiences of families of YP with TS and how they may differ from those of typically developing families. In addition, the IPA studies presented elaborated on the finer aspects of participants’ mealtime experience, exploring beyond what could be quantitatively measured to capture participants' lived experiences and how meaningful their experiences were within the context of their lives (Willig & Rogers, 2017).

Based on these findings, researchers should continue developing and refining measures that assess the quality of family mealtimes instead of relying solely on frequency. It is crucial that this research includes neurodiverse families as what may be a ‘positive’ mealtime attribute for typically developing families may not be for neurodiverse families. Researchers should also explore what outcomes are associated with frequent family meals in neurodiverse families. For example, frequent negative mealtime interactions and experiences (e.g., stressful, challenging, and conflictual) may be barriers to positive outcomes. In addition, they may facilitate adverse family outcomes such as reduced co-parenting quality (Thullen & Bonsall, 2017).

7.2 Transdiagnostic Mechanisms for Selective Eating

Contrary to the findings of Smith et al. (2019), no significant mean differences were found in selective eating rates for YP aged 11-16 years with and without TS. However,

further inspection of the data revealed that proportionally more YP with TS were classified as selective eaters, suggesting that they may be more likely to experience persistent selective eating than their typically developing peers. There are a few likely reasons for these contradictory findings: (1) data were not normally distributed (non-parametric tests were used to account for this), (2) mean distributions were not similar, and (3) the sample sizes were small. Nevertheless, the fact that proportionally more YP with TS classified as selective eaters is of clinical significance, even if the mean difference lacked statistical significance. Namely, because research has found a relationship between selective eating and poor psychosocial outcomes (Ellis et al., 2018; Zucker et al., 2015); adverse effects on general health and wellbeing (Jacobi et al., 2008); risk of being overweight or underweight (Callie L. Brown et al., 2016); and nutritional deficiencies (Taylor et al., 2015).

In the quantitative studies, selective eating was not associated with sensory sensitivity but was associated with a single-food focus; this can be a proxy for rigid eating behaviours (a proclivity towards a repetitive diet, inflexible food rules, and binary food expectations). These findings support the notion that sensory sensitivity and rigidity may be transdiagnostic risk/maintaining factors for selective eating. Furthermore, rigidity may maintain selective eating even after sensory sensitivity diminishes over time (Dovey et al., 2019; Zickgraf et al., 2020). This could explain the higher prevalence of selective eating beyond the normative developmental period in neurodiverse populations who share these neurobiological mechanisms (Galiana-Simal et al., 2017; Isaacs & Riordan, 2020; Whitehouse & Lewis, 2015).

Moreover, the qualitative results further support the connection between sensory sensitivity, rigidity and selective eating in YP with TS. Although notably, clinicians conceptualised sensory sensitivity, rigidity, and selective eating as ‘autistic traits’ rather than neurodevelopmental. This was not surprising as sensory sensitivity research has been predominantly focused on ASD populations (Dunn et al., 2016), and atypical sensory processing and eating behaviours form part of the DMS-5 criteria for ASD (American Psychiatric Association, 2013). Nonetheless, this misconception has clinical implications as clinicians were unlikely to screen for sensory challenges, selective eating and mealtime rigidity if they did not suspect an ASD comorbidity. Thus, these challenges within other neurodiverse populations, like TS, may inadvertently be clinically undetected and neglected. This highlights the broader systemic influences (e.g., Exosystem⁷ and Macrosystem⁸) on the Microsystem⁹ (interactions between clinicians and YP with TS) and Mesosystem¹⁰ (interactions between clinicians and parents of YP with TS). These systemic factors guide the meaning clinicians attribute to YP’s presentations and their access to services/support.

These findings suggest that work needs to be done to increase awareness among clinicians of neurodevelopmental traits. Taking a transdiagnostic approach to eating disorders has helped highlight vulnerability characteristics that underlie and maintain eating disorders that interventions can address (Vervaeke et al., 2021). Broadening the scope of interventions beyond the diagnosis allows those with a variety of diagnostic presentations to be treated. It also appreciates the reality of clinical practice (i.e., atypical

⁷ The Exosystem consists of indirect environments that affect YP

⁸ The Macrosystem consists of widely shared cultural values, beliefs, customs and laws

⁹ The Microsystem consists of direct interactions between YP and others (e.g., parents, friends, teachers, professionals)

¹⁰ The Mesosystem consists of interactions between two microsystems (e.g., mother and father, parent and teacher)

presentations, clinical complexity and frequent comorbidity) (e.g., see Harvey et al., 2004).

Decentring the disorder can be pragmatic as ADHD, ASD, and TS are highly heterogenous and overlap due to shared neuropathology, symptoms, and genetics (Thapar et al., 2017). Some researchers and clinical professionals contend that neurodevelopmental disorders exist on a spectrum instead of being distinct disorders (Gillberg, 2010; Kern et al., 2015). Therefore, clinicians should screen all neurodiverse patients for sensory sensitivity, selective eating and mealtime rigidity instead of only assessing those presenting with, or suspected of, ASD. By focusing on transdiagnostic mechanisms, clinical utility is amplified (Thapar et al., 2017).

Additionally, more research is needed to explore whether YP classified as persistent selective eaters demonstrate greater levels of rigidity and how the relationship between single-food focus, selective eating and sensory sensitivity evolves. As these are transdiagnostic mechanisms, researchers would benefit from including diverse populations who possess these traits. Researchers should also explore the efficacy of interventions which address selective eating and mealtime rigidity in ASD populations with other neurodiverse populations who may also benefit from these interventions.

7.3 Balancing Food Autonomy and Maternal Responsibility

In the qualitative studies, all participant groups described YP with TS having sensory food preferences and aversions. Mealtime rigidity also manifested itself as a lack of flexibility in food choices (e.g., brand loyalty and food jags), food preparation and presentation preferences (e.g., food not touching on the plate or preferences for specific tableware). This expression of mealtime rigidity and selective eating mirrors those reported in the ASD literature (e.g., Adams et al., 2020; Ausderau & Juarez, 2013; Lazaro & Ponde, 2017). While YP were autonomous over their food choices, the responsibility of meeting their preferences appeared to lie with mothers. Mothers undertook additional foodwork to cater to their child's preferences, making YP's eating behaviours and rigidity a source of stress for mothers, not YP.

YP appeared to perceive their eating and mealtime behaviours as reflections of their likes and dislikes, not necessarily a 'problem'. As such, they wished to enact autonomy over their food choices and were reluctant to change their eating behaviours. Power struggles arose when YPs right to independent food choices was discordant with maternal responsibility for their child's dietary needs and requirements (Curtiss & Ebata, 2021). Mothers reported feeling responsible for providing their children with nutritious meals while also being responsible for catering to their child's preferences. These conflicting responsibilities created some dissonance in mothers as they were often incongruent. Mothers felt that they had two choices: (1) adopt controlling feeding practices, which resulted in conflict, or (2) honour their child's food choices which avoided mealtime conflicts but left mothers feeling dissatisfied and unable to fulfil their role as 'good mothers'. Seemingly, mothers had to choose between mealtime battles with their child or within themselves and the chasm between ideal and reality. This

meant that despite increased food autonomy during adolescence, mealtimes were still stressful for mothers, even if no longer characterised by conflicts and ‘meltdowns’. Themes of dissatisfaction, helplessness and an inability to recreate desired mealtime experiences have also been documented in mothers of typically developing YP and YP with ASD (Lazaro & Ponde, 2017; Thompson et al., 2021). This highlights the broader systemic influences on the Microsystem and the meaning mothers attribute to their family mealtime experiences and children’s eating behaviours.

The Dialectical Model states that the parent-child feeding dynamic is bidirectional, with constant food (re)negotiations. As parent and young person influence one another, the dynamic evolves (Ventura & Birch, 2008; Walton et al., 2017; Wolstenholme et al., 2020). Mothers described the dynamic as initially being characterised by strong levels of parent and child control which led to conflictual mealtimes. Over time, mothers relinquished control to keep the peace and learned that controlling feeding practices were counterproductive. The Chronosystem influence on the dynamic also includes developmental changes as YP reach adolescence and acquire greater food autonomy (McCullough et al., 2016; Warren et al., 2008). Interestingly, increased autonomy for YP in this study surpassed what Satter (1995, 2007, 2012) would argue is within the bounds of their responsibility.

Contrary to Satter’s Division of Responsibility in Feeding Model (1995, 2007, 2012), conflict was not necessarily avoided by both parties remaining within the bounds of their responsibilities but by mothers conforming to their child’s will. The autonomy of YP with TS appeared to apply to all aspects of their eating behaviours and also shaped how mothers conducted foodwork; an area that Satter suggested falls within the realm of

parental responsibility and control. As previously noted, mothers described catering to their child's preferences as a source of stress, albeit less stressful than mealtime battles. While other research suggests that additional foodwork undertaken to accommodate selective eaters can be stressful for mothers of typically developing YP (Trofholz et al., 2017), research also suggests that this is intensified for mothers of YP with ASD due to the specificity and sometimes unpredictability of their demands (Lazaro & Ponde, 2017; Rogers et al., 2012). Several mothers of YP with TS also noted precise food preparation and presentation requirements that they needed to accommodate, which placed them under pressure to undertake additional foodwork and 'get it right'. This suggests that some YP with TS exercised high levels of control over their food choices and exerted control over their mothers foodwork. This appeared to be more challenging in cases where mothers feared 'getting it wrong' instead of cases where there was some flexibility (e.g., Naomi and Rita, see p.207-208).

Clinicians' accounts paralleled maternal accounts on the challenges parents faced managing their child's selective eating and the mealtime battles that often arose. Clinicians appeared to view YP's eating behaviours as problematic for parents, not YP, as parents were the ones who discussed these challenges in practice. Although clinicians did note that these challenges were rarely the primary issues families brought to clinic; instead, they often surfaced during conversations about day-to-day life. Interestingly, the two clinicians who worked with selective eating challenges most often (in all patients, not just those with TS) discussed the role that parental expectations had on mealtime interactions. They noted that parents felt under pressure to feed their children in a particular way; this led them to use controlling feeding practices during mealtimes, making mealtimes a pressurised environment for all. These clinicians noted working

with parents to relieve this pressure and teach them about helpful and unhelpful feeding practices.

A qualitative study by Thompson et al. (2021) found that many parents had unrealistic expectations for their typically developing preschool children's mealtime behaviour. The authors suggested that parents would benefit from 'age-appropriate' mealtime expectations. Findings by Mosli et al. (2021) suggest that reducing maternal mealtime stress may be an avenue to improve parental feeding practices (maternal mealtime stress was associated with the use of controlling feeding practices) and support a more favourable mealtime environment. Although, it is important to note that their research was based on typically developing populations and preschool children. Nevertheless, clinicians may be able to support parents of neurodiverse YP to manage their expectations, so they are 'disorder'-appropriate (i.e., realistic expectations that consider a young person's characteristics, symptomology, and disposition).

Managing parental expectations and stress is particularly important for selective eating, as parents can be supported to refrain from using counterproductive practices that may further engrain selective eating (Gonzalez & Ventura, 2021; Mosli et al., 2021; Ruzicka et al., 2021). Although, clinicians should also be mindful that some maternal concern may be founded as selective eating has been linked to adverse health outcomes (for review, see Taylor & Emmett, 2019). In cases where selective eating is extreme and/or YP want support increasing their dietary range, clinicians would benefit from utilising interventions that address both sensory sensitivity and rigidity (Zickgraf et al., 2020). Some families may benefit from a two-pronged approach, one addressing selective eating in YP and the other reducing maternal mealtime stress and encouraging helpful

feeding practices. Clinicians would also benefit from being aware of the intersection between gender and feeding practices (e.g., Harris et al., 2020; Vollmer, 2021). Family interventions should account for these and different systemic factors (e.g., Macrosystem, Exosystem and Mesosystem¹¹) that may influence how mothers and fathers respond to their child's eating and mealtime behaviours.

