An Exploration of Support for Children and Young People with Tourette Syndrome in Schools

Doctorate in Educational Psychology

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Summary

This thesis is divided into three parts: a literature review, a major empirical study and a critical appraisal.

Part A is a detailed literature review which explores relevant literature related to school support for Children and Young People with Tourette Syndrome. The review begins with an overview of TS, including diagnostic procedures, aetiology and treatment. TS within the context of school is considered through exploration of difficulties CYP with TS face in school and support that may be put in place in school. Additionally, research relating to the role of Educational Psychologists in supporting Tourette Syndrome is explored. Finally, academic and professional rationale along with research questions for the current study are presented.

Part B is an empirical study which aims to explore current practices of supporting CYP with TS in mainstream schools and parent's experiences of this support. The research included 2 components, a questionnaire for school staff and parents and interviews with parents of CYP with TS. A summary of relevant literature is followed by details of methods and measurements for both parts of the research. Findings for both components are presented and discussed in detail, along with consideration of implications of this research.

Part C is a critical appraisal of the current research, providing analysis of the research process and decisions made by the researcher. The critical appraisal begins with an overview of contribution that this research makes to the field with consideration to dissemination of findings. The appraisal then discusses decisions made during the research process, including research paradigm, design, recruitment and analysis. Finally, reflections on ethical issues and the researchers position are presented.

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Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
AEP	Association of Educational Psychologists
ALN	Additional Learning Needs
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
BPS	British Psychological Society
BTX	Botulinum Toxin A
CAMHS	Child and Adolescent Mental Health Services
CBIT	Comprehensive Behavioural Intervention for Tics
COMOIRA	Constructionist Model of Informed and Reasoned Action
CYP	Children and Young People
DBS	Deep Brain Stimulation
DSM	Diagnostic and Statistical Manual of Mental Disorders
EHCP	Education Health and Care Plan
ELSA	Emotional Literacy Support Assistant
EP	Educational Psychologist
EPS	Educational Psychology Service
ERP	Exposure and Response Prevention
GOSH	Great Ormond Street Hospital
HRT	Habit Reversal Training
ICD	International Classification of Diseases and Related Health Problems
IEP	Individual Education Plan
IPA	Interpretative Phenomenological Analysis
LD	Learning Difficulties
LSA	Learning Support Assistant
OCB	Obsessive Compulsive Behaviours
OCD	Obsessive Compulsive Disorder
ODD	Oppositional Defiant Disorder
PCP	Personal Construct Psychology
SaLT	Speech and Language Therapist
SANRA	Scale of the Assessment of Narrative Review Articles
SEN	Special Educational Needs
SIB	Self-injurious behaviours
SP	School Psychologist
TA	Teaching Assistant
TEP	Trainee Educational Psychologist
THS-R	Test of Handwriting - Revised
TS	Tourette Syndrome
WG	Welsh Government
WHO	World Health Organisation
YGTSS	Yale Global Tic Severity Scale

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Part A: Literature Review

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1.0 Structure and Key Sources

1.1 Introduction

This literature review will begin with an overview of Tourette Syndrome (TS), including the diagnostic procedures, prevalence, aetiology, co-morbidities and treatments. This will be followed by a review of the literature related to TS in schools, including presenting difficulties and school support for TS. The role of Educational Psychologists (EPs) in this area will also be considered. Finally, the rationale for the current study will be discussed and research questions presented. It is acknowledged that a number of terms for TS exist and are often used interchangeably, such as Tourette Disorder and Gilles de la Tourette Syndrome. For clarity, Tourette Syndrome (TS), described as the preferred term by Robertson and Eapen (2014), is used consistently throughout this thesis. The focus of this review is on TS, as opposed to tic disorders as a category. However tic disorders are discussed to provide context and some research included in the review makes reference to tic disorders generally rather than purely TS. In addition, the term parent is used throughout this thesis to refer to any parent or carer.

1.2 Search Strategy

The question explored in this review was ‘how do schools support children and young people (CYP) with Tourette Syndrome?’ This aimed to gain an insight into the difficulties CYP with TS experience in the school environment and the support offered by schools. The literature within this review was obtained from the following sources: Psycinfo, scopus, web of science, ERIC, ASSIA and British Education Index. Key search terms focussed on TS, schools and pupils, see appendix 1 for search terms and full details of the search process.

The literature that arose from the search process was screened for relevance by the researcher (appendix 2). Inclusion criteria for the screening process was defined as any paper published in English which discussed tic disorders or TS specifically within a school context. During the screening process other literature which related to TS (e.g. prevalence, aetiology, treatment) was categorised to be included in other relevant sections of the literature review. Other appropriate references were identified using the snowball technique, searches using Google Scholar and hand searching of relevant journals and other sources. Due to a relatively small body of research conducted in the UK, research from other countries, including USA, Canada and Australia was included. It is however, recognised that there may be substantial differences in the education systems between the countries.

1.3 Structure

A narrative literature review was used to explore literature for this thesis. Narrative literature reviews aim to synthesise findings from a range of sources in order to provide an account of the relevant history, theories and research related to a specific topic (Siddaway et al., 2019). This was selected to be the most appropriate structure for this thesis as literature related to TS in schools includes research with diverse methodologies and from a range of fields and perspectives (Baumeister & Leary, 1997). The Scale of the Assessment of Narrative Review Articles (SANRA) (Baethge et al., 2019) was used to support the researchers understanding of narrative reviews and to guide the narrative review process.

2.0 Tourette Syndrome

Gilles de la Tourette Syndrome, now more commonly referred to as Tourette Syndrome (TS) or Tourette Disorder is often cited to have been first described by Georges de la Tourette in 1885 (Lajonchere et al., 1996). There are however also reports of earlier accounts by Armand Trousseau in 1873 which described the symptoms associated with TS (Rickards et al., 2010). These and other early accounts of TS described uncontrollable sounds and involuntary movements. More recently TS has become understood as a complex developmental neuropsychiatric disorder falling under the category of tic disorders (Singer & Walkup, 1991).

2.1 Tics and Tic Disorders

Tics are defined as vocalisations or motor movements which are recurrent, rapid and sudden and are often preceded with an urge (Mittal, 2020). Tics can be categorised as complex or simple, examples of these types of tics can be seen in table 1, adapted from Carroll and Robertson (2000). Simple tics involve a brief movement or vocalisation which often do not have any social meaning, such as blinking, sniffing or barking. Complex tics may be a combination of simple tics and can involve gestures or words/phrases that have social meaning and therefore can seem intentional, for example, imitating the movement made by someone else (echopraxia) or obscene words or phrases (coprolalia).

Table 1 *Examples of simple and complex motor and vocal tics, adapted from Carroll and Robertson (2000).*

	Simple Tics	**Complex Tics**
Vocal Tics	Throat clearing Sniffing Coughing Grunting Barking	Making animal sounds (e.g. quack of a duck) Coprolalia: Inappropriate involuntary swearing or use of offensive language Echolalia: Repeating sounds or words heard
Motor Tics	Excessive eye blinking Squinting Facial grimacing Shoulder shrugging Flicking hair out of eyes Head nodding/ jerking	Facial gestures Smelling things Licking things Touching things or people inappropriately Jumping up and down. Copropraxia: Use of sexual or rude gestures Echopraxia: Copying someone’s movements

Tic disorders represent a spectrum of conditions in which an individual experiences vocal or motor tics with severity, types and persistence of tics influencing diagnosis (Singer & Walkup, 1991). Although tics are described as being involuntary, they are often preceded with an urge and may be able to be suppressed or resisted, this can however take a lot of effort from the individual (Leckman et al., 1993). Tics are relatively common in childhood, with an estimated 20% of school-aged children experiencing some form of tic (Scahill et al., 2014), however in many instances these tics are transient and do not lead to a diagnosis of a tic disorder.

2.2 Diagnosis of Tic Disorders

The Diagnostic and Statistical Manual of Mental Disorders (5th ed; DSM-5; American Psychiatric Association [APA], 2013) provides explanations and diagnostic criteria for various tic disorders. Tic disorders fall under the category of neurodevelopmental disorders in the DSM-5. There are no specific medical tests for TS, instead diagnosis relies on observation and discussion of history, however, use of tests or investigative scans may be used to rule out other conditions. DSM-5 criteria proposed for tic disorders, including TS are displayed in table 2.

Table 2 *Diagnostic criteria for tic disorders proposed in DSM-5 [APA,2013].*

Name of Disorder	Diagnostic Criteria
Tourette Disorder	- Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently. - The tics may wax and wane in frequency but have persisted for more than 1 year since first tic onset. - Onset is before age 18 years. - The disturbance is not attributable to the physiological effects of a substance (e.g., cocaine) or another medical condition (e.g., Huntington's disease, postviral encephalitis).
Persistent (Chronic) motor or vocal tic disorder (Previously chronic motor/ vocal tic disorder)	- Single or multiple motor or vocal tics have been present during the illness, but not both motor and vocal. - The tics may wax and wane in frequency but have persisted for more than 1 year since first tic onset. - Onset is before age 18 years. - The disturbance is not attributable to the physiological effects of a substance (e.g., cocaine) or another medical condition (e.g., Huntington's disease, postviral encephalitis). - Criteria have never been met for Tourette's disorder. - Specify if: With motor tics only / with vocal tics only

Provisional Tic Disorder (Previously transient tic disorder)	- Single or multiple motor and/or vocal tics. - The tics have been present for less than 1 year since first tic onset. - Onset is before age 18 years. - The disturbance is not attributable to the physiological effects of a substance (e.g., cocaine) or another medical condition (e.g., Huntington’s disease, postviral encephalitis). - Criteria have never been met for Tourette’s disorder or persistent (chronic) motor or vocal tic disorder.
Other Specified Tic Disorder	This category applies to presentations in which symptoms characteristic of a tic disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for a tic disorder or any of the disorders in the neurodevelopmental disorders diagnostic class. The other specified tic disorder category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for a tic disorder or any specific neurodevelopmental disorder. This is done by recording “other specified tic disorder” followed by the specific reason (e.g., “with onset after age 18 years”).
Unspecified Tic Disorder	This category applies to presentations in which symptoms characteristic of a tic disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for a tic disorder or for any of the disorders in the neurodevelopmental disorders diagnostic class. The unspecified tic disorder category is used in situations in which the clinician chooses not to specify the reason that the criteria are not met for a tic disorder or for a specific neurodevelopmental disorder, and includes presentations in which there is insufficient information to make a more specific diagnosis.

Similarly, the International Classification of Diseases and Related Health Problems (11th ed; ICD-11; World Health Organisation [WHO], 2022) outlines criteria for the diagnosis of different tic disorders. The criteria for the diagnosis of TS in the recently updated ICD-11 highlights the same features as that in the DSM-5, shown in table 3. Previously, criteria outlined in the ICD-10 had not specified that symptoms would occur for a year prior to diagnosis and this change in the ICD-11 brings criteria more in line with those used by DSM-5 (Woods & Thomsen, 2014).

Table 3 *ICD-11 Criteria for diagnosis of TS [WHO, 2022].*

ICD-11 Criteria for diagnosis of TS
“Tourette syndrome is a chronic tic disorder characterised by the presence of both chronic motor tics and vocal (phonic) tics, with onset during the developmental period. Motor and vocal tics are defined as sudden, rapid, non-rhythmic, and recurrent movements or vocalizations, respectively. In order to be diagnosed as Tourette syndrome, both motor and vocal tics must have been present for at least one year, although they may not manifest concurrently or consistently throughout the symptomatic course.” (WHO, 2022)

The remainder of this thesis will focus purely on TS, as the most severe of the tic disorders, rather than the wider category of tic disorders. However, it is recognised that there may be significant overlap between experiences of individuals with TS and other tic disorders.