The emphasis of eating behaviour and mealtime research is primarily on mothers; future research would benefit from capturing paternal perspectives and exploring what informs their feeding practices and how they experience their child's selective eating and mealtime rigidity. Notions of 'good mothering' are intrinsically tied to feeding their children (Elliott & Bowen, 2018) and were reflected in mothers and clinicians' accounts. Nothing was mentioned on how notions of 'good fathering' may influence the father-child mealtime dynamic, if at all. Mothers did report that they and their partners often had different mealtime expectations of their children, which sometimes resulted in co-parenting conflict. While mothers often cited parenting style and intergenerational practices as sources for conflicting views, researchers may also benefit from assessing the influence of gender roles on how fathers of neurodiverse YP respond to selective eating and mealtime rigidity.

¹¹ Harris et al. (2020) found that fathers often described their feeding practices in relation to their partners practices, which suggests that maternal practices may be focal to the family mealtime dynamic; situating mothers as ultimate decision-makers. This highlights the influence of the Mesosystem on Microsystem interactions.

7.4 Disruptive Behaviours and Directive Mealtime Communication

Similarly to selective eating and mealtime rigidity, YP did not generally describe their mealtime behaviours as disruptive, with tics being the main exception (tics are discussed in section 7.5). Disruptive mealtime behaviours reported by mothers were an inability to stay seated, interrupting the mealtime conversation, and tics that affected others (e.g., hitting or throwing tics). Clinicians' accounts also included these behaviours, noting that parents felt they disrupted mealtimes. Sources for these behaviours varied from tics, ADHD, stereotypies, dysgraphia, and ASD highlighting how comorbidities give rise to different presentations of TS in YP. Food refusal and mealtime 'meltdowns' (reportedly more common in younger children) were also noted as disruptive behaviours related to selective eating.

Mothers and clinicians alike sometimes struggled to disentangle YP's presentation to understand which of their diagnoses accounted for their behaviours. However, clinicians did not appear to be as invested in assigning certain behaviours to a young person's diagnostic labels as mothers. In addition, some clinicians appeared to view parental desire to differentiate between disorders as futile due to the considerable overlap between presentations. For example, interrupting conversations could be an expression of ASD, ADHD or TS. Nevertheless, based on maternal accounts and clinician's reports of parental queries, it became apparent that for some parents, there was a need to understand why their child behaved the way they did for them to be able to accept their child's behaviour.

Additionally, there was seemingly a duality between 'bad behaviours' and 'symptoms', which parents drew upon when deciding how, or if, to respond. Himle et al. (2018) also

noted this in their clinicians' guide, although the emphasis was more on differentiating purposeful behaviours from complex tics. While there may be some downsides to parents adopting a dualistic approach to their child's behaviour (e.g., mis-categorisation could support the frequent use of authoritarian or permissive parenting practices (e.g., Himle et al., 2018; Hutchison et al., 2016)), there did appear to be some benefits. Several mothers mentioned that understanding their child's needs allowed them to work with their child's needs rather than against them. Empathy through understanding may be one way mothers can increase their tolerance for their child's behaviour (Himle et al., 2018). Nevertheless, the cumulative effect of these behaviours impacted mothers and their ability to enjoy family mealtimes. Mothers also noted that other family members (e.g., fathers and siblings) were also affected by disruptive behaviours.

Mealtime interactions between YP and other family members also shaped the mealtime experience. For example, mothers described fathers and grandparents as more directive in their communication with YP. Mothers and clinicians described directive mealtime communication as stressful for all, often interfering with the conviviality of mealtimes. Nonetheless, it was difficult for some family members to avoid commenting on YP's behaviours, as they viewed YP's behaviours as being within their realm of control. Therefore, a directive communication style was adopted to encourage YP to modify their behaviour accordingly.

Mealtimes are steeped in behavioural norms and expectations, such as table etiquette (Packer, 2014). As such, some parents and grandparents might feel that it is their duty to correctly socialise YP to act in accordance with these norms (Grieshaber, 1997). For example, the few mothers who noted that their children did not use cutlery in an age-

appropriate way suggested that this made some family members uncomfortable. While only one mother (Ciara, see p.202) explicitly cited middle-class sensibilities making it difficult for her husband and his parents to accept her 11-year old son eating with his hands, the other mothers spoke in a way that inferred the same was true for their relatives. Research corroborates the link between directive communication and class, finding that families with a higher socioeconomic status make more frequent attempts to socialise their children to comply with mealtime etiquette than families with a lower socioeconomic status (Orrell-Valente et al., 2007). This highlights the influence broader systems (e.g., Exosystem and Macrosystem) have on family mealtime interactions and conviviality.

Directive communication is also suggested to be more common in families of YP with disabilities. Harding et al. (2013) found that mealtime communication in families with a young person with a developmental disability tends to be more directive than narrative focused. Essentially, communication was centred around a young person's eating and mealtime behaviours. This can be problematic as there is less opportunity for YP to develop and practice social skills (Harding et al., 2013). Considering that YP with TS have been found to experience a deficit in social skills (Hanks et al., 2015), directive communication during mealtimes may also prevent them from benefiting from the social skills that are typically practised during mealtimes. For example, Lora et al. (2014) found that frequent family meals were associated with healthy social behaviour in typically developing YP (aged 6 to 11 years), increased odds of positive social skills, and decreased the odds of problematic social behaviours.

It is possible that frequent family meals in populations where communication is primarily directive may be associated with adverse outcomes. Therefore, more research is needed to explore the impact mealtime communication patterns may have on the social development of YP and family functioning. In addition, research may benefit from including a diverse socioeconomic sample to account for class differences. Finally, clinicians may benefit from being aware of the directive nature of mealtime communication and could offer parental advice to support a mealtime communication pattern which aids social development. This is particularly important for YP who have an oppositional disposition (e.g., oppositional defiant disorder) as directive communication may create conflictual mealtimes and threaten family cohesion.

7.5 Disruptive Tics: Functional Challenges and Self-Consciousness

In the quantitative studies presented, overall tic severity was not related to positive mealtime attributes. However, the qualitative studies highlighted that the nature of the tics did affect the conviviality of mealtimes for both YP and their families. All participant groups described tics as having a direct impact on YP's mealtimes, sometimes creating a functional challenge that impacted their ability to eat, drink or be seated. Functional challenges associated with tics were typically managed in the following ways: (1) YP suppressing tics (where possible), (2) mothers delaying mealtimes (where practical), and (3) mothers and YP finding practical workarounds or adaptations to minimise the impact of tics (where possible). However, even with these measures in place, tics added a layer of complication to the mealtime experiences of YP with TS and their families.

The qualitative studies demonstrated that tics did challenge the conviviality of mealtimes. As previously noted, tics were sometimes disruptive and a source of frustration for YP. YP and mothers also described tics as impacting other family

members' mealtime enjoyment. Tics which were challenging for others included spitting and throwing. In a few families, tics were so impactful on other family members' ability to enjoy the mealtime that mealtimes were fragmented, with the family unit divided to accommodate separate mealtimes. As addressed in chapter five, fragmented mealtimes may affect family cohesion and sense of belonging. However, it is plausible that this may only be the case for families where a young person is excluded from the family meal instead of opting to eat alone or being indifferent to whether they eat alone or with their family.

Heightened emotions were factors that all participant groups described as mediating the level of disruption tics had on mealtimes. As YP experienced heightened emotions such as anxiety or frustration, their tic severity peaked. All participant groups mentioned a feedback loop between tics and heightened emotional states. Conelea and Woods (2008) emphasised the importance of understanding contextual factors that evoke stress, frustration, and anxiety as these emotional states can exacerbate tics. The findings from this doctoral study highlight mealtimes as a social context where tics might present challenges that evoke these emotional states, which in turn intensifies tics. This feedback loop became more problematic when eating out of home as this was a high-pressure environment for YP, who felt self-conscious about their tics.

Negative past experiences with strangers or dining out created anticipatory anxiety for YP. Malli et al. (2019) explained that alongside past experiences of stigma and discrimination, people with TS were aware that their condition was "*culturally devalued*" (p.837). As such, they often anticipated discrimination and avoided public spaces. This created two challenges for YP and their families in this study: (1) YP avoided eating out of home due to fear of stigma and negative reactions from the general public, or (2) they

ate out but experienced heightened anxiety and self-consciousness, which made eating out stressful. YP described themselves as actively engaging in self-evaluation as they monitored their external image and whether or not they sufficiently met social norms (Lee et al., 2016). Their tics made them conscious that their atypical behaviour was being witnessed by others, which increased anxiety and often intensified tics (Coffey et al., 2000; Conelea & Woods, 2008).

Feeling self-conscious was not limited to YP with TS, as mothers also described themselves and other family members as acutely aware that other diners looked at them when they ate out. The whole family engaged in the looking-glass self, a theory by Cooley (1902) that describes a process where individuals base their sense of self on how they imagine others view them. Moreover, the family appeared to experience stigma-by-association as the unit was being stared at, not just the young person with TS. Mothers and YP also described people making remarks about YP's behaviour and perceived it to be a lack of discipline on behalf of the parents (i.e., perceiving them as 'bad' parents because they let their child do X). While uncomfortable for the whole family, parents described the resilience of their family. They made attempts to ease some of their child's anxiety by trying to be nonchalant about people staring or making comments. Nevertheless, despite best efforts to 'put on a brave face', these experiences did seem to affect families and contributed to them not eating out as frequently as they otherwise might.

The effect of concerns about how members of the public would react to YP's tics on families' mealtimes when dining out highlights the role of systemic forces. Lack of TS awareness from the general public and cultural norms and expectations for behaviours

all created a pressurised mealtime environment for families of YP with TS. Families appeared to be caught in a double bind as what made them visible was also invisible. YP's tics drew attention towards them and their families, yet the fact that a young person had a neurodevelopmental disorder that made them tic remained invisible; tics can easily be misconceived as behavioural and purposeful action (Davis et al., 2004). Notably, two families mentioned making people aware that a young person's behaviour was related to a disability; this helped release some of the tension, presumably because onlookers would understand that the behaviours were not purposeful.

YP with TS struggle to conform to societal norms (Cox et al., 2019; Lee et al., 2019) and mealtimes are steeped in norms surrounding behaviours (Packer, 2014). Therefore, eating out of home may not be an affirmative social experience for YP with TS and may further 'othering' and heighten social isolation. While not much was said about the impact of tics on mealtime interactions at friends' houses, YP noted that they typically felt uncomfortable and worried about how others might respond to their tics. As a result, some YP explained that they avoided eating at friends' houses. Whether this had an impact on the quality of their friendships was unclear. Rich social relationships are important for quality of life, health and wellbeing (Umberson & Karas Montez, 2010). Therefore, it is important to explore the experiences of YP within different social contexts and how these experiences affect their social lives and relationships. Despite attempting to explore multiple food environments, the findings were predominantly related to the family mealtime environment. Future researchers should explore the mealtime experiences of YP with TS in other foodscapes (e.g., at school) and whether their mealtime experiences have an effect on their peer relationships (e.g., do their

friends experience stigma-by-association, if so, what impact does this have on their mealtime experiences and friendships?).

Himle et al. (2018) recommended that clinicians remain cognisant that tics and comorbid behaviours often affect not only YP but also their families. Himle and colleagues endorsed a function-based approach to tic management, where clinicians work with YP and their families to identify contextual factors that might exacerbate tics in a problematic way. This approach may be helpful to address some of the tic-related mealtime challenges noted in this dissertation. Clinicians and families can work together to identify contextual tic triggers and create adjustments to minimise tic disruptions to mealtimes. For example, if families desire to dine out more, clinicians may also support them in finding ways to make the experience more affirmative. Normalising eating out may desensitise YP and their families to the pressure of the experience, which could, in turn, reduce tic severity. However, contextual triggers would need to be addressed to avoid exposure further engraining the tic-response.

7.6 Medication, Appetite and Weight Concerns

Lastly, two YP were unhappy with the effects of medication on their appetite, namely appetite stimulation due to antipsychotics and associated weight gain. These YP found the need to manage/control their appetite challenging. Clinicians also noted medication as influencing YP's eating behaviours, although the emphasis was mainly on appetite-suppressing stimulant medications as these were a concern for clinicians and reportedly mothers. However, none of the mothers who participated whose children took stimulants cited appetite-suppressing medication as being a mealtime challenge. This may be due to differences in samples. While this study drew upon the accounts of six of YP with TS and seventeen mothers, clinicians relied upon their experience working with a broader sample of approximately 2,500 YP with TS and their families.

Guidelines and research likely inform clinical priorities; clinical guidelines (NICE, 2018) and best practice reviews (Cortese et al., 2013; Graham et al., 2011) focus on managing the appetite-suppressing side effects of ADHD medication. As such, this may explain clinicians' focus on the effect of stimulants on appetite and weight. Research also suggests that antipsychotic medication-related weight gain may only be a temporary side effect (Dayabandara et al., 2017; Degrauw et al., 2009), therefore it may not be considered as clinically significant as weight loss. While temporary weight gain may not be clinically significant, the effect it can have on YP's self-concept is worthy of consideration as YP are likely to experience weight stigma and body dissatisfaction (Pont et al., 2017; Shin et al., 2008).

While clinicians need to monitor weight loss as a side effect of stimulant medications, weight gain associated with antipsychotics should also be monitored, and where possible addressed. Clinicians should also be cognisant of the knock-on effects of weight gain on

YP's eating behaviours (e.g., frequent snacking or weight management strategies) and psychosocial wellbeing (e.g., self-esteem). Obesity and TS are already stigmatised identities, therefore the intersection of the two are likely to marginalise YP further and reduce quality of life (Cox et al., 2019; Malli et al., 2016; Pont et al., 2017). Where possible, YP may benefit from specialist dietary advice to support them to manage their appetite and weight proportionally and appropriately.

7.7 Main Strengths and Methodological Limitations

As an understudied phenomenon, this PhD lays the groundwork for future research on the eating behaviours of YP with TS and mealtime experiences of them and their families. This dissertation included several novel studies that contribute significantly to the literature base and understandings of the eating behaviours and mealtime experiences of YP with TS and their families. As with all research, this doctoral study has some limitations. Firstly, the sample sizes in some of the studies were small. For the qualitative studies, this was purposeful and in line with IPA's commitment to the idiographic. This allows for rich data that maintains each account's idiosyncrasy while also exploring convergences and divergences between accounts (Smith et al., 2009). It was not the intention of these studies to find statistically generalisable findings but to capture an array of experiences that may be theoretically generalised to this population and others that share similar traits and characteristics. Data for the comparison studies (chapters four and five) was collected during the COVID-19 pandemic, contributing to a small sample size. It is also important to note that Power calculations were not conducted for any of the quantitative studies.

A second limitation with the quantitative studies relates to the inability to explore the BMI-SDS of YP. For BMI to be meaningful in YP it must be compared to a reference-standard that accounts for biological sex and age (Must & Anderson, 2006). Gender was collected for the self-report studies (chapters 3 and 4) which could impact the accuracy of calculations due to possible differences between gender identity and biological sex. Nevertheless, BMI-SDS were calculated using the Child Growth Foundation Package (1996) with the assumption that gender and biological sex aligned for the self-report samples. The subsequent mother's study rectified this by asking for their child's biological sex. Nevertheless, BMI-SDS appeared to be beyond the normative range for all samples, by as much as 5 standard deviations. A possible reason could be due to the calculation not taking height into consideration (e.g., difference between a 14-year-old who weighs 60kg and is 5ft 1 as opposed to 5ft 8) and nor developmental differences within the same age in years (e.g., 11 years and 0 months compared to 11 years and 11 months).

The third limitation for the empirical studies presented was that participants were not ethnically diverse. Sample characteristics like ethnicity are important as Cardona Cano et al. (2015) suggest that persistent selective eating is higher in YP with non-white mothers.

Additionally, different cultural contexts may exert different systemic influences on the YP with TS, mothers of YP with TS, and mealtime interactions. Due to the lack of ethnic diversity, none of these was able to be assessed. While the patients of the clinical professionals who participated were likely more diverse than the rest of this sample, little arose about the role of different cultural contexts on mealtime experiences and

interactions. Future research would benefit from recruiting a more ethnically diverse sample to explore the influence of ethnicity and culture on mealtime experiences within this clinical population. Despite this, a strength was the high proportion of YP with comorbidities who participated or whose mothers participated. TS is a heterogeneous condition, with most people having comorbid diagnoses. Therefore, their experiences are vast and diverse. The sample sizes and participants in this doctoral study allowed for an understanding of how tics and common comorbidities interact to create mealtime challenges.

7.8 Concluding Remarks

As demonstrated by this doctoral study, there are several ways that the mealtimes of YP with TS and their families could be adversely affected by traits or characteristics associated with TS and common comorbidities. There was no singular mealtime experience or challenge. In the same way that there is no typical young person with TS, as each individual exhibits a multifaced and complex clinical presentation shaped by the interplay of their diagnoses. Each characteristic can create a challenge, and it is often dependent on many factors, such as the severity of the behaviour/characteristic and, most importantly, how others respond. Due to the repetitive nature and social significance of mealtimes, stressful or unpleasant experiences have the potential to diminish quality of life. YP with TS and their families are not immune to the common mealtime challenges most families face, such as scheduling conflicts and time poverty (Jones, 2018; Middleton et al., 2020). Therefore, it is important to understand how additional barriers might interplay to have a diminishing effect on family functioning and wellbeing. YP with TS and their families could benefit from tailored mealtime support to address these challenges, particularly on managing parental expectations and informing parents about productive ways to work with, rather than against, their child's mealtime behaviour. This doctoral study contributes unique insights to the field, an essential step towards designing larger studies in the future and highlighting the clinical significance of eating behaviours and mealtime experiences in the TS population.

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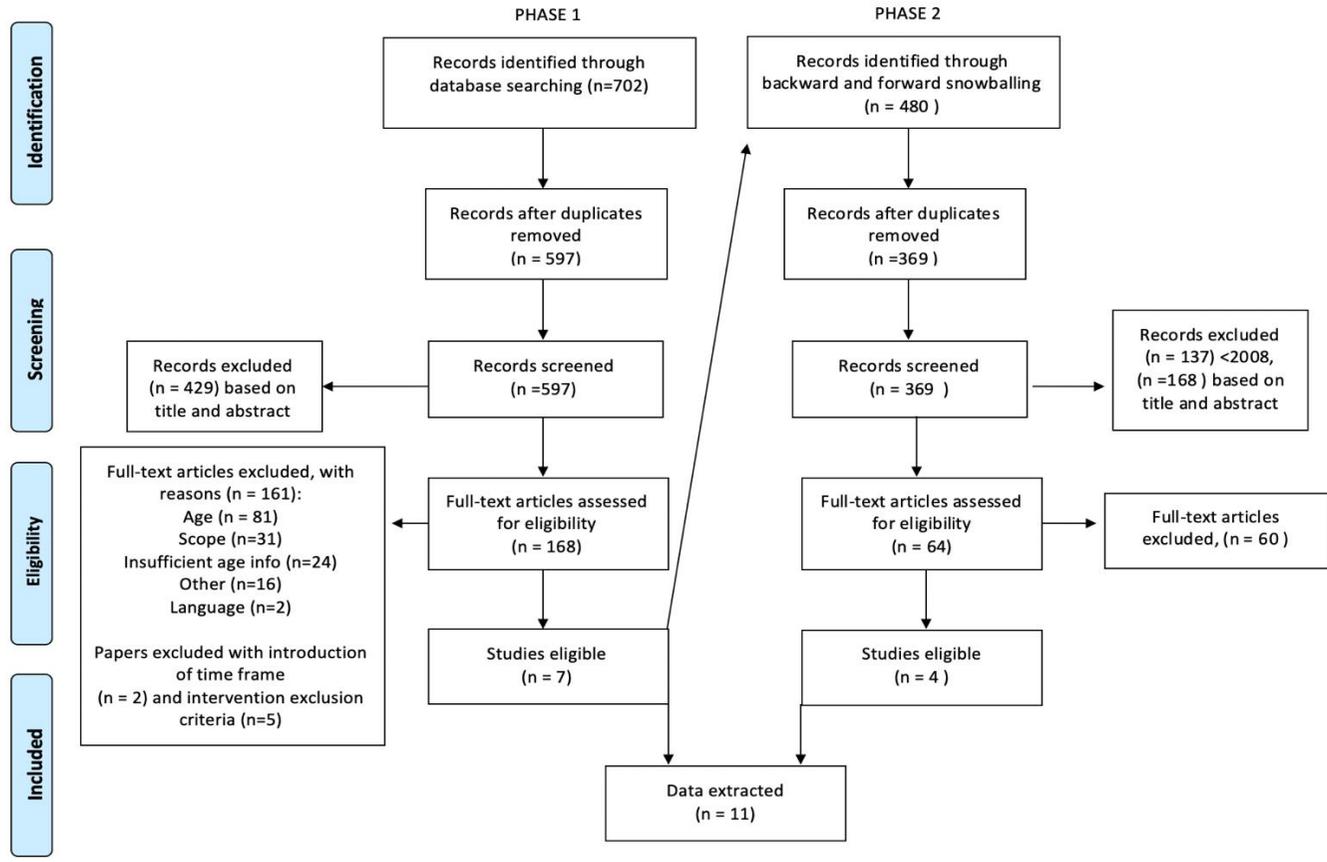
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Appendices

Appendix A: PRISMA from systematic literature review



Appendix B: University of Hertfordshire Ethics Protocol Numbers

Study Titles	Primary Ethics Application Number and Date	Amendments and Dates
Eating Difficulties in Tourette Syndrome Population: A Clinical Perspective	Number: HSK/PGR/UH/03680 Date: 04/03/2019 to 30/12/2019	Number: aHSK/PGR/UH/03680(1) Date: 15/07/2020 to 31/01/2021
Understanding Shared Mealtime Experiences of Adolescents with Tourette Syndrome and Tic Disorders.	Number: HSK/PGT/UH/03340 Date: 04/06/2018 to 31/09/2019	Number: aHSK/PGT/UH/03340(1) Date: 25/07/2018 to 31/09/2019 Number: aHSK/PGT/UH/03340(2) Date: 02/08/2018 to 31/09/2019 Number: aHSK/PGT/UH/03340(3) Date: 31/10/2018 to 31/09/2019 Number: aHSK/PGT/UH/03340(4) Date: 27/11/2018 to 31/09/2019 Number: aHSK/PGT/UH/03340(5) Date: 8/05/2020 to 01/04/2021
Exploring The Relationship Between Sensory Processing, Anxiety and Family Meals in School-Aged Children.	Number: HSK/PGR/UH/03748 Date: 16/05/2019 to 30/08/2019	Number: aHSK/PGR/UH/03748(1) Date: 03/07/2019 to 30/08/2019 Number: HSK/PGR/UH/03748(1) Date: 17/07/2020 to 31/01/2020 Number: HSK/PGR/UH/03748(3) Date: 22/07/2020 to 31/01/2021 Number: aHSK/PGR/UH/03748(4) Date: 31/09/2020 to 31/01/2021 Number: HSK/PGR/UH/03748(5) Date: 29/09/2020 to 31/01/2021

Number: HSK/PGR/UH/03748(6)

Date: 23/10/2020 to 31/01/2021

Exploring High-School Children with Tourette
Syndrome's Family Mealtime Experiences

Number: HSK/PGR/UH/04107

Date: 23/03/2020 to 01/10/2020

Number: aHSK/PGR/UH/04107(1)

Date: 17/04/2020 to 01/10/2020

Appendix C: School Consent Form (Chapter three:

Quantitative Study)

Dear Institutional Review Board,

The purpose of this letter is to inform you that I give **Sandra-Eve Bamigbade** permission to conduct the research titled:

Exploring the relationship between sensory processing, anxiety and family meals in school-aged children (UH protocol number aHSK/PGR/UH/03748(1))

at [School Name].....