TS is a heterogenous condition with symptoms, severity and level of impairment varying between individuals (Cravedi et al., 2018). Given the diversity of manifestation of TS some literature has suggested TS can be divided into subtypes; these however are not outlined in the DSM-5 or ICD-11 diagnostic criteria. Three subtypes were suggested by Robertson and Baron-Cohen (2000):

- Pure TS: consisting of motor and vocal tics.
- Full blown TS: including coprophenomena, echophenomena, paliphenomena and self-injurious behaviours.
- TS plus: in which an individual also has another disorder, e.g. Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD) etc.

2.2.1 Challenges of Diagnostic Labels

There are arguments against using diagnostic labels for conditions such as TS, with some suggesting that the use of these labels increase stigma and are not always helpful in treatment decisions (Timimi, 2014). Johnstone (2018) argues that the use of diagnostic labels can lose the meaning of personal experiences prior to diagnosis, instead being seen only as a person with a disorder. There is also some controversy regarding arbitrary criteria related to tics, specifically the presence of multiple motor tics required for a diagnosis of TS according to the DSM-5 and ICD-11 is suggested to make the diagnostic criteria unnecessarily complex, with researchers suggesting ‘one or more motor tics’ as an appropriate criteria (Woods & Thomsen, 2014). As a condition, TS is agreed to be difficult to diagnose (Rivera-Navarro et al., 2009) and the common diagnoses of co-occurring conditions alongside TS presents challenges in disentangling symptoms of different conditions (Timimi, 2014).

However, counter arguments suggest that diagnostic labels have a function for families and professionals. Zinner (2004) suggested that a diagnosis of TS brings understanding and opportunities to begin to manage the condition, which can often come as a relief to an individual or family, particularly as the diagnosis process can be lengthy. It is also suggested that parents may view their child more favourably following diagnosis due to having a better understanding of their child’s behaviour (Fernald & Gettys, 1980). Similarly, Kuther (1994) suggests that within the education system diagnostic labels can assist in securing appropriate support, funding arrangements and better understanding from teachers and peers. A review of the lived experiences of individuals with TS reported a range of experiences of diagnosis including elation, acceptance and disappointment, suggesting diagnosis can be both a positive or negative experience for individuals (Smith et al., 2015). It has also been reported that the way in which the diagnosis is communicated is important in ensuring understanding through; sensitivity, avoiding clinical language and ongoing relationships with medical professionals involved in diagnosis (Rivera-Navarro et al., 2009).

The process of receiving a diagnosis of TS may impact the view an individual holds of themselves. Social Identity Theory suggests that an individual defines their own identity, at least partly, based on groups to which they belong (Tajfel, 1978). Following a diagnosis of TS, CYP with TS describe experiences of accepting TS as a part of themselves despite the negative effects it has on their lives, suggesting that without TS they wouldn’t be themselves (Cutler et al., 2009). In contrast, CYP with TS in research by Wadman et al. (2013) described experiencing TS as a component attached to the self rather than as integrating within the self-concept as a whole. In addition, Malli and Forrester-Jones (2021) reported that adults with TS, shared experiences of lower self-confidence and devaluing their own skills and abilities due to TS. This suggests that a diagnosis of TS may significantly impact an individual’s self-concept and self-efficacy.

2.3 Assessment of TS and tics

TS can present some challenges in diagnosis as there is no straightforward test to confirm TS. There are however a number of tools and instruments that have been developed to assess TS and tics. In a comprehensive systematic review of severity scales and screening instruments for tics Martino et al. (2017) identified 16 severity rating scales and 13 screening instruments. This systematic review concluded that the scales available were sufficient in providing the tools to explore tic severity (Martino et al., 2017). The Yale Global Tic Severity Scale (YGTSS) is the most widely used tool to assess tics and TS, commonly used in research to provide a measure of tic severity (Cohen et al., 2013); it is described to be the most comprehensive, reliable and valid instrument available (Martino et al., 2017).

2.4 Misconceptions Associated with TS

Public perception of TS is often influenced by easily accessible portrayals of the condition in media or fictional representations, with TS being referred to as the ‘cursing disease’ (Davis et al., 2004). Davis et al. (2004) described the stereotype associated with TS being perpetuated by media portrayals of TS as: disruptive to public order, over-representation of coprolalia and misunderstandings related to individuals’ control over tics. Zinner (2004) highlights the importance of changing the perception of TS through increased awareness, particularly in relation to the diversity of TS presentation between individuals.

Film and television are a common source of misinformation relating to TS. Analysis of the depiction of TS in 36 films and television programs concluded that these fictional portrayals misrepresented TS as a disorder (Calder-Sprackman et al., 2014). This research reported that incidents of coprolalia were over-represented as a tic and that individuals with TS were frequently depicted as experiencing symptoms often associated with Autism Spectrum Disorder (ASD) (Calder-Sprackman et al., 2014).

Additional research has considered how TS is depicted in YouTube videos, finding that 22% of videos posted online portrayed TS in a negative light with derogatory or depreciative content, while 20% were neutral and 59% presented a positive portrayal of TS (Fat et al., 2012). However, those videos portraying TS in a positive light were associated with reduced numbers of views and comments compared to the negative videos, suggesting these negative portrayals of TS had the opportunity to perpetuate negative stereotypes and stigma. Similar to findings from TV and film, YouTube videos were also found to over-represent coprolalia in individuals with TS, reinforcing this as a stereotype (Fat et al., 2012). In reality, coprolalia is only present in approximately 19% of males and 15% of females with TS (Freeman et al., 2009).

Research has suggested that these misconceptions of TS can have an impact on individuals diagnosed with the condition. Malli et al. (2019) reported on the personal experiences of adults with TS who shared concerns of being discriminated against and devalued based on negative group stereotypes of TS in society. These concerns may lead to Stereotype threat, a form of social identity threat, described by Steele et al. (2002) as occurring when “a negative stereotype about a group that one is part of becomes personally relevant” (p. 389). Social identity threat for individuals with TS is suggested to be linked with social withdrawal, increased anxiety and suppression of tics (Malli et al., 2019), demonstrating the impact that misconceptions and stereotypes can have on individuals.

2.5 Onset and Course of TS

As outlined in the diagnostic criteria, the onset of TS typically occurs in childhood. A review of literature by Robertson (2003) suggests the majority of research reports an average onset age of 6.7 years. However, the same review reports a range of 1-17 years of age, suggesting a large amount of variance in the figures reported in the literature (Robertson, 2003). In addition, it is reported that motor tics, such as eye blinking, tend to occur first, followed by vocal tics, at a mean age of onset of 9 years old. Complex tics, such as coprolalia, tended to have a later age of onset, reported at around age 15 (Robertson, 2003).

Following initial onset of TS, it is reported that symptoms typically worsen. Research reports that peak severity of TS symptoms is typically around 10 years of age (Hassan & Cavanna, 2012; Leckman et al., 1998). Following a peak in severity, symptoms of TS have a tendency to decline in adolescence (Leckman et al., 1998). Research suggested that by adulthood 75% of individuals with TS will have diminished symptoms while over 30% experience no TS symptoms in adulthood (Bloch & Leckman, 2009).

2.6 Prevalence of TS

Early estimation of prevalence of TS suggested it to be a rare disorder, reporting a prevalence of 0.005% (Burd et al., 1986). However, as more research is conducted it has become evident that TS is more common than previously estimated, with a large range of figures between 0.03%- 5.26% being reported in the literature (Knight et al., 2012; Robertson et al., 2009; Scharf et al., 2015). It is reported that TS occurs in all cultures where it has been explored and therefore the characteristics are reported to be independent of culture (Robertson & Baron-Cohen, 2000). Prevalence figures of TS within the UK also demonstrate variance, with research reporting estimates between 0.3-3.2% in UK school-aged populations (Mason et al., 1998). Despite the variance in prevalence figures reported in the literature a prevalence figure for TS of approximately 1% of CYP is commonly cited in research and medical information sources (e.g. Robertson et al., 2009; Great Ormond Street Hospital for Children [GOSH], 2018).

It is widely acknowledged in the literature that TS is more common in males than females. Research exploring gender differences in TS report a ratio of approximately 4:1 (Freeman et al., 2000; Robertson, 2008a). This gender difference is reported to be more prominent in children than adults with TS (Freeman et al., 2000).

Research has also explored the prevalence of TS in an adult population. A meta-analysis reported an estimate of 118 cases of TS per million adults (0.02%) (Levine et al., 2019). Similarly, Knight et al. (2012) reported a figure of 0.05% prevalence of TS in adults. This research is consistent with the reduction of TS symptoms in adulthood as reported in research exploring the course of TS (e.g. Leckman et al., 1998).

2.6.1 The Current Context

In the current context, as the impact of the global COVID-19 pandemic is being researched, there is an emerging body of literature exploring the impact on CYP with TS. There is a suggestion that during the pandemic in the UK there has been an increase in tic symptoms in CYP already diagnosed with tic disorders, including TS (Heyman et al., 2021). In addition, research suggests that symptoms of TS often increase with anxiety and stress (Eapen et al., 2004), and given the increased levels of anxiety and stress in CYP during the pandemic (Racine et al., 2020), it could be expected that TS symptoms may worsen.

There is also a growing body of literature exploring the use of social media and tics or TS. There has been a recent increase in social media content showing tics, with hashtags related to TS and tics growing in popularity. It is suggested that there are some similarities between the tics presented in this social media content and the presenting tics and symptoms experienced by CYP in clinics (Pringsheim et al., 2021). Although in the early stages of research several studies have reported on the impact social media has on the onset, or worsening, of tics (Heyman et al., 2021; Hull & Parnes, 2021; Pringsheim et al., 2021). Research has suggested that viewing tics on social media may trigger tics in the individual through modelling patterns of movement, and may reinforce and maintain tics through gaining a sense of belonging to a community and CYP may view tics as a catalyst to peer acceptance (Heyman et al., 2021; Hull & Parnes, 2021; Pringsheim et al., 2021). Some participants in this research suggested that onset of their tics occurred as a result of viewing specific social media content related to TS (Heyman et al., 2021; Pringsheim et al., 2021). Pringsheim et al. (2021) also recognised the increase in social media use of CYP during the COVID-19 pandemic as a factor in considering the recent increase in cases of tics and TS.

2.7 Comorbidities

TS is widely acknowledged to have common co-morbid or co-occurring conditions. Freeman et al. (2000) reported that around 88% of an international sample of individuals with TS reported at least one co-morbidity. Within this sample Freeman et al. (2000) reported a co-morbidity score of 2.06, representing an average of 2.06 additional disorders alongside TS. This co-morbidity score was reported to be significantly higher for male participants than females (2.11 vs 1.83) (Freeman et al., 2000). Hirschtritt et al. (2015) reported that the age of the greatest risk of onset for most comorbid psychiatric disorders for individuals with TS was between 4 to 10 years of age. However, eating disorders and substance use disorders had a later age of onset, occurring in adolescence (Hirschtritt et al., 2015).