I have spoken with Sandra-Eve Bamigbade in detail about the study and have reviewed the study documents, including the participant information sheets (parent and child), opt-out letter and form, questionnaire and debrief. I understand that:

- The role of the school is voluntary.
- I may decide to withdraw the school's participation at any time without penalty.
- Several classes from the school will be invited to participate in the project.
- All information obtained will be treated in strictest confidence.
- The students' names will not be used in publication and individual students will not be identifiable in any written reports about the study.
- The school will not be identifiable in any written reports about the study.
- An opt-out process of consent is in place for this project meaning that parental consent is assumed unless parents return the opt-out form (or contact the school) before the day of data collection.
- Students will be asked to give consent on the day of data collection and may withdraw from the study at any time without penalty.
- A report of the findings will be made available to the school.
- I may seek further information on the project from Sandra-Eve Bamigbade at s.bamigbade@herts.ac.uk or 070000000000.

Additional consent:

- I am happy to be contacted by the researcher in the future about other studies that the school may participate in.

Name:

Job Title:

Signature:

Contact details:

Date.....

Signature of investigator:

.....Date.....

Name of investigator: *Sandra-Eve Bamigbade*

Appendix D: Parent Letter and Information Sheet (Chapter three: Quantitative Study)

Dear Parent(s)/Guardian(s),

Date:

RE: INFORMATION ABOUT RESEARCH PROJECT AT *<INSERT SCHOOL NAME>*

Research Title: *Exploring the relationship between sensory processing, anxiety and family meals in school-aged children*

I am conducting research as part of my PhD in Food and Public Health with the University of Hertfordshire. Your child's/children's school has granted permission for a class questionnaire about mealtimes and eating behaviours to be conducted during a lesson.

This letter is to give you some information about the questionnaire and background to my study.

What is the project about?

I am interested in learning more about children's eating behaviours, their mealtime experiences and what can influence these experiences. I want to find out whether factors such as picky eating, anxiety and increased sensitivity to smells/textures/sounds etc can influence the enjoyment of mealtimes. To do this, I would like to ask your child/children and their peers to complete a series of questionnaires to better understand a child's view of mealtimes and their eating behaviours.

Current research has focused only on parental opinions so this is an exciting opportunity for your child to participate and share their perspective. The hope is that the findings can help identify what makes mealtimes difficult and help support families to create better mealtime experiences.

What do I need to do?

Please read the information sheet attached to this letter. We are proposing your child/children complete a series of questionnaires in class with their peers. Their teacher will be present at all times and the researcher has a valid enhanced DBS. The information provided by your child/children will be anonymous and their names will not be used or published in any way.

The study is planned to take place on *<INSERT DATE AND TIME>*.

If you are happy for your child/children to take part in this study no action is required.
If you **do not want** your child/children to take part, please sign and complete the form attached by **<INSERT DATE>**.

Disclaimer: You are required to opt out of the questionnaire. If the attached form is not **completed and returned** to the school reception it will be assumed that your child/children will be taking part in the study.

Additionally, **please tell your child/children** that they will not be completing the questionnaire so they can opt out of on the day.

If you have any further questions about the research, please contact me Sandra-Eve Bamigbade at s.bamigbade@herts.ac.uk or call me on 07000000000. Also, if you have any concerns about the research please contact my supervisors: Professor Wendy Wills at w.j.wills@herts.ac.uk or Dr Amanda Ludlow at a.ludlow@herts.ac.uk.

Thank you for taking time to consider your child's participation in this project.

Yours sincerely,

Sandra-Eve Bamigbade

PhD Candidate in Food and Public Health

University of Hertfordshire

Centre for Research in Public Health and Community Care (CRIPACC)

PARENT INFORMATION SHEET

1 Title of study

Exploring the relationship between sensory processing, anxiety and family meals in school-aged children

2 Introduction

Your child/children is being invited to take part in a study. Before you decide whether you would like them to do so, it is important that you understand the study that is being undertaken and what your child's/children's involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish for your child/children to take part. The University's regulations governing the conduct of studies involving human participants can be accessed via this link:

<http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this.

3 What is the purpose of this study?

We want to learn more about family meals from children's perspectives and factors that might influence family mealtime experiences. That being said, we are also interested in hearing from parents who wish to share their perspectives. Please visit email Sandra-Eve Bamigbade (s.bamigbade@herts.ac.uk) for more information about the parent study.

4 Does my child have to take part?

It is completely up to you whether or not you decide if you want your child/children to take part in this study. If you do decide that your child/children can take part then you do not need to do anything. We are operating on an opt-out basis so **you only need to tell us if you wish for your child/children not to take part.** During class, your child/children and their peers will be given a similar information sheet to inform them of the project and will have an opportunity to ask questions about the project. They will be able to keep the information sheet and will be asked to sign a consent form. Agreeing to join the study does not mean that your child/children has to complete it. They are free to withdraw at any stage without giving a reason and will be reminded of this right during the study. **There are no consequences associated with withdrawing at any time, or deciding not to take part.**

5 Are there any age or other restrictions that may prevent my child/children from participating?

All high-school children age 11 to 16 are able to partake in this study. Parents are also able to participate in a separate parent study.

6 How long will my child's/children's part in the study take?

If your child/children decides to complete the questionnaires, it will take up to 30 minutes. This may be split into 2x 15-20-minute sessions depending on what is agreed with your child's/children's school.

7 What will happen to my child/children if they take part?

If you and your child/children agree to take part and your child/children provide consent, they will be given some questionnaires to complete. They will be asked about themselves and your family mealtimes. If they have any questions or need help understanding any of the questions, they can ask the researcher or their teacher for help. Once they complete the questionnaire, they will be asked to seal them in an envelope provided alongside their signed consent form. Their teacher or the researcher will then collect the envelopes. Only the researchers will see their responses.

8 What are the possible disadvantages, risks or side effects of taking part?

Participating will take some time out of your child's/children's school day but otherwise there are no other disadvantages, risks or side effects. They do not have to answer any questions that they do not want to and can withdraw from participation at any time.

9 What are the possible benefits of taking part?

Currently, we do not know much about family mealtimes from children's perspectives or how anxiety or sensory processing (smell, taste, sound, touch etc) influences mealtime experiences. Your child's/children's voice is important, and this is a chance to be heard and contribute towards exciting new research.

10 How will my child's/children taking part in this study be kept confidential?

Your child's/children's completed questionnaires will be sealed in the envelopes to stop anyone other than the researchers seeing their answers. To keep their envelopes safe, we will store them in a lockable briefcase until we can transfer them to a locked draw in our office (at the University of Hertfordshire). If their teachers collect their envelopes, they will store them safely in a locked location until the researchers can collect them. We will store all of data anonymously for up to 5 years after the completion of the researcher's PhD (approx. 2025). This means that we remove any information that might identify your child/children from their answers. Instead of using their name, we will use a number.

12 What will happen to the data collected within this study?

The data collected will be stored electronically, in a password-protected environment;

The data collected will be stored in hard copy by me in a locked cupboard until five year post the completion of the PhD (approx. Sept 2025), after which time it will be destroyed under secure conditions;

All data will be anonymised prior to storage.

13 Will the data be required for use in further studies?

No, your child's/children's data will not be used within further studies.

Who has reviewed this study?

This study has been reviewed by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is aHSK/PGR/UH/03748(1)

15 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities.

16 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, Sandra-Eve Bamigbade by email: s.bamigbade@herts.ac.uk. Additionally, if you would like to contact my supervisors you can email Professor Wendy Wills at w.j.wills@herts.ac.uk or Dr Amanda Ludlow at a.ludlow@herts.ac.uk.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix E: Parent Opt-Out (Chapter three: Quantitative Study)

PARENT OPT-OUT FORM

(PLEASE RETURN TO SCHOOL RECEPTION)

Research Project Title: *Exploring the relationship between sensory processing, anxiety and family meals in school-aged children*

I have read the information about the study and talked about this with my child and **I am not willing** for my child to take part in the study.

Name of child:

School:

Class:

Date of participation (see letter):

Signature of parent/guardian:

Date:

***NOTE:** Please hand this form into the school before **<INSERT DATE>** or email the researcher, Sandra-Eve Bamigbade, at s.bamigbade@herts.ac.uk. Additionally, your child will be asked to provide consent on the day so they may opt themselves out of the study.

Appendix F: Parent Debrief (Chapters three and four:

Quantitative Studies)

* A copy of the debrief for typically developing young people is presented below. The same key information was on the information sheet for young people with TS, with small variations the addition of a special TS mental health support resource.

Title of study: *Exploring the relationship between sensory processing, anxiety and family meals in school-aged children*

Thank you for taking the time to participate in this study.

If any part of your participation has raised difficult issues for you or concerns, you may wish to speak with your parent(s) or teacher(s). Additionally, you may wish to contact appropriate professional services such as your GP.

Just as a final reminder, your personal details will be kept confidential and all data will be anonymised. Please feel free to contact the researcher, Sandra-Eve Bamigbade (s.bamigbade@herts.ac.uk) if you have any questions, including questions about how your data will be handled. You may also request the results from the questionnaires you completed. However, you must email this request within 2-weeks of participating (before data is anonymised). You can also contact the supervisors about the research project if you have any complaints or concerns. The supervisors are Professor Wendy Wills (w.j.wills@herts.ac.uk) and Dr Amanda Ludlow (a.ludlow@herts.ac.uk).

Would your parent(s) like to participate?

If your parent/caregiver would like to complete an online questionnaire to share their views they can visit <https://herts.onlinesurveys.ac.uk/mealtimestudy> or email Sandra-Eve Bamigbade (s.bamigbade@herts.ac.uk) for more information.

Changed your mind about participating?

If you or your parent(s) would like to withdraw your consent to participate within the study, please email Sandra-Eve Bamigbade (s.bamigbade@herts.ac.uk) within 2 weeks of participating to have your data deleted. After this period all data will be anonymised which would mean that your data will no longer be identifiable from the dataset.