Some gender differences in comorbidities have been reported, suggesting that females are more likely to experience major depressive disorder, self-injurious behaviours (SIB), anxiety and eating disorders (Freeman et al., 2000; Hirschtritt et al., 2015). Males, on the other hand, appear more likely to experience ADHD, oppositional defiant disorder (ODD) and learning difficulties (LD) and both genders have equal likelihood of OCD and sleep disorders (Freeman et al., 2000; Hirschtritt et al., 2015). Findings relating to gender differences lead to questions as to how these gender differences come about, whether males and females experience TS differently and if they are more likely to be labelled with specific disorders.

The most commonly reported comorbid conditions to occur alongside TS are ADHD and OCD (Hirschtritt et al., 2015), these are explored below. Other reported comorbidities and their estimated prevalence in individuals with TS are reported in table 4. As shown by prevalence figures in table 4, there is significant variance in prevalence figures reported for many co-morbid conditions.

Table 4 *Prevalence of common co-morbid conditions.*

Co-morbid disorder	Estimated prevalence of comorbidity in individuals with TS
Autism Spectrum Disorder (ASD)	23% (Darrow et al., 2017)
Mood disorders	20% (Freeman et al., 2000) 29.8% (Hirschtritt et al., 2015) Depressive symptoms – 13-76% (Kumar et al., 2016)
Anxiety	18% (Freeman et al., 2000) 36.1% (Hirschtritt et al., 2015)
Sleep disorders	16-25% (Freeman et al., 2000) 65% (Ghosh et al., 2014)
Learning difficulties	23% (Freeman et al., 2000) 51% (Burd et al., 1992)
Self-injurious behaviours (SIB)	14% (Freeman et al., 2000)
Rage Attacks	25-75% (Kumar et al., 2016)
Migraine	25% (Kwak et al., 2003)

2.7.1 TS and ADHD

ADHD is characterised by difficulties in focussing attention, hyperactivity and impulsivity (Furman, 2005). ADHD is commonly cited as the most common co-morbid condition for individuals with TS. Freeman et al. (2000) reported that in an international sample of 3,500 TS patients in a clinic, 60% also reached diagnostic criteria for ADHD. Similar rates of ADHD prevalence in individuals with TS have been reported consistently in the literature with percentages falling between 54–61% (Freeman & Tourette Syndrome International, 2007; Hirschtritt et al., 2015; Scharf et al., 2013). It is reported that ADHD symptoms tend to precede TS symptoms by around 2-3 years (Kumar et al., 2016). Comorbid ADHD is reportedly associated with an earlier diagnosis of TS, anger problems, sleep difficulties as well as other comorbidities (Freeman & Tourette Syndrome International, 2007).

2.7.2 TS and OCD

OCD is characterised by recurrent obsessive thoughts images or impulses alongside compulsions which are purposeful, deliberate and often repetitive (Stein, 2002). Hirschtritt et al. (2015) reported that around 50% of a sample of individuals with TS also had OCD. Other research has reported similar figures of OCD comorbidity at 42% (Scharf et al., 2013), while Eddy and Cavanna (2014) reviewed prevalence from various studies falling between 28-63%. There is also research which provides evidence for a strong aetiological link between TS and OCD, with similar findings relating to genetics and neurophysiological factors (Eddy & Cavanna, 2014).

3.0 Aetiological Theories of TS

The aetiology of TS is complex and there is a large body of literature, particularly in the medical field, in this area. Despite this, Seideman and Seideman (2020) argue that the data regarding causes of TS is insufficient to identify exact causes of the condition. Research has explored TS from a range of theoretical perspectives, including biological, psychodynamic, behavioural and environmental approaches. Consideration of all aetiological theories of TS is beyond the scope of this review, however key areas of research suggesting evidence for biological, psychological and environmental theories are outlined in table 5.

Table 5 *Summary of Aetiological Theories of TS.*

Summary of Aetiological Theories of TS		
Biological	Genetic factors	- Higher concordance rates of TS in monozygotic (52%) compared to dizygotic (8%) twins (Price et al., 1985). - Segregation analysis research suggests evidence for single gene with autosomal dominance inheritance (Curtis et al., 1992; Pauls & Leckman, 1986). - Linkage analysis has identified a single gene mutation associated with TS (Ercan-Sencicek et al., 2010). - Evidence of cytogenetic abnormalities in 3 regions associated with TS (O'Rourke et al., 2009).
	Neurophysiological	- Differences in the basal ganglia region of the brain (Peterson et al., 2003). - Differences in the caudate nucleus, with degree of abnormality correlating with tic severity (Moriarty et al., 1997). - Differences in fronto-striatal regions of the brain (Müller-Vahl et al., 2009). - Cortical thinning in premotor and sensorimotor areas associated with simple tics and cortical thinning in premotor, prefrontal and parietal associative areas linked to complex tics (Worbe et al., 2010). - Differences in dopamine system (Maia & Conceicao, 2018).
	Infections	- Streptococcal infections increase risk of TS (Mell et al., 2005).
Psychological	Psychodynamic	- Tics resulting from repressed desires (Ferenczi, 1921). - Tics as a result of Psychosexual disturbances (Mahler & Rangell, 1943). - Tics, specifically echolalia and coprolalia, described as an expression of supressed attitudes, typically toward a parent. (Ascher, 1948).
	Behavioural	- Tics as a learned behaviour (Yates, 1958). - Tics as an operant response (Rosen & Wesner, 1973).

	Cognitive	- Emotional states, such as stress, increase TS symptoms (Eapen et al., 2004; Findley et al., 2003).
Environmental	Pre, peri and post natal risk factors	- Maternal stress and smoking increase risk of TS (Motlagh et al., 2010). - Older paternal age is linked to TS (Burd et al., 1999). - Birth complications increase risk of TS and increase tic severity (Bos-Veneman et al., 2010). - Low birth weight and maternal smoking or medication use linked to TS (Mathews et al., 2006).
	Family and lifestyle factors	- Nuclear families and poorer parental relationships are risk factors for TS (Zhu et al., 2020). - Frequent changes in primary caregiver and fewer children in the family are linked with TS (Hong et al., 2013).

In addition to aetiological theories of TS from various perspectives there are models which consider the impact of multiple factors. The Comprehensive Integrated Model of TS described by Woods et al. (2007) considers the neurobiological factors associated with TS alongside the external and internal environmental factors influencing tic expression in TS. This model suggests that premonitory urges which often precede tics exist due to genetic and neurobiological factors, and that the frequency, form and intensity of tics are influenced by environmental factors (e.g. emotional states, reinforcing factors) (Gagné, 2019). Support for this model from Robertson (2008b) suggested that the interactions between different causal mechanisms account for the heterogeneity seen in TS.

4.0 Treatment/ Management of TS

As a long-term condition, there is no cure for TS, although as previously discussed the symptoms do often reduce or disappear into adulthood (Leckman et al., 1998). Given the absence of a clear aetiology of TS, treatment and management tends to focus on the symptoms experienced rather than the cause. There is however a suggestion that as understanding of biological mechanisms increases and the causes of tics in TS are better understood, treatment options are likely to evolve towards disease modification rather than be based on reducing symptoms (Dale, 2017). Kurlan (2014) recognised the importance of finding appropriate management or treatment based on severity of TS, suggesting education about TS and counselling may be sufficient for individuals experiencing mild tics while further treatment aiming to reduce TS symptoms may be required for those with disabling tics. It is key in the management and treatment of TS to ensure the individual with TS and the family are informed and involved in the process (Holman & Lorig, 2000). It is also important to consider co-morbidities in treatment plans for TS, where priorities are often based on functional impairment.

As with discussion of aetiological theories, a comprehensive review of research exploring treatment for TS, particularly in the medical field, is beyond the scope of this review. However, key biological and psychological treatments are discussed below.

4.1 Biological Treatments

There is a vast body of medical literature exploring medication as a treatment option for individuals with TS, a summary of common TS medication is presented in table 6. The NHS states that medication is usually only recommended for TS in cases in which tics are more severe or are impacting day-to-day activities (NHS, 2021). It has been suggested that males are more likely than females to receive medication for tics (Freeman et al., 2000). The common co-morbidities of TS can add to the complexity of treating TS as some medication used to treat symptoms of one disorder may worsen symptoms of TS. For example, use of methylphenidate, a stimulant prescribed to treat ADHD, has been suggested to worsen tics for an individual with TS (Carroll & Robertson, 2000).

Table 6 *Summary of medications used in treatment of TS.*

Class of medication (examples)	Biological mechanisms	Advantages	Disadvantages	References
Neuroleptics (Haloperidol, Pimozide, Fluphenazine)	Block dopamine receptors.	78-91% reduction of tics.	Side effects: sedation, depression and increased appetite	Eddy, Rickards et al. (2011) Kurlan (2014).
Atypical antipsychotic medications (Risperidone, Clozapine, Olanzapine)	Selective dopamine receptor D2 blockers and can also impact serotonin levels.	Fewer side effects than neuroleptics whilst maintaining similar levels of effectiveness.	Side effects: weight gain and fatigue.	Eddy, Rickards et al. (2011)
		Improvements of co-morbid symptoms including obsessions and compulsions, aggression and ADHD symptoms.	High rates of discontinuation	
Alpha adrenergic agonists (Clonidine, Guanfacine)	Act on noradrenaline.	Can improve other symptoms often experienced by individuals with TS.	Effects from use of alpha adrenergic agonists is generally lower than neuroleptics.	Kurlan (2014). Leckman et al. (1991) . Eddy, Rickards et al. (2011)
		Useful for patients who do not reach the high threshold of tic severity suggested for use of neuroleptics.	Response can vary significantly between patients	
		Few side effects.		

Research has found evidence for the use of neurosurgical techniques in treating TS. Specifically, deep brain stimulation (DBS) which involves implanting electrodes in specific target structures within the brain to deliver electricity which intervenes with neural circuits (Lozano et al., 2019). Research has shown some improvement in reduction of tics for patients with severe tics following DBS (Visser-Vandewalle & Kuhn, 2013). However, research in this area is relatively limited and the best practices for optimal location of electrodes within the brain and patient selection are yet to be established (Kurlan, 2014). Guidelines for use of DBS for TS, alongside comprehensive inclusion and exclusion criterion for DBS demonstrate that this form of treatment is used only for a small proportion of individuals with more severe cases of TS, for which other treatment options have proved ineffective (Schrock et al., 2015).

Finally, Botulinum Toxin A (BTX) injections, involving the intramuscular injection of BTX into the site of problematic tics are suggested for some patients with TS. Research into this treatment has suggested that not only are BTX injections effective in reducing the tics but also the premonitory urges often associated with tics (Kwak et al., 2000). Research into use of BTX injections in a range of injections sites reported an average effect of 2.8, rated on a 0-4 self-report scale (Kwak et al., 2000), however other research suggested limited evidence for the effectiveness of this treatment (Pandey et al., 2018).

4.2 Psychological Treatments

4.2.1 Psycho-education

Often the first form of TS management following a TS diagnosis involves psycho-education, educating the individual with TS and those around them about TS, the associated behaviours and tics as well as supportive reassurance (Carroll & Robertson, 2000). Kurlan (2014) suggests that a key focus while working with children diagnosed with TS should be on self-esteem and self-confidence. As previously discussed TS may impact an individual’s self-concept and therefore psycho-education may be important in the acceptance and understanding of the condition. Psycho-education also extends beyond the family, with leaflets, fact sheets and information often being shared with school staff, classmates and other key people involved in the life of the individual with TS (Carroll & Robertson, 2000). Psycho-education provided to the people around an individual with TS is suggested to improve knowledge of TS, attitudes and behaviours towards the individual with TS (Nussey et al., 2013). However, research has suggested that psycho-education does not show any improvements to tic symptoms or quality of life measures (Rizzo et al., 2018).