Date of participation: **<INSERT DATE>**

Deadline for data withdrawal: **<INSERT DATE>**

PLEASE SHARE THIS PAGE WITH YOUR PARENT(S) OR GUARDIAN(S)

Please see below for some resources that might be useful.

Online Resources for Mental Health Support¹²

<https://youngminds.org.uk/>

<https://www.childline.org.uk/>

Need someone to talk to?

If you feel that you need to speak to someone you can message Young Minds Crisis Messenger 24/7 by texting **'YM'** to **85258**. This service is free from EE, O2, Vodafone, 3, Virgin Mobile, BT Mobile, GiffGaff, Tesco Mobile and Telecom Plus and will be answered by a trained volunteer. Alternatively, you can call Childline for free at **0800111**.

WE STRONGLY RECOMMEND THAT YOU SAVE THESE NUMBERS IN YOUR PHONE IN THE CASE YOU MIGHT NEED TO TALK TO SOMEONE IN THE FUTURE.

¹² <https://www.tourettes-action.org.uk/78-young-people.html?116> added for TS version.

Appendix G: Information Sheet for Young People (Chapters three and four: Quantitative Study)

*A copy of the information sheet for typically developing young people is presented below. The same key information was on the information sheet for young people with TS, with small variations (e.g., TS specific language and inclusion of prize draw).

1 Title of study

Exploring the relationship between sensory processing, anxiety and family meals in school-aged children

2 Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulations governing the conduct of studies involving human participants can be accessed via this link:

<http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this.

3 What is the purpose of this study?

We want to learn more about family meals from children's perspectives and factors that might influence family mealtime experiences.

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. There are no consequences associated with withdrawing at any time, or deciding not to take part.

5 Are there any age or other restrictions that may prevent me from participating?

All high-school children age 11 to 16 are able to partake in this study.

6 How long will my part in the study take?

If you decide to complete the questionnaire, this will take approximately 30-40 minutes.

7 What will happen to me if I take part?

If you agree to take part and provide consent, you will be given a questionnaire to complete. You will be asked about yourself and your family mealtimes. If you have any questions or need help understanding any of the questions, please ask the researcher, Sandra-Eve Bamigbade, or your teacher(s) for help. Once you complete the questionnaire, please seal them in the envelop provided alongside your signed consent form. Your teacher or the researcher will then collect your envelope. Only the researchers will see your completed questionnaire.

8 What are the possible disadvantages, risks or side effects of taking part?

Participating will take some time out of your school day but otherwise there are no other disadvantages, risks or side effects. You do not have to answer any questions you do not want to and can withdraw from participation at any time.

9 What are the possible benefits of taking part?¹⁸

Currently, we do not know much about family mealtimes from children's perspectives or how anxiety or sensory processing (smell, taste, sound, touch etc) influences mealtime experiences. Your voice is important, and this is a chance to be heard and contribute towards research.

10 How will my taking part in this study be kept confidential?

Your completed questionnaires will be sealed in the envelopes to stop anyone other than the researchers seeing your answers. To keep your envelopes safe, we will store them in a lockable briefcase until we can transfer them to a locked draw in our office (at the University of Hertfordshire). If your teachers collect your envelopes, they will store them safely in a locked location until the researchers can collect them. We will store all of your data anonymously for up to 5 years after the completion of the researcher's PhD (approx. 2025). This means that we remove any information that might identify you from your answers. Instead of using your name, we will use a number.

12 What will happen to the data collected within this study?

- The data collected will be stored electronically, in a password-protected environment;

¹³ In the version for young people with TS, the following was also added "Upon completing your questionnaire, you will be entered into a prize draw where you could win a £25 Amazon voucher. Upon completing your questionnaire, you will be entered into a prize draw where you could win a £25 Amazon voucher."

- The data collected will be stored in hard copy by me in a locked cupboard until five year post the completion of the PhD (approx. Sept 2025), after which time it will be destroyed under secure conditions;
- All data will be anonymised prior to storage.

13 **Will the data be required for use in further studies?**

No, your data will not be used within further studies.

14 **Who has reviewed this study?**

This study has been reviewed by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is aHSK/PGR/UH/03748(1)

15 **Factors that might put others at risk**

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities.

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, Sandra-Eve Bamigbade (s.bamigbade@herts.ac.uk). Additionally, if you would like to contact my supervisors you can email Professor Wendy Wills at w.j.wills@herts.ac.uk or Dr Amanda Ludlow at a.ludlow@herts.ac.uk.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane, Hatfield
Herts, AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix H: Consent Form

***A copy of the consent form for typically developing young people. The same format was used with all the other participants.**

I, the undersigned *[please give your name on the dotted line below, in BLOCK CAPITALS]*

[Name]

of *[please give sufficient contact details such as a your postal or email address below on the dotted line]*

[Email or postal address]

hereby freely agree to take part in the study entitled “*exploring the relationship between sensory processing, anxiety and family meals in school-aged children*” (UH Protocol number aHSK/PGR/UH/03748(1))

Please tick the following boxes if you agree with the statements:

- I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.
- I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.
- I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

Please turn over to sign this document

Signature of participant

(You).....Date.....

Signature of (principal) investigator:

.....Date.....

Name of (principal) investigator: *Sandra-Eve Bamigbade*

Appendix I: Demographic questions asked of young people

1. What is your full name?
2. How old are you?
3. What gender do you identify with?
4. How tall are you?
5. Which ethnicity do you identify with most? Please select one option below
 - a. White
 - i. English/Welsh/Scottish/northern Irish/British
 - ii. Irish
 - iii. European
 - iv. Other
 - b. Black/African/Caribbean/Black British
 - i. African
 - ii. Caribbean
 - iii. Other Black/African/Caribbean
 - c. Mixed/Multiple ethnic groups
 - i. White and black Caribbean
 - ii. White and Black African
 - iii. White and Asian
 - iv. Other Mixed/Multiple ethnic background
 - d. Asian/Asian British
 - i. Indian
 - ii. Pakistani
 - iii. Bangladeshi
 - iv. Chinese
 - v. Other Asian Background
 - e. Other ethnic group
 - i. Arab
 - ii. Any other ethnic group
6. Do you know how much you weigh? (Y/N)
 - a. If yes, please answer the next 3 questions
 - i. How much do you weigh?
 - ii. When were you last weighed?
 1. Less than 1 month ago
 2. 2-6 months ago
 3. 7-12 months ago
 4. Over a year ago
 - iii. Is this your usual weight? (Y/N)
 1. If no, please provide more information about recent fluctuations (changes) in your weight.
7. When we say family dinner, we mean the last meal of the day, as long as you were there with your parent(s), even if one of you is not eating.
 - a. During a typical week, how many dinners do you eat with your parent(s)?
 - i. 0 dinners
 - ii. 1 dinner
 - iii. 2 dinners
 - iv. 3 dinners
 - v. 4 dinners

- vi. 5 dinners
 - vii. 6 dinners
 - viii. 7 dinners
- b. About how many minutes do family dinners usually last? (do not include the time it takes to make the meal or clean it up?)
- i. 15 minutes or less
 - ii. 30 minutes
 - iii. 45 minutes
 - iv. An hour or more
8. Have you been diagnosed with a mental health, developmental or neurological condition by a medical professional (psychologist/psychiatrist/neurologist/doctor...?) (Y/N)
- a. If yes, please write down your diagnoses below
9. Are you on any medication that can influence your appetite or weight? (Y/N)
- a. If yes, please write down the medication and the effect below.

Appendix J: Missing Data Table (Chapter three: Quantitative Study)

Variable	TD (n=188)		
	Little's MCAR	Missing Values	Missing Cases
SCARED (Anxiety)	X^2 938.141, DF = 900, p = .183	2.763%	15.43%
SESP (Sensory Eating)	X^2 227.893, DF = 256, p = .166	1.838%	9.043%
AASP (Sensory)	X^2 2566.308, DF = 2563, p = .478	*6.152%	**31.91%
FDI (Mealtimes)	X^2 23.554, DF = 15, p = .073	0.957%	4.255%
AEBQ (Eating)	X^2 851.082, DF = 754, p = .008	0.897%	16.49%
NOTES			
<p>*AASP Variable 56 has 10.1% missing, this item had a typo on the printed copies; “drown out” was written as “down out”. This was highlighted at the start of every survey with typos listed on a white board. Nevertheless, this might have explained why this variable had a higher incomplete rate.</p>			
<p>**AASP was the last questionnaire in the battery and children had to complete it within the time given. Classes were often 45-50 minutes, the first 10-15 minutes would be spent settling them in, introducing the study, answering questions, getting consent forms completed and distributing the survey. This left them with 30-35 minutes to complete the survey.</p>			

Appendix K: Normality Data (Chapter three: Quantitative Study)

Measures	Subscale	Alpha	Skewness	Kurtosis	Shapiro-Wilk
AASP ¹	Sensory Sensitivity	.78	.33	-.005	.09
AASP	Taste Reactivity	.43	.22	-.20	.12
AEBQ ²	Food Fussiness	.80	.001	-.67	.02
M-SEPS ³	Temperature Sensitivity	.61	-.01	-.87	< .001
M- SEPS	Single-Food Focus	.51	.60	-.31	< .001
M- SEPS	Food-Touch Avoidance	.60	1.43	1.57	< .001
M- SEPS	Gagging	.55	1.07	.62	< .001
M- SEPS	Expulsion	.43	1.41	2.57	< .001
M- SEPS	Overstuffing	.75	1.21	1.34	< .001
SCARED-C ⁴		.95	.53	-.39	< .001
FDI-C ⁵		.76	-1.80	3.97	< .001

MEASURES

1. Adult Adolescent Sensory Profile
2. Adult (Adolescent) Eating Behaviour Questionnaire
3. Modified Sensory Eating Problem Scale
4. Screen for Child Anxiety Related Disorder
5. Family Dinner Index, Child-report

Blue denotes unacceptable Cronbach's alpha (<.5)

Green denotes not being normally distributed

Appendix L: Implicit Consent (Chapter four: Quantitative

Study)

If you agree with the statements above (*all of the information was on the previous page*) and would like to take part in the study, please type your first and last name below and move onto the next page.

1. What is your full name?
2. What is your email address?
3. Do you have parental/guardian permission to take part in this questionnaire?
 - a. Yes, they know about this and are happy for me to take part
 - b. No, they do not know about this.
 - c. No, they are not happy for me to take part.
4. What is your parent/guardian's email address?
5. What is their name?

Before you begin, you are only able to participate if you are...

- Between 11-16 years of age
- Have been diagnosed with Tourette Syndrome
- Have parental/guardian permission to take part

The questionnaire will take 30-40 minutes in total to complete. You may take a break and return to the questionnaire at any time, so long as you use the same device. So please do feel free to pause if you need to. Those who complete the questionnaire will be entered into a prize draw to win a £25 Amazon voucher. We will contact the winner via email once we close the survey.

If you agree with the statements above (*all of the information was on the previous page*) and would like to take part in the study, please type your first and last name below and move onto the next page.

1. What is your full name?
2. What is your email address?
3. Do you have parental/guardian permission to take part in this questionnaire?
 - Yes, they know about this and are happy for me to take part
 - No, they do not know about this.
 - No, they are not happy for me to take part.
4. What is your parent/guardian's email address?

5. What is their name?

Before you begin, you are only able to participate if you are...

- Between 11-16 years of age
- Have been diagnosed with Tourette Syndrome
- Have parental/guardian permission to take part

The questionnaire will take 30-40 minutes in total to complete. You may take a break and return to the questionnaire at any time, so long as you use the same device. So please do feel free to pause if you need to. Those who complete the questionnaire will be entered into a prize draw to win a £25 Amazon voucher. We will contact the winner via email once we close the survey.