4.2.2 Psychotherapy

Psychosocial interventions have been designed with the aim to go beyond a target of reducing tics and focus on wellbeing of individuals with TS. For example, a cognitive behavioural intervention known as ‘Living with Tics’ described by McGuire et al. (2015) included sessions on emotions, psycho-education, coping strategies, problem solving as well as training for parents. The ‘Living with Tics’ intervention was found to increase child-reported quality of life as well as tic-related impairment (McGuire et al., 2015). This suggests that therapeutic approaches for management of TS can go beyond simply reducing tics and consider the psychosocial impact of TS to improve overall wellbeing.

4.2.3 Behavioural Therapy

Behavioural therapies for TS focus on reducing the tics that individuals experience. Premonitory urges play an important role in any behavioural therapies and learning to recognise and adapt responses to the urges can lead to reduction in tics (Capriotti & Woods, 2013). These therapies require commitment and motivation from the individual with TS. Critics of behavioural therapies for TS suggest that the focus required to monitor and adapt responses to urges and tics may detract from an individual focussing attention on other tasks, such as school work (Kurlan, 2014).

Behavioural therapies known as Habit Reversal Training (HRT) and Comprehensive Behavioural Intervention for Tics (CBIT) have the most empirical evidence in reducing tics (Capriotti & Woods, 2013). HRT for TS typically involves increasing awareness of tics, particularly the premonitory urges and signs that occur before a tic. Competing-response training then focusses on performance of a voluntary response which is incompatible with the tic, thus interrupting the negative reinforcement cycle (Piacentini et al., 2010). In addition to the habit reversal process, CBIT includes relaxation training and works to identify antecedents influencing tic severity (Piacentini et al., 2010). A 10-week course of CBIT was reported to reduce tic severity, measured using the YGTSS, by 7.6 points, compared to a 3.5 decrease in a control group (Piacentini et al., 2010). However, a recent review of behavioural therapies targeting TS suggested that further research in this area is necessary to further understand the efficacy and mechanisms underlying this treatment (Liu et al., 2020).

An alternative behavioural therapy, Exposure and Response Prevention (ERP), relies on building an individual's ability to suppress tics in order to reduce tic severity. The treatment process involves practice in suppressing all tics, focusing on premonitory urges to be able to interrupt the reinforcement cycle and suppress tics before they occur (Essoe et al., 2019). ERP has been found to be effective in reducing tic severity and frequency in the short term (Verdellen et al., 2004) however, further research to explore the long term efficacy of ERP is needed (Essoe et al., 2019).

5.0 TS and the Influence of Systems

Many treatment or management options for TS view the condition through a medical lens which views tics and symptoms of TS as a deficiency which needs to be addressed in order for an individual with TS to function in society (Malli & Forrester-Jones, 2021). However, the influence of interactions, discrimination and exclusion experienced by individuals with TS, often driven by stereotypes and misconceptions, can have a significant impact on the social experiences of individuals with TS and their quality of life (Malli & Forrester-Jones, 2021). This suggests that viewing TS through a systemic lens may be beneficial in exploring the influences and factors surrounding an individual with TS.

Bronfenbrenner’s Ecological Systems Theory places the child in the centre of the model but also highlights the role and impact of reciprocal relationships with the world around the child on their development (Bronfenbrenner, 1979). The diagram below (figure 1) depicts the levels of interaction as described by Bronfenbrenner (1979). Table 7 gives examples of various influences which may surround a CYP with TS.

Figure 1 *Diagram of Bronfenbrenner's Ecological Systems Theory.*

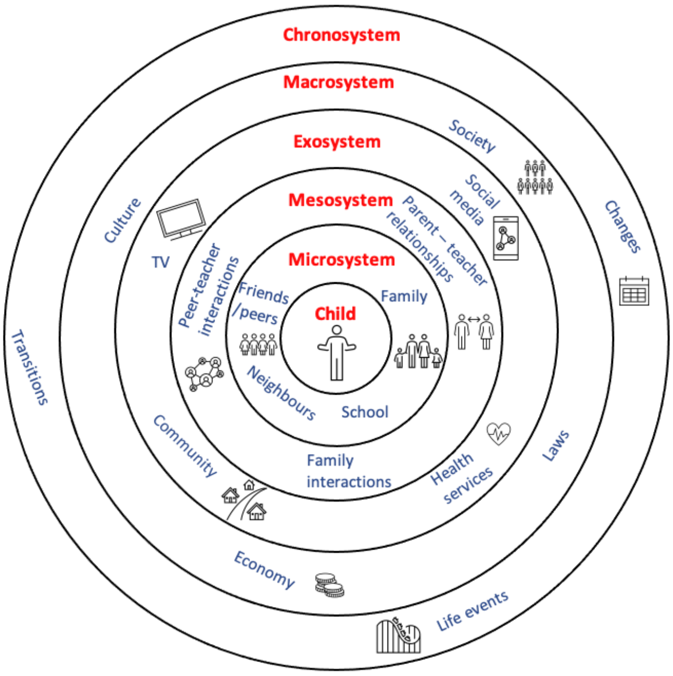

Table 7 *Examples of systemic influences on a child with TS based on Bronfenbrenner's Ecological Systems Theory (1979.)*

Child	Health (impact of tics)
Microsystem	Family (support for TS) School (recognition of TS and support) Peers (acceptance of TS)
Mesosystem	Interaction between parents and school (advocacy) Interactions between family members
Exosystem	Social media (representations of TS) Health systems (policies related to TS) Neighbourhood (acceptance and understanding of TS in the community)
Macrosystem	Culture Society (stereotypes and understanding of TS in society) Legislation Economy (funding for support for TS)
Chronosystem	Changes to TS symptoms over time

Dowling et al. (2003) discuss the importance of considering the family and school systems (microsystems) in supporting CYP, with particular value being placed on a joint systems approach requiring communication between systems (mesosystem). Specifically, it is important to consider the cultures, values, rules and boundaries of each system to establish successful joint approach to support (Dowling et al., 2003).

Dolowitz (2014) explored school experiences of learners with TS, considered alongside Bronfenbrenner's ecological theory, and reported that CYP with TS experienced internal difficulties due to TS symptoms but also difficulties related to external interactions, such as with peer and teachers. This suggests that the wider systemic context is an important factor to consider in exploration of experiences of CYP with TS. Dolowitz (2014) also reported that imbalances within or between components of a system can impact the learning and wellbeing of CYP with TS. The changeable nature of TS, with waxing and waning of symptoms over time (chronosystem) could be considered to disrupt homeostasis of systems and require continual adaptation and adjustments for parts of the system, which is likely to include both family and school (Dowling et al., 2003).

6.0 Difficulties Associated with TS in School

There is a large body of literature that considers the difficulties that CYP with TS face. As with much of the research on TS there are challenges in disentangling the difficulties which are associated with TS to those that are associated with the many common co-occurring conditions. Although this review will consider a range of difficulties CYP with TS experience there will be a focus on those which may impact their schooling. Research has explored this topic by gathering views of school staff, parents and CYP with TS, all of which are included in this review.

Some research has explored the differences between challenges for CYP with TS at home and at school as reported by their parents and teachers (Christie & Jassi, 2002). Teachers' mean scores on a behaviour checklist were consistently lower than scores reported by parents, suggesting more of these behavioural challenges were seen at home in comparison to school (Christie & Jassi, 2002). Similarly, Wadman, Glazebrook, Beer, et al. (2016) reported that school staff tended to report fewer TS-related difficulties for CYP compared to parents and the CYP themselves. In addition, parents reported higher concerns overall, whilst attentional difficulties were rated as the highest area of concern by both parents and teachers (Christie & Jassi, 2002). The suggestion that teachers and parents have different views of TS in CYP, may be due to the difference in relationships but may also be related to CYP suppressing some TS symptoms in school environments (Sasnett, 2008). From a systemic perspective a difference in TS presentation in various systems may be to expected, given the differences in rules, expectations and interactions within different systems and how these may influence CYP (Dowling et al., 2003). Differences between parental and school views or opinions about CYP with TS have been reported to be a potential source of conflict (Christie & Jassi, 2002). Specifically, parents highlight disputes within the family or with schools about managing TS, particularly in distinguishing between TS symptoms and misbehaviour (Cooper & Livingston, 2003).

Research has suggested that TS can have a significant impact on various areas of CYP's functioning in school. It is however important to note that the heterogenous nature of TS requires each individual to be considered independently and not all

CYP with TS will experience difficulties in school. Generally, it has been suggested the impact that TS has on school functioning can be a significant factor in the lives of CYP with 46% of a sample of CYP with TS being found to have school-related problems (Abwender et al., 1996). Similarly, Storch, Lack, et al. (2007) found that 49% of a sample of CYP with TS were reported to have at least one significant problem at school, with 39% having at least one significant problem at home and 42% having at least one significant problem with social activities. Parents reported the highest levels of impairment for school activities as concentration, homework, preparedness, exams, writing and friendships (Storch, Lack, et al., 2007).

6.1 Impact on Family

As previously mentioned, CYP with TS may attempt to suppress tics when outside of the home, this however can lead to a build up at home which may undoubtedly impact the wider family (Sasnett, 2008). Some of the impacts on families of CYP with TS include impact on mental health, financial hardship, family relationships and daily functioning of the whole family (Sasnett, 2008). A Canadian survey considered the impact on families where at least one family member had TS and suggested that 58.5% of participants felt that TS impacted the rest of the family’s day-to-day activities to some extent or a great deal (Hubka et al., 1988). Parents reported that accurate information, particularly at diagnosis was beneficial in being able to manage TS at home, explain TS to others and maintain a better balance within the family (Khoury, 2015).

It has also been suggested having a child with TS can create specific challenges and vulnerabilities for parents. Sasnett (2008) reported on the lived experiences of parents of CYP with TS and found that parents at times felt concerned witnessing tics, found some TS symptoms difficult to manage and reported being the victims of specific tics their child experienced, such as hitting or unkind words directed towards them. Parents of CYP with TS have also been reported to be at higher risk of psychiatric morbidity when compared to parents of CYP with Asthma (Cooper & Livingston, 2003).

6.2 Quality of life

CYP with TS have been reported to have poorer quality of life compared to controls in research using the youth quality of life instrument and clinical scales (Eddy, Rizzo et al., 2011). Specifically CYP with TS had more challenges in relation to home, social activities and relationships than controls (Eddy, Rizzo et al., 2011). Eddy, Rizzo et al. (2011) also reported that CYP with more severe tics and diagnosed co-morbidities had a poorer quality of life.

6.3 Homework

Homework was highlighted by 37% of parents as a challenge for their child with TS (Storch, Lack, et al., 2007). Parents suggested that challenges related to homework included CYP forgetting about the tasks, or tics, frustration and exhaustion making it difficult to do these tasks at home (Christie & Jassi, 2002). Parents also reported that they themselves experience challenges in trying to encourage their child to complete homework and committing the time to support them with homework tasks (Sasnett, 2008). In addition, school data suggests that CYP with TS are more likely than controls to not complete homework tasks (Claussen et al., 2018).

6.4 Peer Difficulties

Peer difficulties are commonly cited as a challenge for CYP with TS, particularly in schools. In a survey, 48% of parents of CYP with TS reported that their child’s tics had a moderate to severe impact on peer relationships, this included tic-related teasing and peer rejection (Packer, 2005). In addition, research described the lived experiences of parents of CYP with TS “mourning the absence of normal social relationships and social/ emotional development in their child” (Sasnett, 2008, p. 100). Dolowitz (2014) reported that a majority of CYP with TS in their research had experiences of negative peer interactions and that these led to feelings of marginalisation and negative self-esteem.

Levels of peer victimisation have been reported to be higher for CYP with TS, compared to CYP with type one diabetes and healthy controls, in addition, there was a correlation between tic severity and levels of peer victimisation reported (Storch, Murphy, et al., 2007). Similarly, Bawden et al. (1998), reported that CYP with TS were at risk of poorer peer relationships than their classmates, however this research found no significant association between relationships and tic severity. Interviews with CYP with TS, their parents and school staff also suggested that peers reacted negatively to tics, with mimicking and teasing being reported by parents and CYP (Wadman, Glazebrook, Beer, et al., 2016). In contrast, school staff reported fewer difficulties with peer relationships, suggesting teasing or name-calling tended to occur when staff were not present and may not be reported to school staff (Wadman, Glazebrook, Beer, et al., 2016). A large proportion of parents reported that their child with TS had been subject to discrimination, with 75% reporting that they were treated differently (Conelea et al., 2011). CYP with TS report that they feel they need to supress tics in order to be accepted by peers and avoid victimisation (Dolowitz, 2014). A systematic review suggested that there was a stigma present towards CYP with TS and that this stigma can have an impact on the wellbeing of CYP with TS (Malli et al., 2016).

Research has also explored the perspective of the peers, videos of children showing TS symptoms was rated less favourably than videos of children showing no TS symptoms (Friedrich et al., 1996). Similarly, Malli and Forrester-Jones (2017) conducted a free writing task and focus groups with CYP, findings suggested they would avoid social interaction with CYP with TS, due to fears of “social contamination” (p. 293). They also viewed people with TS as deserving pity and in need of support. CYP in this research were found to have misconceptions about TS, perpetuated by stereotypes portrayed in the media (Malli & Forrester-Jones, 2017).

In contrast, some positive friendships were described by CYP interviewed by Wadman et al. (2013), with four of the six participants describing close friendships, which provided a source of support for the participants. However, participants also described friendships becoming easier as they grew older and developed coping strategies for their TS. All participants also felt that TS overall had a negative impact on their social interactions, with unfamiliar people and large crowds being a particularly challenging environment (Wadman et al, 2013).

6.5 Handwriting

It is reported that CYP with TS often have difficulties with handwriting. Research using the Test of Handwriting Skills-Revised (THS-R), found around 80% of handwriting samples by CYP with TS scored below the 50th percentile (Simpson et al., 2020). CYP with TS were also more likely to make substitution errors and took longer to complete the handwriting task (Simpson et al., 2020). In self-report research 42% of parents of CYP with TS mentioned handwriting in an open-ended survey question about the impact of TS in school (Packer, 2005). In some cases, motor tics can have a direct impact on handwriting, this may include repeating letters or words, outlining letters multiple times and sudden hand movements while writing. Handwriting tics were reported in 40% of a sample of 66 individuals with TS (Dina et al., 2016).

6.6 Academic outcomes

In terms of academic attainment, Conelea et al. (2011) reported that parents typically rated academic impairment in their children with TS as mild to moderate. CYP with TS themselves have described decreased academic performance due to the debilitating impact of tics they experience (Dolowitz, 2014). A large scale study found that in comparison to a non-TS sample, those with TS were less likely to complete secondary school and to start or complete a university degree (Pérez-Vigil et al., 2018). In addition, research by Claussen et al. (2018) reported that students with TS in the US were more likely to have an Individual Education Plan (IEP), not complete homework and have a parent contacted about school problems. Similar findings have been reported from the UK with CYP with TS being significantly more likely to have a statement of Special Educational Needs (SEN) compared to the whole school population (Hornsey et al., 2001). In addition, longitudinal research has suggested a link between tic disorders, such as TS, and poor academic performance, however, it also suggested that recognition and appropriate management of tic disorders and co-morbidities can have a positive impact on academic performance (Cubo et al., 2017).

6.7 Exploration of Cognitive Functioning

Research using cognitive assessment to explore IQ scores of TS and non-TS CYP reported that participants with TS scored a mean IQ of 92.9, which is lower than the general population average of 100 as well as scores obtained by a control group (Debes et al., 2011). It was further suggested that these differences in IQ scores could not be accounted for by co-morbid ADHD, OCD or the presence of tics (Debes et al., 2011). However, additional research in this area presents conflicting evidence, suggesting that individuals with TS scored within average range on verbal and performance IQ (Brand et al., 2002). Additionally, Brand et al. (2002) reported that individuals with diagnoses of both TS and ADHD scored lower on several measures, including IQ, psychosocial functioning and word fluency, this highlights the challenge of research in this area given the complex nature of co-morbidities and the range of presentations of TS.

6.8 Learning

Despite conflicting evidence regarding impact of TS on cognitive skills, literature consistently recognises the impact that TS had on learning for CYP in schools. In interviews with CYP with TS it was reported that TS makes schoolwork more challenging, reasons for this included writing, reading, attention, homework and exams (Wadman, Glazebrook, Beer, et al., 2016). Challenges within the classroom for CYP with TS may include increase in tics due to time pressure, difficulties copying from a board, tic-related interference with reading and writing (Packer, 2005). It is reported that 23% of CYP with TS in a large sample also had a diagnosed learning disability (Burd et al., 2005), highlighting the commonality of other complexities and co-occurring conditions present in CYP with TS which will undoubtably influence learning.

6.9 Attention/concentration

CYP with TS reported concentration and attention as one of the biggest challenges faced in schools (Wadman, Glazebrook, Beer, et al., 2016). Parents and school staff also reported concentration as a challenge for CYP with TS, with 66% of parents and 51% of school staff reporting this difficulty (Wadman, Glazebrook, Beer, et al., 2016). In addition, CYP themselves reported that tics, as well as efforts to suppress tics, can be distracting during school (Edwards et al., 2017). Research has recognised a relationship between attention difficulties and academic attainment in CYP (Rabiner et al., 2016), suggesting that attention difficulties experienced by CYP with TS are likely to have a wider impact on their school performance.

6.10 Emotions

Wadman, Glazebrook, Beer, et al. (2016) discussed challenges of TS in schools with parents, school staff and CYP and report TS can make managing emotions challenging in school. Wadman, Glazebrook, Beer, et al. (2016) stated that stress and anxiety were often reported by the CYP, parents and school staff and that the most commonly reported sources of stress and anxiety were about letting tics out, completing schoolwork and exams. CYP also reported that they became angry easily in school leading to aggressive behaviour, which they felt was a result of TS (Wadman, Glazebrook, Beer, et al., 2016). Additional research considering the views of CYP with TS, found similar difficulties with emotions, including anxiety about tics in front of peers, embarrassment and depression from difficulties at school (Edwards et al., 2017).

6.11 Physical Symptoms

CYP with TS often report discomfort as a result of tics, this may include muscle aches, pain and fatigue (Edwards et al., 2017). Chronic pain due to severe tics has been reported to interfere with learning for CYP with TS (Claussen et al., 2018). Pain for CYP with TS may arise from the repeated performance of specific tics, self-injurious tics or due to suppression of tics (Riley & Lang, 1989). There are also specific physical tics which may interfere with specific areas of learning, for example, eye-movement tics are reported to have an impact on reading (Packer, 2005).

Physical side effects from medication taken to reduce tics have also been suggested to impact the functioning of CYP with TS in schools (Packer, 2005). Some side effects reported in CYP with TS taking medication for the condition include drowsiness, depression, increased appetite, fogginess and restlessness (Robertson, 2000). In addition, some research has suggested that neuroleptic pharmacological treatments, often used for CYP with TS, can cause onset of a specific variant of school phobia termed ‘neuroleptic separation anxiety syndrome’ (Linet, 1985).

7.0 Support in school for CYP with TS

Given the range of difficulties that CYP with TS may face in school, specific strategies may be necessary to ensure that they are supported appropriately in school. Tics and other symptoms of TS can vary significantly between each individual with TS and therefore it is likely to be helpful for each individual to be considered using a person-centred approach to ensure appropriate individualised support is put in place. Sulkowski et al. (2016) commented that not all CYP with TS will require intervention in school, however this should be considered when tics or TS interfere with academic progress, participation in activities, peer relationships or self-esteem.

CYP may have their needs formalised in a statutory statement of SEN, however in many cases the support put in place will be on an informal basis as decided by school staff. Approximately 72% of CYP with TS reportedly have strategies or accommodations of some kind in place at school specifically for tics (Packer, 2005). The importance of support for CYP with TS in school was recognised by their parents in research by Ludlow et al. (2018), parents reported the need for a balance of appropriate support whilst not singling out a student as being different. There is some suggestion in the literature that parents of CYP with TS are not always satisfied with support in schools; Shady et al. (1988a) reported than 50.7% of respondents with TS in their Canadian survey reported that they felt school could take steps to improve the situation.

7.1 Home- school relationships

Research by Wilson et al. (2003) indicated that parents, students and school staff agreed that regular three-way communication is important for satisfaction in education. However, there is some suggestion that parents may have some reluctance and anxiety about discussing their child’s TS with teachers. In research by Wilson et al. (2003) parents suggested that they didn’t want to be seen as a burden or that they wouldn’t be believed regarding difficulties when approaching school staff. Similarly, parents of CYP with TS in research by Ludlow et al. (2018) suggested that although the communication with school was important, there was also frustration at the number of meetings required and feelings that agreed actions were not always followed through by the school. Likewise, qualitative research by Sasnett (2008) reported on the lived experiences of parents of CYP with TS and reported that they made special efforts in communicating with schools but were often frustrated when attempting to organise appropriate support in school. Parents shared experiences of advocating for their child in the school setting (Sasnett, 2008), this included requesting adjustments to school support, educating school staff about TS and informing staff about issues that occur in school for their child.

7.2 Learning support for CYP with TS

There are many strategies which could be implemented to support the learning of CYP with TS. Appropriate strategies would need to be considered based on specific difficulties a child experiences with their learning. Some strategies suggested to be useful in supporting CYP with TS include; adjustments to classwork, homework and examinations, use of teaching assistants and a reduced or individualised timetable (Wadman, Glazebrook, Parkes, et al., 2016). In addition, specific accommodations such as use of word processor and reducing the amount of handwriting were suggested as useful strategies to reduce pressure on writing for CYP with TS who found this difficult (Packer, 2005).

7.3 Social Emotional support for CYP with TS

Social and emotional support strategies suggested by school staff to support TS included providing a key worker and supporting social relationships though social skills groups and buddy systems (Wadman, Glazebrook, Parkes, et al., 2016). US research highlights the role of the school psychologist in planning and implementing social and emotional support strategies (Walter & Carter, 1997), suggesting input from additional professionals may be beneficial for CYP with TS.

Counselling in schools has also been reported as a useful strategy in supporting CYP with TS experiencing social and emotional difficulties. However, literature suggested that this is not commonly available to CYP with TS, with 60% of a sample of parents of CYP with TS reporting that this had not been offered (Packer, 2005). In addition, group work with a group of CYP with TS has been suggested to be beneficial in managing tics, building self-esteem, learning, bullying and management of emotions (Murphy & Heyman, 2007). It has been suggested that use of group interventions such as these may be useful in school settings, however practical implications of this would require additional consideration (Sulkowski et al., 2016).