Appendix M: Parent Opt-Out Email (Chapter four:

Quantitative Study)

Dear _____

I am writing to you to confirm that your child has participated in the online study: 'Exploring High-School Children With Tourette Syndrome's Family Mealtimes Experiences' (UH Protocol Number: HSK/PGR/UH/04107(1)).

Child's ID number: _____

Date of participation: _____

They provided your email address to confirm that you have given consent for them to take part in the study. I appreciate them taking time out of their day to contribute towards my research and would like to thank you for making it possible. I have attached a copy of the participant information sheet that your child read before participating in the study. It should answer any questions you may have about their participation and how their data will be anonymised and protected. Should you have any further questions, please do not hesitate to get in touch.

With that being said, I recognise that in hindsight, parents can sometimes change their mind about their child's participation in a study. If this happens to be the case for you, I have attached an opt-out form so you may request I withdraw their data from my study. Please note that you have until midnight on the **<INSERT DATE>** to submit your request.

I hope that your child found the questionnaire interesting and that it was a unique way to pass some time during lockdown. I am also looking to interview a few children who participated in the study so that I may have a chance to understand their responses in a richer way. If you think this is something your child would be interested in, please do get in touch. The interview would be hosted over Zoom at a time and date that suits them and will typically last between 30-60 minutes, depending on how much your child would like to share.

If you would like to be updated on the findings of the research, please do let me know, and I will add you to a mailing list for study findings. Results are expected to be shared towards the end of my PhD, which would be in approximately one year from now.

Thank you again and I wish you and yours all the best in these strange times we find ourselves in.

Stay safe,

Sandra-Eve Bamigbade

PhD candidate in Food and Public Health

Centre for Research in Public Health and Community Care (CRIPACC)

University of Hertfordshire

Appendix N: Parent Opt-Out Form (Chapter four: Quantitative Study)

Research Project Title: *Exploring High-School Children With Tourette Syndrome's Family Mealtime Experiences (UH Protocol Number: HSK/PGR/UH/04107(1))*

I have read the information about the study and talked about this with my child and **I am not willing** for my child to take part in the study. Please withdraw their data from your study.

Child's ID number: <INSERT ID NUMBER>

Date of participation: <INSERT DATE>

Child's Name:

Parent/Guardian Name:

Parent/Guardian Signature (can be typed) :

.....

Date of request:

PLEASE RETURN via EMAIL TO S.BAMIGBADE@HERTS.AC.UK

*NOTE: Please send this form to the researcher before <INSERT DATE>. After this point data will be anonymised making it impossible to separate your child's responses from the dataset.

Appendix O: Missing Data Table (Chapter four: Quantitative

Study)

Variable	TS (n=15)		
	Little's MCAR	Missing Values	Missing Cases
SCARED (Anxiety)	-	0	0
SESP (Sensory Eating)	X^2 1.077, DF = 21, p = 1.000	0.325%	7.143%
AASP (Sensory)	X^2 .000, DF = 57, p = 1.000	0.347%	7.143%
FDI (Mealtimes)	X^2 5.190, DF = 4, p = .268	1.429%	7.143%
AEBQ (Eating)	-	0	0
PUTS (Tics)	-	0	0

Appendix P: Normality Table (Chapter four: Quantitative Study)

Measures	Subscale	Cronbach's Alpha		Skewness		Kurtosis		Shapiro-Wilk	
		TS	TD	TS	TD	TS	TD	TS	TD
C-AEBQ ¹	Food Fussiness	.80	.80	-.52	.18	-.29	-1.45	.37	.09
AASP ²	Taste Reactivity	.16	.71	-.78	-.34	-.27	-.44	.19	.80
AASP	Sensory Sensitivity	.61	.62	-.44	-.13	-.88	-.84	.30	.61
M-SEPS ³	Temperature Sensitivity	.34	.69	.12	.03	-1.46	-.80	.18	.75
M-SEPS	Single-Food Focus	.69	.68	.75	1.04	.04	.17	.12	.02
M-SEPS	Food-Touch Avoidance	.68	.35	1.40	2.18	2.44	4.41	.007	<.001
M-SEPS	Gagging	.76	-.31	1.17	.78	.27	-.98	.001	.001
M-SEPS	Expulsion	.36	.48	.003	2.20	-.72	6.19	.15	.001
M-SEPS	Overstuffing	.86	.68	.27	1.85	-1.22	4.36	.16	.004

SCARED ⁴	.97	.86	-.33	.12	-.83	.67	.60	.99
FDI-C ⁵	.53	.79	-1.07	-1.94	1.76	5.18	.11	.007

MEASURES

1. Adult (Adolescent) Eating Behaviour Questionnaire
2. Adult Adolescent Sensory Profile
3. Modified Sensory Eating Problem Scale
4. Screen for Child Anxiety Related Disorder
5. Family Dinner Index, Child-report

Blue denotes unacceptable Cronbach's alpha (<.5)

Green denotes not being normally distributed

Appendix Q: Information Sheet (Chapter four: Qualitative Study)

*A copy of the qualitative information sheet for young people with TS is presented below. The same key information was on the information sheet for mothers and clinicians.

1 Title of study

Understanding Shared Mealtime Experiences of Children and Adolescents with Tourette Syndrome and Tic Disorders

2 Introduction

You are being invited to take part in a study that seeks to explore children and adolescents' mealtime experiences. Before you decide whether to do so, it is important that you understand why the study is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with your parents/guardians if you are interested in participating. Do not hesitate to ask us anything that is not clear or for any further information, you would like to help you make your decision.

The University's regulations governing the conduct of studies involving human participants can be accessed via this link <http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this.

3 What is the purpose of this study?

This study seeks to explore shared mealtime experiences for children and adolescents with Tourette Syndrome (and Tic Disorders). I will be asking you some questions about your eating habits and food preferences both in and outside of your family home.

4 Do I have to take part?

It is completely up to you whether you decide to take part in this study. Agreeing to join the study does not mean that you must complete it, you can withdraw at any stage.

5 Are there any age or other restrictions that may prevent me from participating?

The research is looking for children and adolescents aged 9-16 years who have been diagnosed with Tourette Syndrome or a Tic Disorder.

6 How long will my part in the study take?

The interview should take 60-90 minutes depending on how much you would like to share.

7 What will happen to me if I take part?

A. Your parent/guardian will need to fill out a consent form stating they are happy for you to participate. This needs to be signed and returned before you can participate;

B. Once we have parental consent, the interview will be scheduled. Your parent(s) must be present before the beginning of your interview.

C. Before we start the interview, we'll have a quick chat about the study to make sure that you understand what you'll be asked about and that you are still happy to participate. The interview will be audio-recorded so that accurate notes can be made. This recording will not be made available to the public;

D. At the end, we will discuss how you found the interview process and you will be given some useful links and if necessary, signposted to services that might be helpful.

8 What are the possible disadvantages, risks or side effects of taking part?

The subject of the research may cause you some distress and make you feel uncomfortable. If you feel at any time that you need to take a break, skip a question, or want to stop participating, that is perfectly fine. You won't be asked to do anything you don't want to do.

9 What are the possible benefits of taking part?

Little is known about mealtime experiences for children and adolescents with Tourette Syndrome and their families, which means that you have an opportunity to share your experiences. Your voice is important and this is a chance to be heard.

10 How will my taking part in this study be kept confidential?

Data will be anonymised to protect your identity. Only the research team which includes Sandra-Eve Bamigbade, Dr S Rogers, Dr A Ludlow and Prof W Wills will have access to the data. Quotations may be used in publication, these will not contain any identifiable information (such as your name). If you have any further questions about the data protection plan, please contact the researcher who will be happy to explain how your data is being kept safely and securely.

11 Audio material

Your interview will be audio-recorded; this is to help with creating a record of the interview for analysis purposes. Both an Olympus Recorder and an iPhone 7 Plus will be used to record the interview to protect against any technological glitches. Both

recordings will be transferred to secure online platforms then deleted from the devices. Once transcribed, all audio files will be deleted and transcripts will be anonymised.

12 What will happen to the data collected within this study?

The data collected will be stored electronically, in a password-protected environment. The data collected will be stored in hard copy by me in a locked cupboard until five-year post the completion of the PhD (approx. Sept 2025), after which time it will be destroyed under secure conditions. All data will be anonymised prior to storage.

13 Will the data be required for use in further studies?

No, your data will not be used within further studies.

14 Who has reviewed this study?

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority.

The UH protocol number is **aHSK/PGT/UH/03340(5)**

The research has also been reviewed and approved by Tourettes Action.

15 Factors that might put others at risk

Everything you tell me is confidential; this means that I will not tell anyone what you have said. The only exception to this is if you share any information that suggests that you or someone else are at risk or in danger.

16 Who can I contact if I have any questions?

Principal Researcher: Sandra-Eve Bamigbade, s.bamigbade@herts.ac.uk, 07000000000

Primary Supervisor: Dr Samantha Rogers, s.rogers7@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix R: Parental Consent Form (Chapter four: Qualitative Study)

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

.....
of [please give contact details here, sufficient to enable the investigator to get in touch with you, such as a postal or email address]

.....
hereby freely agree to take part in the study entitled ‘Understanding shared mealtime experiences for adolescents with Tourette Syndrome and Tic Disorders’

.....
(UH Protocol number **aHSK/PGT/UH/03340(5)**)

- 1) I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my child’s personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed and asked to renew my consent to participate in it.
- 2) I have been assured that I may withdraw my child’s data from the study at any time without disadvantage or having to give a reason.
- 3) In giving my consent for my child to participate in this study, I understand that voice-recording will take place and I have been informed of how this recording will be used by the researcher and for what purposes.
- 4) I have been told how information relating to my child (data obtained in the course of the study, and data provided by my child and my family) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.
- 5) I have been told that I may at some time in the future be contacted again in connection with this or another study.

- 6) I have been informed that the researcher may use anonymised quotes in publications, such as the thesis, presentation and publications

Signature of participant.....Date.....

Signature of (principal)
investigator.....Date.....

Name of (principal) investigator

SANDRA-EVE BAMIGBADE

Appendix S: Interview Schedule (Chapter four: Qualitative

Study)

BEFORE INTERVIEW:

Thank you for agreeing to participate in this study. This study aims to explore your mealtime experiences of food and eating, whether that's at home, at school, or in other places like when you're out with friends or family.

The interview should last an hour although it depends on how much you have to say. This interview is all about you and having your say, there is no right or wrong answer so please do speak freely ☺

Everything you tell me is confidential; this means that I will not tell anyone what you have said. The only exception to this is if you share any information that suggests that you or someone else are in danger.

After the interview, I will create a pseudonym (fake name) for you so that you are not identifiable in any of the published or shared work. Any identifiable information such as names etc that you may mention in the interview will also be changed to protect your identity.

If you consent, this interview will be recorded, although the recording will only be accessible by me. The reason why I would like to record, is so that I may accurately type up our conversation today. After which, the audio will be deleted. Copies of the transcripts will be sent to you following the interview so that you can provide your feedback.

If there's anything that you want to talk about off the record, please feel free to let me know and I can pause/stop the audio. You are also free to stop the interview at any time; be it for a break or to end the interview process. You don't have to answer any questions that you don't want to.

Ask about how they prefer people to respond to their vocal tics and ask about transcription of vocal tics whether they would prefer they are retracted or transcribed.

Do you have any questions you want to ask?