7.4 Knowledge of TS

In a survey of parents of CYP with TS Shady et al. (1988) reported that 70% of participants rated school staff as not at all knowledgeable, while only 4% rated them as very knowledgeable about TS. This research was conducted in Canada over 30 years ago so may not be an accurate representation of current school staff knowledge of TS in the UK. However, recent qualitative findings from the UK, provide support to this view suggesting that school staff have a limited knowledge of TS (e.g. Ludlow et al., 2018; Wadman, Glazebrook, Beer, et al., 2016).

In addition, peer knowledge of TS in school has also been highlighted as a challenge for CYP with TS in school. Lack of understanding of TS and tics can lead to increased teasing, fear of tics and bullying (Kepley & Conners, 2007), therefore, peer education programs are commonly recommended to improve understanding of tics and TS in schools. These can be effective in increasing knowledge, positive attitudes and behaviour towards individuals with TS (Nussey et al., 2013). It was highlighted that disclosure of a pupil having TS was a key component in changing behaviour towards them following a peer education intervention (Nussey et al., 2014). However, Kepley and Conners (2007) emphasise that care is required in planning and delivering this session as occasionally CYP may use the information provided, such as triggers for tics, against the CYP with TS. In a sample of parents of 71 CYP with TS, only 13% of the sample reported any peer education to have taken place within school to educate peers about TS (Packer, 2005). Research involving interviews with CYP with TS themselves also highlighted the importance of educating peers about TS as an important coping strategy (Edwards et al., 2017).

It is reported that limited understanding of TS in schools can lead to inappropriate or unhelpful responses to tics from both staff and other students in school (Wadman, Glazebrook, Beer, et al., 2016). Raising awareness and understanding of TS in schools is commonly cited in the literature as a key component in providing appropriate support for CYP with TS in schools (Ludlow et al., 2018; Sasnett, 2008; Wadman, Glazebrook, Beer, et al., 2016; Wadman, Glazebrook, Parkes, et al., 2016).

7.5 Support from teachers

CYP with TS suggested that an empathetic and patient approach from teachers, in trying to understand how TS impacts the CYP and how they experience school would be beneficial (Wilson et al., 2003). Grace and Russell (2005) stated that the attitude of the teachers and a tolerant classroom were essential factors in ensuring CYP with TS could have positive school experiences. Similarly, other literature has suggested that teacher characteristics valued by CYP with TS and their parents include flexibility, understanding, sensitivity and compassion (Grace & Russell, 2005; Wilson et al., 2003).

In contrast, research has also highlighted some of the reactions to TS by teachers which have been found to be unhelpful for CYP with TS, this included being disciplined for tics or being told not to tic, lack of understanding and shouting (Wadman, Glazebrook, Beer, et al., 2016; Wilson et al., 2003). Distinguishing between TS symptoms and ‘naughtiness’ has been described as a challenge for school staff, with increased knowledge of TS and collaboration with parents being useful in supporting understanding to make this easier (Grace & Russell, 2005). These responses from staff may be a result of an attributional error, with staff misattributing negative behaviours as intentional acts rather than a result of involuntary tics.

7.6 Classroom Based Support

In addition to approaches used by school staff, adaptations to school classrooms can be made to ensure they are best suited for CYP with TS. Thomas et al. (2013) suggested that CYP with TS benefit from a learning environment which feels emotionally safe, respect for all students is promoted and has predictable rules and expectations with a degree of flexibility. Similarly, Grace and Russell (2005) suggest that flexibility and responsiveness to individual needs in the classroom are important. Specific classroom accommodations may include; preferential seating, reduction in homework, permission to leave the classroom when needed, support from teaching assistants, providing a separate exam location and additional time for classwork and exams (Packer, 2005; Wadman, Glazebrook, Parkes, et al., 2016).

Watson et al. (2005) analysed antecedents in classroom environments which appeared to worsen tics and this allowed for specific interventions to be put in place to reduce severity of tics in these specific environments. Given the range of tics and antecedents that will be experienced by CYP with TS, as well as the tendency for tics to wax and wane, this approach requires a highly individualised approach which will be continuously evolving as tics change.

Providing a safe place, particularly to use to tic, was recognised as an important support for CYP with TS (Wadman, Glazebrook, Parkes, et al., 2016). Similarly, allowing CYP with TS to take a break from class, whether this was a specific movement break or the opportunity to use a card to leave the classroom when they felt this would help, was also suggested as a useful strategy in schools (Wadman, Glazebrook, Parkes, et al., 2016). Managing responses to tics in the classroom by encouraging school staff and pupils to ignore or limit responses to tics was also suggested to be useful (Wadman, Glazebrook, Parkes, et al., 2016).

7.7 Challenges to supporting TS in schools

Research by Wadman, Glazebrook, Parkes, et al. (2016) explored the ease of implementing a number of recommended strategies for CYP with TS in schools. Some of the challenges reported included; shortages of staff, limited flexibility of staff, difficultly accessing support from external agencies, lack of funding, time and space in school (Wadman, Glazebrook, Parkes, et al., 2016). This suggests that even when schools possess the knowledge of appropriate strategies to support CYP with TS there are a range of barriers to implementing these strategies.

7.8 Support from External Agencies/ Professionals

CYP with TS are reportedly more likely, compared to a whole school population, to be referred to children's mental health services in the UK (Stern et al., 2005), suggesting external agencies are an important source of support for schools in supporting CYP with TS. School staff participating in research by Wadman, Glazebrook, Parkes, et al. (2016) highlighted seeking support from external agencies, such as Educational Psychology Services (EPSs) or Child and Adolescent Mental Health Services (CAMHS), as a support strategy for CYP with TS. However, in the same research this strategy was seen as a challenge compared to some of the easier to implement strategies.

7.9 Parental Perceptions of School Support for CYP with TS

As previously discussed, TS can have a significant impact on the whole family including parents. Parents report having a large input in securing school support for their child and in advocating for their child with TS (Sasnett, 2008). In addition, parents of CYP with TS are reported to have accurate judgement in understanding the educational needs of their child (Shady et al., 1988), their views and contributions are therefore important. In some cases discussed by Grace and Russell (2005) parental dissatisfaction with school support for their child with TS led to the child being withdrawn from school completely, demonstrating potential consequences of parental dissatisfaction with school support.

Previous research has to some extent explored parental perceptions of the school-based support for TS. Canadian research explored the perceived usefulness of a range of strategies in school for TS, parents endorsed a range of strategies in this research, the most common of which were: student paying attention and being informed, teacher cueing listening to important information and teacher supporting organisation of work (Thomas et al., 2013). The least useful strategies, from parents perspective, in this research were those that differentiated the individual with TS from their classmates, such as provision of a desk with high sides or a desk separated from peers (Thomas et al., 2013). Grace and Russell (2005) explored school experiences of CYP with TS and their parents, finding a range of areas for improvement with 23 of 26 participants being categorised as either dissatisfied or completely dissatisfied with their school experiences. Experiences with teachers, peer acceptance, parental advocacy and concern for other CYP in the class emerged as commonly discussed challenges by parents (Grace & Russell, 2005). A qualitative study explored experiences of parents and carers of CYP with TS and highlighted negative experiences of education as a theme discussed by participants (Ludlow et al., 2018). Specific experiences shared by parents included frustration with a perceived lack of willingness to offer support from school as well as frustrations with promised support not being provided (Ludlow et al., 2018).

8.0 The Role of EPs in TS

A document from the Association of Educational Psychologists (AEP) and Welsh Government (WG) (AEP/WG, 2016) discusses the role of EPs in Wales and refers to a range of needs the CYP might have that may lead to EP involvement, these include; learning, language and communication, sensory and physical impairments, social and emotional development, well-being, behaviour and mental health issues. As previously highlighted, many of these areas have been found to be areas of need for CYP with TS, suggesting that the impact of TS on CYP may lead to EP involvement. Some literature has reported that EPs may be a source of support for schools in working with CYP. An information sheet produced by the Great Ormond Street Hospital (GOSH) for Children NHS Foundation Trust (2016) about supporting TS in schools suggests “input from other specialists, such as an educational psychologist or another health professional” (p.1). Similarly, an online article in the SEN magazine (Chowdhury, 2011), suggests in relation to supporting CYP with TS “input from an educational psychologist is appropriate and can be very helpful” (para. 13). Research exploring useful strategies to support secondary school pupils with TS in the UK highlighted involvement from external agencies, such as Educational Psychology Services, as an important strategy (Wadman, Glazebrook, Parkes, et al., 2016). It is therefore evident that EPs may become involved in supporting a CYP with TS either directly or indirectly.

There is a body of literature in the USA exploring the work of School Psychologists (SPs) in supporting CYP with TS. The role of a SP in the USA differs from that of an EP in the UK in that there tends to be a focus on assessment and counselling and greater emphasis on direct work with CYP (Watkins et al., 2001). There are however similarities in the roles, in that both SPs in the USA and EPs in the UK conduct consultations with school staff and parents, work with a range of difficulties in schools and advise on interventions or support to be implemented (Hagemeier et al., 1998; Watkins et al., 2001). Glassman (2010) discussed the role of SPs in both planning and implementation of interventions for CYP with TS as well as having a role in the diagnosis of TS. Glassman (2010) also highlights the importance of collaboration between the SP, school staff and parents of CYP with TS. Similarly, SPs are suggested to be key in supporting the development and presentation of peer education sessions in schools (Kepley & Conners, 2007). Research has demonstrated that 88% of SPs were knowledgeable about TS and 78% of SPs had worked with at least one case with TS however it was also noted that most SPs felt they did not have adequate training in TS (Cornejo, 2015). This research, although not specifically about EPs suggests that the role of EPs in working with CYP with TS may be an area for future research. Literature in the area of psychological support for CYP with TS in school comes predominately from the USA and is related to SPs, therefore there seems to be a lack of published research considering the context of EPs in the UK.

9.0 Summary

Existing literature has suggested that TS may affect around 1% of CYP (Robertson et al., 2009), a higher percentage than previously estimated. Literature has highlighted a range of difficulties that CYP with TS may experience including challenges which can impact their time in school. Difficulties for CYP with TS in schools reported in the literature include academic underachievement (Cubo et al., 2017), difficulty managing emotions (Wadman, Glazebrook, Beer, et al., 2016) and physical symptoms associated with tics and side effects from medication (Packer, 2005). In addition, systems around CYP with TS and the social environment of school presents additional difficulties, including victimisation and rejection from peers (Packer, 2005) and challenging interactions with school staff often due to limited understanding of TS (Wadman, Glazebrook, Beer, et al., 2016). Lack of understanding of TS or knowledge based on stereotypes and misconceptions can lead to negative or inappropriate responses towards CYP with TS (Wadman, Glazebrook, Beer, et al., 2016).

Support for CYP with TS in schools has also been explored to some extent in the literature, including findings from the UK, US, Australia and Canada. Communication between home and school systems and increasing understanding of TS in school are viewed as important factors in securing appropriate support (Sasnett, 2008; Wadman, Glazebrook, Parkes, et al., 2016; Wilson et al., 2003). In addition, existing literature has suggested that CYP with TS may benefit from support with learning tasks in school such as additional time, exam arrangements, support with handwriting and reduced homework demands (Packer, 2005; Wadman, Glazebrook, Parkes, et al., 2016). Individualised considerations around creating a safe and comfortable classroom environment, including support from teachers are also suggested to be useful for CYP with TS (Grace and Russell, 2005; Thomas et al., 2013). Futhermore, social and emotional supports such as social skills groups and buddy systems may support with difficulties relating to friendships and management of emotions (Wadman, Glazebrook, Parkes, et al., 2016). Alongside support offered in school the existing literature has highlighted a role for external professionals, including EPs to support CYP with TS in school (Wadman, Glazebrook, Parkes, et al., 2016). Literature has also recognised that there are challenges for schools in providing some support strategies for CYP with TS, including lack of funding, staff shortages and difficulty in accessing external support (Wadman, Glazebrook, Parkes, et al., 2016).

10.0 Academic and Professional Rationale

This literature review provides some insight into the challenges that CYP with TS face in schools across a range of areas. The review has also highlighted a range of support strategies that may be beneficial for CYP with TS in schools, however much of this research was completed in Canada, the USA and Australia, with limited research exploring this in the UK. This review identified only one piece of research explicitly exploring support for CYP with TS in the UK mainstream schools, this focused on secondary schools only and gathered the perspectives of school staff (Wadman, Glazebrook, Parkes, et al., 2016). This research used a survey design to present school staff with a hypothetical scenario and asked for ways in which they would support the fictional child with TS. In addition, the survey considered ease of implementation of various support strategies in school. Although this research provides useful insight into school staff views of appropriate support for CYP with TS, it does not explore the current practices in schools, nor does it consider the perspective of parents. It is hoped that the current study will begin to explore these gaps in the literature.

Exploring the current practices in supporting CYP with TS from both parental and school staff perspective allows opportunities for triangulation of data. The importance of parental involvement and perspectives with regards to the support that CYP with TS is evident in international research, highlighting the valuable contribution that parental perspective can have (Sasnett, 2008). Research from the USA and Australia suggested that parents often have a role in advocating for their child and ensuring support for CYP with TS is provided (Grace & Russell, 2005; Sasnett, 2008). Some UK research has explored the perspectives and experiences of parents of CYP with TS in a general sense and has highlighted some dissatisfaction with support provided in school for their child with TS (Ludlow et al., 2018). However there is a lack of research in the UK specifically exploring parents' perspectives of current practices in supporting CYP with TS in schools.

There is also limited research considering the role of the EP in supporting CYP with TS in the UK. International research has explored the role of SPs in this suggesting that there may be a role for SPs in collaborating with school staff and parents in planning and implementing support for CYP with TS (e.g. Glassman, 2010). However, despite EPs being suggested as sources of support for CYP with TS, specific implications for EP practice in the UK are rarely explored in the literature.

Overall, research suggests that TS and tics in CYP has increased in recent years and that this can have significant impact on their school experience if not adequately supported. It is therefore timely to explore the support these CYP are receiving in school and how this support is perceived by their parents. The current study aims to expand on existing literature in the area to explore the following research questions:

- What are the current practices for supporting CYP with TS in mainstream schools in the UK?
- What are parent’s experiences of school support for their child with TS?

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An Exploration of Support for Children and Young People with Tourette Syndrome in Schools

Part B: Major Empirical Study

Word Count: 8,630

1.0 Abstract

Tourette’s Syndrome (TS) is a complex neurodevelopmental disorder which impacts around 1% of Children and Young People (CYP) in the UK. Typical onset of TS symptoms occurs at school age with symptoms often reaching peak severity around the age of 10 years old. CYP with TS can experience a range of difficulties in school including physical, emotional, learning and social difficulties. This research aims to explore the current practices in mainstream schools in the UK for supporting CYP with TS. School staff (n=25) and parents of CYP with TS (n= 74) completed bespoke online questionnaires to gather data on: staff knowledge, difficulties for CYP with TS and support in school for CYP with TS. A second stage of the research involved semi-structured interviews with six parents of CYP with TS, analysed using Interpretative Phenomenological Analysis (IPA). Findings from the questionnaires suggested that common difficulties experienced by CYP with TS in schools included attention and concentration difficulties, sensory difficulties, stress or anxiety and exhaustion. Support that was commonly in place to support TS included: time out cards, quiet spaces, involvement of external services and exam arrangements. Analysis of interviews resulted in three themes being conceptualised, these were: understanding of TS, role of the parents and the journey. This research highlights the range of difficulties CYP with TS may experience in school, support that may be helpful and challenges in accessing support. In addition, the importance of raising awareness and knowledge of TS is discussed alongside implications for Educational Psychologists.

2.0 Introduction

2.1 Tourette Syndrome

Tourette Syndrome (TS) is a complex developmental neuropsychiatric condition which falls under that category of tic disorders (Singer & Walkup, 1991). Tics are defined as vocalisations or movements which are recurrent, rapid and sudden, they are often preceded with an urge (Mittal, 2020). Diagnostic criteria for TS are outlined by the Diagnostic and Statistical Manual of Mental Disorders (5th ed; DSM-5; American Psychiatric Association [APA], 2013) and International Classification of Diseases and Related Health Problems (11th ed; ICD-11; World Health Organisation, 2022). These characterise TS as an individual experiencing both motor and vocal tics which cannot be attributed to physiological effects of substances or medical conditions (APA, 2013). These symptoms will occur before the age of 18 and are present for at least a year prior to diagnosis (APA, 2013).

TS is a commonly misunderstood condition with representations in popular media often overemphasising tics involving swearing, known as coprolalia, which can perpetuate negative stigma and stereotypes around TS (Calder-Sprackman et al., 2014; Davis et al., 2004). In reality, this class of tics is only present in approximately 19% of males and 15% of females with TS (Freeman et al., 2009).

International prevalence figures reported for TS suggest that approximately 1% of CYP have TS (Robertson et al., 2009). However, a range of prevalence figures are reported in the literature (e.g. Knight et al., 2012; Scharf et al., 2015) and given the complex diagnostic criteria associated with TS, there may be many more CYP with the condition that remain undiagnosed. In addition, there is an emerging body of literature proposing that there is an increase in tics and TS in recent years, with a suggestion that portrayals of TS in social media content and the COVID-19 pandemic may be contributors to this increase (e.g. Heyman et al., 2021; Hull & Parnes, 2021). TS is reported to be more common in males than females, with an approximate ratio of 4:1 (Freeman et al., 2000). As suggested by the diagnostic criteria, TS typically occurs in childhood, with an average age of onset reported as 6.7 years of age (Robertson, 2003). Following initial onset symptoms typically worsen, reaching peak severity at around 10 years of age, before symptoms tend to decline into adulthood (Leckman et al., 1998). It is suggested that 75% of individuals with TS have diminished symptoms by adulthood, with 30% experiencing no TS symptoms in adulthood (Bloch & Leckman, 2009). This is supported by prevalence figures of TS in adults reported to be around 0.02% (Levine et al., 2019), significantly lower than the figures reported for CYP. TS often co-occurs with other conditions, it has been reported that around 88% of individuals with TS have a co-occurring condition (Freeman et al., 2000). The most common of these being Attention Deficit Hyperactivity Disorder (ADHD) (60%) and Obsessive Compulsive Disorder/Behaviours (OCD/ OCB) (59%) (Freeman et al., 2000). Other co-occurring conditions included anxiety, mood disorders, learning difficulties and sleep disorders (Freeman et al., 2000).

The aetiology of TS is complex and a range of theories are present in the literature, however it has been argued that data is not sufficient to identify exact causes of TS (Seideman & Seideman, 2020). There is a large body of literature in the medical field suggesting that there may be a genetic component to TS (Curtis et al., 1992) as well as neurophysiological differences (Peterson et al., 2003). However, alternative perspectives have also suggested TS may be influenced by learned behaviours (Yates, 1958), affective states (Eapen et al., 2004) and environmental risk factors (Motlagh et al., 2010). In addition, some researchers have suggested models such as the Comprehensive Integrated Model, described by Woods et al. (2007), in an attempt to consider the interaction between internal neurobiological factors and environmental factors in the development of TS.

There is no cure for TS as a condition, however, there are a range of management and treatment options which are used to reduce the impact of TS symptoms. TS is a heterogenous condition which can involve a range of symptoms and difficulties for individuals and management of these alongside any co-occurring conditions is therefore considered on an individual basis. The importance of finding appropriate management or treatment based on severity of TS was highlighted by Kurlan (2014), suggesting that for individuals experiencing mild tics education about TS and counselling may be sufficient while further treatment aiming to reduce TS symptoms may be required for those with more disabling tics. Some TS management strategies focus on reducing the tics, these include biological treatments including a range of medication options (Eddy et al., 2011), Botulinum Toxin A injections (Kwak et al., 2000) and Deep Brain Stimulation (Visser-Vandewalle & Kuhn, 2013). In addition, behavioural therapies aim to reduce tics through a range techniques such as habit reversal training (Capriotti & Woods, 2013), over-rehearsal of tics (Crawley & Powell, 1986), or relaxation therapies (Bergin et al., 1998). On the other hand, there are TS management options which focus on CYP's wellbeing as a whole, beyond reduction of tics. Psychoeducation is used to increase understanding of TS, the associated symptoms and offer reassurance to both the individual with TS and those within the systems around them (Carroll & Robertson, 2000). Cognitive behavioural interventions are also designed to increase overall quality of life through supporting with emotions, psychoeducation, coping strategies and problem solving (McGuire et al. (2015).

2.2 Tourette Syndrome in Schools

Given the age of onset and peak severity of TS occurring at school-age, difficulties associated with the condition are likely to impact CYP's functioning in school, with a range of difficulties reported in the literature. There can be differences in the presentation of TS in school and at home (Christie & Jassi, 2002), suggesting the school environment presents unique challenges for CYP. It has been estimated that approximately 49% of CYP with TS have at least one significant problem at school (Storch, Lack, et al., 2007). The importance of support for CYP with TS in school was recognised by their parents who highlight the need for a balance of appropriate support whilst not singling out a student as being different (Ludlow et al., 2018). Research suggests that approximately 72% of CYP with TS in an international sample have strategies or accommodations of some kind in place at school (Packer, 2005). However, as with much of the research on TS there are challenges in disentangling the difficulties which are associated with TS from those that are associated with the many common co-occurring conditions.

2.2.1 Learning and Cognition

Assessment of cognitive skills have reported conflicting results with regards to IQ of individuals with TS, with some research suggesting a lower IQ (Debes et al., 2011) while others suggest individuals with TS score average on IQ assessments (Brand et al., 2002). Despite these contradictory findings related to cognitive skills, there is an agreement in the literature that TS has an impact on learning for CYP in school (e.g. Wadman, Glazebrook, Beer, et al., 2016). In terms of academic attainment, Conelea et al. (2011) reported that parents typically rated academic impairment in their children with TS as mild to moderate. In comparison to a non-TS sample, Pérez-Vigil et al. (2018) found those with TS were less likely to complete secondary school and less likely to start or complete a university degree.

CYP with TS, school staff and parents often report concentration and attention as one of the biggest challenges faced in schools (Wadman, Glazebrook, Beer, et al., 2016). CYP with TS report that tics, as well as efforts to supress tics are a source of distraction in school impacting their attention (Edwards et al., 2017). Additional challenges for CYP with TS within the classroom may include: time pressure related increase in tics, difficulties copying from a board and tic-related interference with reading and writing (Packer, 2005). In interviews, CYP with TS reported that TS makes schoolwork more challenging, this included writing, reading, attention, homework and exams (Wadman, Glazebrook, Beer, et al., 2016).