If you are happy to begin, I will turn the recorder on after consent has been provided by them and their guardian.

****RECORDER TO BE TURNED ON****

INTERVIEW GUIDE:

- 1 Tell me a bit about yourself.
 - Who do you live with?
 - What do you like doing in your spare time?
 - How long have you had TS?
 - How would you describe your eating habits?

- 2 Ask the participant to describe their day today, yesterday and tomorrow, focusing on food and eating (one day at a time – include school days to ask about food at school)
 - (a) Can you describe that mealtime for me? Who/What/Where?
 - (b) How do you decide what to eat?
 - (c) What influences what you eat?
 - (d) Are there any tastes, smells or textures that you like or don't like? Tell me more about that...
 - (e) What sort of flavours do you like/dislike? Tell me more about that...
 - (f) Probe about food groups

NOTE: Ensure both weekends and weekdays are covered, if not, probe. Prompt: Do you eat like this on the weekend/schooldays? How is it different on weekends/schooldays? What did you eat last weekend/week? Ask about whether response is typical i.e. do they typically eat X or with Y etc.

- 3 Family meal questions and prompts
 - How often do you eat meals with your family on a weekly basis?
 - Who is usually at each family meal? Is this different according to whether the meal is breakfast, lunch and dinner?
 - When did you last eat with your family?
 - Was everyone present at this meal? If not, when was the last time you all sat down to eat a meal together?
 - Who cooked the food? Did you help? Did anyone else help?
 - Who decides what food is served during family meals?
 - Where did you sit to eat?
 - Are there any rules about the food eaten at family meals? For example, does everyone have to finish their food or taste everything?
 - Does everyone eat the same meal or are different meals served at the same time? Why?
 - What meals/foods so you prepare yourself? How often and why?
 - What do you like the most about family meals? Why?
 - What's your least favourite thing about family meals? Why?

- 4 Out-of-home eating questions and prompts
 - When do you buy food or drink for yourself?
 - Who/What/Where/Why?
 - How did you decide where to go?
 - How did you decide what to buy/order?
 - How do you feel when you go somewhere new to eat?

- Are the foods and drinks you buy when you eat out with friends/family different to those you would choose when you are with your family/friends?
- What do you like most about buying food and drink and why?
- What's your least favourite thing about buying food and drink and why?
- What do you like most about eating out and why?
- What's your least favourite thing about eating out and why?

5 Tics and Mealtimes

- Does your TS/Tics influence your mealtimes/ when you eat?
- Do you take any medication?
 - If yes, ask about changes they have noticed since starting medications - focusing on appetite and weight
- How have your mealtimes changes since you were diagnosed with TS?

6 Is there anything else that you'd like to mention that we haven't covered relating to your eating habits?

END - RECORDER TO BE TURNED OFF

Thank participant for their time and contribution to the research. Reiterate the importance of sharing their experiences.

Tell the participant what will happen to the information (i.e. how it will be analysed, anonymised and added to the PhD project as well as how it will appear in presentation/papers). Agree email address to send the anonymised transcript.

Appendix T: Case Summary Template

*Used in the qualitative studies presented in chapters four and five

Interview Information	
Date of interview	
Participant pin	
Interviewee pseudonym	
Duration of interview	
Interview type	
Location of interview	
Where interviewee lives	
Sent transcript copy	

TC Information	
TC Pseudonym	
TC Age at interview	
TC Gender	
TC diagnoses (AOO; AOD)	
TC Medication	

Family Information	
Other family members' pseudonyms, including birth order and additional diagnoses	
Other pseudonyms	
Who currently lives in the family home	
Family Ethnicity	
Primary caregiver	
Adult occupations and working patten	
Other	

Mealtimes at home	
Typical routine, what food/drink, with who, who prepares/cooks?	
Breakfast	
Lunch	
Evening Meal	
Snacks	
Drinks	
Other occasions	
Weekend changes	
Mealtime experiences and foodwork	

Eating together as a family. What does 'family meal' mean? Parents' routine and impact on meal times. Frequency of meals.	
Parental control Do parents try to control TC's diet? If so, how. Are there contradictions? Rules or expectations when eating at home. Prohibited foods or cupboards.	
Feeding dynamic and communication style.	
TC involvement with foodwork.	
Other family members helping with foodwork.	
Food Shopping and Family Food choices Household routine? Where? When? Does TC help? Can TC ask for additional items? What influences decisions surrounding family food choices.	
TC's eating and mealtime behaviours.	
TC's favourite and least favourite food items and meals.	
TC response to food they do not like or food not presented in their preferred way.	
Has TC eating behaviour changed overtime?	
Variety of food types eaten. Different types of cuisines?	

Regularity and type of takeaways.	
Changes to family life.	
Influencing factors	
Tics and mealtimes	
Sensory-sensitivities and mealtimes	
Disruptive mealtime behaviours	
Medication and mealtimes	
Other	

Mealtimes at school	
Routine and experiences	
Breakfast	
Mid-morning Break	
Lunch	
After school activities	
Socialising with friends after school	
Are there any rules when eating/buying food at school?	
Challenges with school eating environment	
Influencing factors	
Tics and mealtimes	
Sensory-sensitivities and mealtimes	
Disruptive mealtime behaviours	
Medication and mealtimes	

Eating out of Home	
At restaurants or similar establishments	
With friends	
With extended family	
With immediate family	
At other people's homes	

At a friends'/relative's houses	
Influencing factors	
Tics and mealtimes	
Sensory-sensitivities and mealtimes	
Disruptive mealtime behaviours	
Medication and mealtimes	

Other challenges mentioned	
Food-related	
Non-food related	

Catalogue of tics	
	▪
<i>Comments:</i>	
Comments about TS diagnosis and acceptance:	

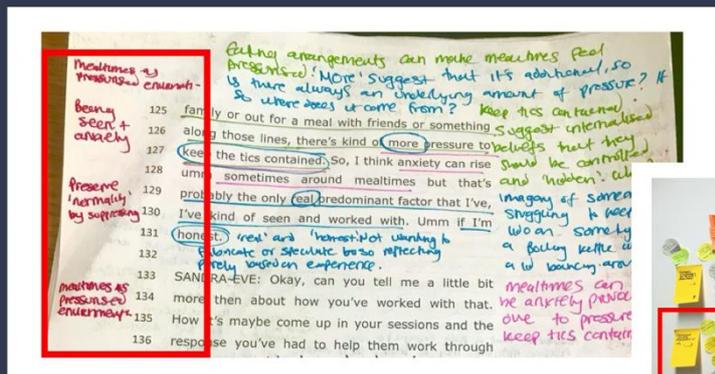
Summary of key points

Appendix U: Qualitative Data Analysis and Mind Map

Example

The example given below is for the study presented in chapter six (clinician study) taken from lecture slides. Effectively the same IPA process was followed for all qualitative studies, with one main difference. For the studies in chapters four and five, a case summary template was completed during step 1, before moving onto the next case. For chapter six, a narrative was written before moving onto the next case.

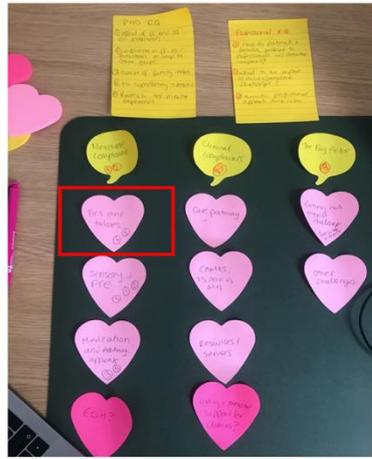
Step 1: Read, code and interpret each transcript. Search for patterns within each case.



Step 2: Search for patterns across cases - development of emerging themes



Step 3: Structure your themes into a hierarchy and develop a narrative for your write-up



Superordinate themes	Subthemes
Tics and Tables: How tics shape children's mealtime experiences	Disruptive tics
	Tic visibility and self-consciousness
Mealtime battles: Parental mealtime complaints and factors that shape their mealtime experiences	Won't eat: picky eating and feeding practices
	Can't eat: appetite suppression and parental worry
	Won't stop moving: Tics, ADHD and Stereotypies

Step 4: Write up your findings then edit, edit and edit some more...

Tic visibility and self-consciousness

A more common challenge that children raised to clinicians in relation to tics and mealtimes was the increased visibility of tics and the self-consciousness that often ensued. In the spirit of this sentiment, Theo described TS as a "socially conscious movement disorder" thus self-consciousness was deemed to be part-and-parcel of life with TS. In general, all clinicians noted self-consciousness as a challenge that many patients with TS faced. Mealtimes were described by a few clinicians as a pressurised environment. Andrea described how mealtimes were pressurised by explaining that having to sit "directly facing someone" makes tics "much more visible". Theo built upon this, adding the dimension of "unspoken rules" associated with mealtimes as an additional source of pressure. Typical mealtime etiquette, such as sitting still, engaging in appropriate dinnertime conversation, being relatively quiet, and eating with one's mouth closed could all be challenging if children had discordant tics.

Patients were noted to complain about mealtimes both within and outside of the family home; although, more commonly about mealtimes around non-immediate family and members of the general public. Additionally, these types of challenges were more prevalent in older adolescents than younger children as adolescents tended to be more aware of social norms and their differences. This made them more attuned to people noticing their tics which often left them feeling embarrassed.

"[...] especially teenagers, they often have an insight, they are aware of their tics. So, they are worried about other people watching them." (Harry)

Appendix V: Debrief (Chapter five: Quantitative Study)

Thank you for taking the time to participate in this study.

Title of study: Exploring the relationship between sensory processing, anxiety and family meals in school-aged children

If any part of your participation has raised difficult issues for you or concerns, you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

Just as a final reminder, your personal details will be kept confidential and all data will be anonymised. Please feel free to contact the researcher, Sandra-Eve Bamigbade (s.bamigbade@herts.ac.uk) if you have any questions, including questions about how your data will be handled. You may also request the results from the questionnaires you completed. However, you must email this request within 2-weeks of participating (before data is anonymised). You can also contact the supervisors about the research project if you have any complaints or concerns. The supervisors are Dr Sam Rogers (s.rogers7@herts.ac.uk), Professor Wendy Wills (w.j.wills@herts.ac.uk) and Dr Amanda Ludlow (a.ludlow@herts.ac.uk).

Online Mealtime Resources:

<https://www.ellynatterinstitute.org/resources-and-links-for-the-public/>

<https://www.optionsautism.co.uk/wp-content/uploads/2017/09/May17-Food-Challenges-Help-Sheet-Issue-9-050917.pdf>

<https://www.aboutkidshealth.ca/Article?contentid=638&language=English>

<https://www.betterhealth.vic.gov.au/health/healthyliving/eating-tips-for-school-children>

Recommended Books:

1. Food Refusal and Avoidant Eating in Children, including those with Autism Spectrum Conditions by Gillian Harris and Elizabeth Shea (2018) Link: <http://amzn.eu/d/h8Dpi6g>

2. Secrets of Feeding a Healthy Family: How to Eat, How to Raise Good Eaters, How to Cook by Ellyn Satter (2008) Link: <http://amzn.eu/d/dLjon8q>

Appendix W: Demographic questions asked of mothers

1. Which of the following best describes your relationship to the child?
 - a. Mother
 - b. Father
 - c. Stepmother
 - d. Stepfather
 - e. Grandmother
 - f. Grandfather
 - g. Aunt
 - h. Uncle
 - i. Guardian
 - j. Other
2. Are you their primary caregiver?
 - a. If no, who is?
3. What is your date of birth?
4. Which ethnicity do you identify with most? Please select one option below
 - a. White
 - i. English/Welsh/Scottish/northern Irish/British
 - ii. Irish
 - iii. European
 - iv. Other
 - b. Black/African/Caribbean/Black British
 - i. African
 - ii. Caribbean
 - iii. Other Black/African/Caribbean
 - c. Mixed/Multiple ethnic groups
 - i. White and black Caribbean
 - ii. White and Black African
 - iii. White and Asian
 - iv. Other Mixed/Multiple ethnic background
 - d. Asian/Asian British
 - i. Indian
 - ii. Pakistani
 - iii. Bangladeshi
 - iv. Chinese
 - v. Other Asian Background
 - e. Other ethnic group
 - i. Arab
 - ii. Any other ethnic group
5. How tall are you?
6. Do you know how much you weigh? (Y/N)
 - a. If yes, please answer the next 3 questions
 - i. How much do you weigh?
 - ii. When were you last weighed?
 1. Less than 1 month ago
 2. 2-6 months ago
 3. 7-12 months ago
 4. Over a year ago

- iii. Is this your usual weight? (Y/N)
 - 1. If no, please provide more information about recent fluctuations (changes) in your weight.
- 7. Does your child have the same ethnicity as you?
 - a. If no, what is your child's ethnicity?
 - i. White
 - 1. English/Welsh/Scottish/northern Irish/British
 - 2. Irish
 - 3. European
 - 4. Other
 - ii. Black/African/Caribbean/Black British
 - 1. African
 - 2. Caribbean
 - 3. Other Black/African/Caribbean
 - iii. Mixed/Multiple ethnic groups
 - 1. White and black Caribbean
 - 2. White and Black African
 - 3. White and Asian
 - 4. Other Mixed/Multiple ethnic background
 - iv. Asian/Asian British
 - 1. Indian
 - 2. Pakistani
 - 3. Bangladeshi
 - 4. Chinese
 - 5. Other Asian Background
 - v. Other ethnic group
 - 1. Arab
 - 2. Any other ethnic group
- 8. What is your child's date of birth?
- 9. What is your child's biological sex at birth?
 - a. Male
 - b. Female
 - c. Other
- 10. How tall is your child?
- 11. Do you know how much your child weighs? (Y/N)
 - a. If yes, how much does your child weigh?
 - b. When were they last weighed?
 - i. Less than 1 month ago
 - ii. 2-6 months ago
 - iii. 7-12 months ago
 - iv. Over a year ago
 - c. Is this your child's usual weight? (Y/N)
 - d. Please provide more information about recent fluctuations in your child's weight.
- 12. Has your child been diagnosed with a mental health, developmental or neurological condition by a medical professional (psychologist/psychiatrist/neurologist/doctor...?) (Y/N/awaiting)
 - a. If yes, please write down their diagnoses below and identify their primary diagnosis with an asterisk.

13. Is your child on any medication that can influence their appetite or weight?
(Y/N)
- a. If yes, please write down the medication and the effect below.
14. How many other adults (18 years and over) live with you?
15. How many other children (under 18 years) live with you?
16. If your child has a tic disorder, what is their diagnosis?
- a. Tourette Syndrome
 - b. Chronic Tic disorder
 - c. Other
 - d. Not applicable, my child does not have a tic disorder
17. When we say family dinner, we mean the last meal of the day, as long as you were there with your parent(s), even if one of you is not eating.
- a. During a typical week, how many dinners do you eat with your parent(s)?
 - i. 0 dinners
 - ii. 1 dinner
 - iii. 2 dinners
 - iv. 3 dinners
 - v. 4 dinners
 - vi. 5 dinners
 - vii. 6 dinners
 - viii. 7 dinners
 - b. About how many minutes do family dinners usually last? (do not include the time it takes to make the meal or clean it up?)
 - i. 15 minutes or less
 - ii. 30 minutes
 - iii. 45 minutes
 - iv. An hour or more

Appendix X: Normality Data (Chapter five: Quantitative Study)

Measures	Subscale	Cronbach Alpha		Skewness		Kurtosis		Shapiro-Wilk	
		TS	TD	TS	TD	TS	TD	TS	TD
M-SCNFS ¹		.95	.88	-.28	.23	-.77	-1.05	.32	.35
AEBQ ²	Food Fussiness	.93	.91	.04	1.01	-.80	.21	.37	.003
SEPS ³	Temperature Sensitivity	.73	.43	.81	.84	-.42	-.94	.001	<.001
SEPS	Single-Food Focus	.65	.69	1.01	1.19	.96	.31	.04	<.001
SEPS	Food-Touch Avoidance	.50	.00*	1.40	4.47	1.16	20.00	<.001	<.001
SEPS	Gagging	.52	.63	.99	1.61	-.42	.93	<.001	<.001
SEPS	Expulsion	.86	.58	1.37	2.43	.51	.51	<.001	<.001
SEPS	Overstuffing	.82	.89	.78	2.07	-.67	5.24	.002	<.001
SCARED ⁴		.98	.94	.92	2.08	-.42	5.65	.01	.001
PSS ⁵		.85	.89	.46	-.26	1.82	-.84	.36	.49
FDI-P ⁶		.67	.72	-.42	-.18	-.59	-1.56	.42	.04

MEASURE NOTES

1. Modified Spanish Child Food Neophobia Scale
2. Parent-Report Adult (Adolescent) Eating Behaviour Questionnaire
3. Sensory Eating Problem Scale
4. Screen for Child Anxiety Related Disorder
5. Parental Stress Scale
6. Family Dinner Index, parent report

Blue denotes unacceptable Cronbach alpha (<.5)

Green denotes not being normally distributed

* All participants responded the same, no SD to calculate the Cronbach alpha.

Appendix Y: Interview Schedule (Chapter five: Qualitative

Study)

- 1 Tell me a bit about yourself and your family
 - (a) **Could you tell me about a typical day in your life?**
 - (b) Probe about any mentions of mealtimes/food/eating to move into conversations about the nature of family meals in their household and what shapes them.
 - (c) **What does a family meal look like in your home?**
 - (d) Probe about whether that is typical, or if there are any times that's different from this routine and how mealtimes have changed over the years.

- 2 When was the last time you sat down to eat a meal with your family?
 - (a) Can you describe that mealtime for me? Who/What/Where?
 - (b) How do you decide what to eat?
 - (c) What influences what you eat?
 - (d) Was there any planning involved? If so, can you please explain. Do you usually plan for family meals?
 - (e) Can you talk to me a little bit about how you shop for family meals? Probe for planning of meals and routine of meal provision
 - (f) Do you typically eat breakfast/lunch/dinner together? Are there any exceptions?

***ASK ABOUT YESTERDAY AND TOMORROW TOO**

NOTE: Ensure both weekends and weekdays are covered, if not, probe. Prompt: Do you eat like this on the weekend/schooldays? How is it different on weekends/schooldays? What did you eat last weekend/week? Ask about whether response is typical i.e. do they typically eat X or with Y etc.

- 3 Family meals
 - (a) How often do you eat meals together as a family on a weekly basis? What do you think about that?
 - (b) What do family meals mean to you?
 - (c) Who is usually at each family meal? Is this different according to whether the meal is breakfast, lunch and dinner?
 - (d) Who cooks family meals? Does anyone else help?
 - (e) Who decides what is served during family meals?
 - (f) What types of food does your child like/dislike? Probe about food groups, tastes, textures etc and drinks.
 - (g) Where do you sit to eat?
 - (h) Are there any rules about what food is eaten during family meals? For example, does everyone have to finish their food?
 - (i) Does everyone eat the same meal or are different meals served at the same time? Why?
 - (j) How would you describe family meals in your household?

- (k) What do you like the most about family meals? Why?
- (l) What's your least favourite things about family meals? Why?

4 Out-of-home eating questions and prompts

- (a) When was the last time you ate out as a family? What was it like? Can you describe it to me.
 - Who/What/Where/Why?
 - How did you decide where to go?
 - How did you decide what to buy/order?
 - What do you like most about going out to eat as a family and why?
 - What's your least favourite thing about going out to eat as a family and why?

5 Tics and Mealtimes

- (a) Can you talk to me about tics and mealtimes.
- (b) Does your child's TS/Tics influence your mealtime experience or their eating behaviours?
- (c) Does your child take any medication? Probe for names of medications
 - If yes, probe about side effects such as on appetite etc
 1. How have mealtimes/their eating changed since your child started taking medication?
 2. What advice did you receive about this medication and side effects? Probe for any appetite or weight management related advice and if they saw a nutritionist/dietician
 3. Can you talk to me a little bit about your child's weight? Has your child's weight changed since they started medication? Do you monitor your child's weight? If so, how?
- (d) How have mealtimes changed since your child was diagnosed with TS?
- (e) Do you have any concerns about your child's mealtimes as they age and become more independent?

6 Is there anything else that you'd like to mention that we haven't covered relating to your family mealtimes?

Appendix Z: Interview Schedule (Chapter six study)

1. Can you tell me a little about yourself and your involvement with the TS community.

Probes:

- (a) What is your educational background?
- (b) What is your profession?
- (c) What's the nature of your role?
- (d) How long have you been working as a _____ for?
- (e) What type of clients/patients do you typically work with?
- (f) Do you see patients on the NHS, privately or both?
- (g) Are you on the TA Therapist list?
- (h) How long have you been working with individuals with TS?
- (i) Roughly how many patients with TS have you worked closely with?
- (j) Do you tend to work with individuals or families? Can you tell me a little bit about the nature of your work with families?

2. Can you describe any eating difficulties you have encountered within the TS population during your clinical career.

Probes:

- (a) What have you encountered?
- (b) How typical is that?
- (c) What influences those experiences?
- (d) What advice/treatment did you give?
- (e) What was the impact of that?
- (f) Have you noticed any other patterns?
- (g) How do these patients typically present?
- (h) What do you consider the most impactful implications or consequences are of these difficulties?
- (i) Can you talk to me about how this impacted the wider family unit/daily life?

3. Can you talk to me about fluctuations in the weight of your patients with TS either before or after medication.

- (a) What do you think influences their weight?
- (b) What role, if any, does impulse control play in relation to their weight?

4. Can you talk to me a little bit about sensory processing difficulties or heightened sensations in the TS population.

Probes:

- (a) How prevalent do you think these issues are?
- (b) What the consequences of these sensitivities?
- (c) How do these patients typically present?
- (d) Have these difficulties interfered with eating or mealtimes before?
- (e) How has this impacted day-to-day (family) life?

5. Anecdotal evidence suggests that tics can get in the way of eating, influence the

social element of the meal or present a risk during mealtimes. Can you tell me about tics you've encountered that influence eating and mealtimes.

- (a) How common are these?
- (b) What is the impact on the individual and their family?
- (c) How did you manage this? Who else was involved in the management of this?
- (d) Can you talk to me about referrals to other professionals related to eating/mealtime difficulties.

6. Can you talk to me about medication prescribed to people with TS and possible side effects.

Probes:

- (a) How common is this?
- (b) What advice do you give regarding weight, medication and eating to your patients with TS?
- (c) What are the typical complaints patients present with?
 - i. Probe about weight gain and lethargy

7. In your experience, what are the challenges with treating this patient group?

- (a) What do you feel there's not enough information surrounding?
- (b) What type of support/research would help you improve your practice when working with this patient group?
- (c) What would be useful in helping other clinical staff manage eating/mealtime difficulties with this population?

8. Is there anything else you would like to add that we have not yet covered?