Strategies to support learning suggested in the current literature include: adjustments to classwork, homework and examinations, use of teaching assistants and a reduced or individualised timetable (Wadman, Glazebrook, Parkes, et al., 2016). In addition; preferential seating, reduction in homework, permission to leave the classroom when needed, use of word processors, providing a separate exam location and additional time for classwork and exams were highlighted as useful strategies in school (Packer, 2005).

2.2.2 Social and Emotional Difficulties

Difficulties with peers are commonly reported for CYP with TS, 48% of parents of CYP with TS reported that their child's tics had a moderate to severe impact on peer relationships (Packer, 2005). Difficulties in this area include: negative peer reactions to tics, peers mimicking tics and teasing, peer victimisation, social exclusion and difficulties with friendships (Bawden et al., 1998; Storch, Murphy, et al., 2007; Wadman et al., 2013). It has been suggested that the teasing, peers fear of tics and bullying experienced by CYP with TS is, at least in part, due to limited peer knowledge of TS (Kepley & Conners, 2007). Therefore, peer education programs are commonly recommended to improve understanding of tics and TS in schools and can be effective in increasing knowledge, positive attitudes and behaviour towards individuals with TS (Nussey et al., 2013). However, in a sample of parents of 71 CYP with TS, only 13% of the sample reported any peer education to have taken place within school to educate peers about TS (Packer, 2005).

Wadman, Glazebrook, Beer, et al. (2016) discussed challenges of TS in schools with parents, school staff and CYP reporting that TS can make managing emotions challenging in school. Wadman, Glazebrook, Beer, et al. (2016) reported that stress and anxiety were often reported by CYP, parents and school staff and that the most commonly reported sources of stress and anxiety were about letting tics out, completing schoolwork and exams. CYP also reported that they became angry easily in school which had led to aggression which they felt was as a result of TS (Wadman, Glazebrook, Beer, et al., 2016). Social and emotional support strategies suggested by school staff to support TS included providing a keyworker and supporting social relationships though social skills groups and buddy systems (Wadman, Glazebrook, Parkes, et al., 2016).

2.2.3 Physical

CYP with TS have reported physical discomfort as a result of tics, this included muscle aches, pain and fatigue (Edwards et al., 2017). Physical side effects from medication taken to reduce tics have also been suggested to impact the functioning of CYP with TS in schools (Packer, 2005). Side effects include drowsiness, depression, increased appetite, fogginess and restlessness (Robertson, 2000). In addition, some research has suggested that neuroleptic pharmacological treatments, often used for CYP with TS, can cause onset of a specific variant of school phobia (Linet, 1985). These side effects would likely impact the functioning of CYP with TS in schools and it would therefore be important for school staff to be aware of potential side effects and discuss any concerns with parents.

2.2.4 Knowledge of TS in schools

Research, from the perspectives of school staff, parents and CYP suggests that school staff knowledge of TS is somewhat limited and that this can make school particularly challenging for CYP with TS (e.g. Ludlow et al., 2018; Shady et al. ,1988; Wadman, Glazebrook, Beer, et al., 2016). School staff knowledge of TS is likely to impact day-to-day interactions with CYP with TS, the importance of which has been highlighted in research with CYP with TS suggested that an empathetic and patient approach from teachers, in trying to understand how TS impacts the CYP and how they experience school would be beneficial (Wilson et al., 2003). Similarly, literature has suggested that teacher characteristics valued by CYP with TS and their parents include flexibility, understanding, sensitivity and compassion (Grace & Russell, 2005; Wilson et al., 2003). Research has also highlighted some of the reactions to TS by teachers which have been found to be unhelpful for CYP with TS, this included being disciplined for tics or being told not to tic, lack of understanding and shouting (Wadman, Glazebrook, Beer, et al., 2016; Wilson et al., 2003).

2.3 Role of the EP in supporting CYP with TS

Educational Psychologists (EPs) work with CYP who may have a range of needs including: learning, language and communication, sensory and physical impairments, social emotional development, wellbeing, behaviour and mental health difficulties (AEP/WG, 2016). Existing literature has demonstrated that CYP with TS may experience difficulties with many of these areas, therefore may require EP involvement while at school. EPs have also been highlighted as a source of support for schools when supporting CYP with TS, for example, an online magazine article about supporting CYP with TS in schools suggests “input from an educational psychologist is appropriate and can be very helpful” (Chowdhury, 2011, para.13). Similarly, research has suggested that EPs and other external agencies involvement in supporting CYP with TS in school is an important source of support (Wadman, Glazebrook, Parkes, et al., 2016).

2.4 The Current Research

TS is suggested to impact approximately 1% of CYP (Robertson et al., 2009), and typical age of onset as well as peak severity occur at school-age (Leckman et al., 1998) and therefore often impacts CYP's functioning at school. There is also a suggestion that cases of and severity of TS may be increasing following the COVID-19 pandemic (e.g. Heyman et al., 2021), it is therefore timely to consider how these CYP are supported in school. Previous literature has highlighted the range of difficulties that CYP with TS may experience in school as well as some support strategies that may be useful (e.g. Packer, 2005; Wadman, Glazebrook, Parkes, et al., 2016). Research in this area often comes from international sources or utilises hypothetical scenarios to consider support for TS rather than current practice in place in UK mainstream schools. This study will therefore explore the current practices of supporting CYP with TS in mainstream schools in the UK. Data from parents of CYP with TS and school staff will be triangulated with the aim to increase completeness of data. In addition, although there is existing literature exploring the lived experiences of parents of CYP with TS, there are limited UK findings specifically on their experiences or views related to the support their child with TS receives in school. This research will therefore aim to explore these experiences of parents of CYP with TS.

2.5 Research Questions

1. What are the current practices for supporting CYP with TS in mainstream schools in the UK?
2. What are parent's experiences of school support for their child with TS?

3.0 Methods and Measurements

This research comprises of two components, which are from here on referred to as part 1 and part 2. Although the two parts of the research were carried out simultaneously they will be discussed separately. Following discussion of the epistemological and ontological positions and overall research design the specific methods and measurements for the two parts of the research will be discussed individually. From this point onward the term child/children will be used in place of CYP as all children referred to by school staff and parents were under the age of 16, as stipulated by the inclusion criteria, and child/children is suggested to be an appropriate term for this age group (United Nations Children Fund UK, 1989).

3.1 Ontological and Epistemological Positions

This research adopted a critical realist ontology. The critical realist stance recognises that an objective reality exists but is influenced by subjective, socially-constructed knowledge (Braun & Clarke, 2013). Critical realism allows for acceptance of the reality of TS as a diagnosable condition (although there are controversies relating to diagnostic labels as discussed in part A), while recognising that this reality will be influenced by individual social constructions and experiences. This research will therefore only be able to access the reality of school support for children with TS through the lens of specific social constructions held by participants.

The epistemological position was contextualism, this assumes that there is a truth that can be accessed, at least partially, through language (Braun & Clarke, 2013). Contextualism, which considers context and language to be important in accessing truth and meaning, fits well with the critical realist ontology. The contextualist epistemology allows for each participant to share their view of their own reality which is influenced by their individual context and circumstances.

3.2 Research Design

In keeping with the ontological and epistemological positions, a mixed-methods approach was used to gather both quantitative and qualitative data. Tashakkori and

Teddlie (2009) describe how triangulation of qualitative and quantitative data can be used to obtain greater completeness of data. The critical realist stance has been shown to be compatible with the methodological triangulation of data for the purpose of completeness (McEvoy & Richards, 2006). Data source triangulation was used in gathering data from both school staff and parents, this method of triangulation has been described as useful in expanding perspectives to strengthen research (Krahn & Putnam, 2003). In addition, use of questionnaires and interviews to gather quantitative and qualitative data provides an opportunity to balance inherent limitations of each specific method (Todd et al., 2004).

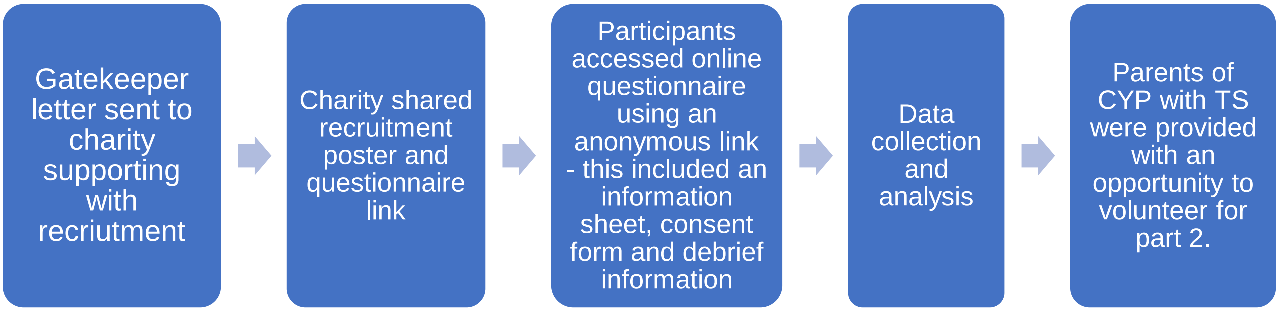
3.3 Part 1: Methods and Measures

Part 1 of this research involved administering online questionnaires to school staff and parents of children with TS to gather quantitative and qualitative data about their experiences and perspectives.

3.3.1 Part 1: Procedure

The procedure for part 1 is displayed in figure 2.

Figure 2 *Part 1 Research Procedure.*



3.3.2 Part 1: Measures

Two bespoke questionnaires were designed, one for school staff and one for parents of children with TS. The use of bespoke questionnaires was decided to ensure that the data required to answer the research questions could be gathered (Roopa & Rani, 2012). Questionnaires were designed and completed using Qualtrics software and gathered both quantitative and qualitative data. The questionnaires were both suitable for completion on computers, mobile phones or tablet devices. The school staff questionnaire collected data on demographic information, experiences of supporting children with TS in schools and information about the knowledge and confidence school staff have about TS (appendix 3). Similarly, the parental questionnaire gathered information about the experiences of support for their children with TS in mainstream settings, how satisfied parents were with this support and perceived levels of confidence and knowledge of school staff (appendix 4). Questions about difficulties experienced by children with TS and support offered were based on findings from previous literature (Wadman, Glazebrook, Beer, et al., 2016; Wadman, Glazebrook, Parkes, et al., 2016). Each questionnaire included an information sheet (appendices 5&6), consent form (appendices 7&8) and debrief information (appendices 9&10).

As suggested by Roopa and Rani (2012) questionnaire pilots were conducted with contacts of the researcher to ensure the questions were clearly presented and could easily be completed on a range of devices. In addition, the stages of planning described by Roopa and Rani (2012) were considered in the development of the bespoke questionnaires with the aim to increase validity and reliability of these measures. This included exploring good practice in existing questionnaires, considering the presentation and response options for each question and the overall sequence of questions. Detailed considerations of the validity and reliability of measures are presented in appendix 11.

3.3.3 Part 1: Recruitment and Inclusion Criteria

For part 1 of the research parents of children with TS were recruited using volunteer sampling through a UK charity supporting families of children with TS. The charity shared the recruitment poster (appendix 12) and questionnaire link via their website and social media. Similarly school staff were recruited through social media utilising a range of education based hashtags and being shared by the same TS support charity (appendix 13). Inclusion criteria for both participant groups are outlined in table 8. The age range of 10-16 years was selected as previous literature suggests that symptoms of TS and therefore need for support may be most evident in this age range (Robertson et al., 2009). It was specified that children should have a diagnosis of TS with the aim to increase homogeneity of the sample.

Table 8 *Part 1 participant inclusion criteria.*

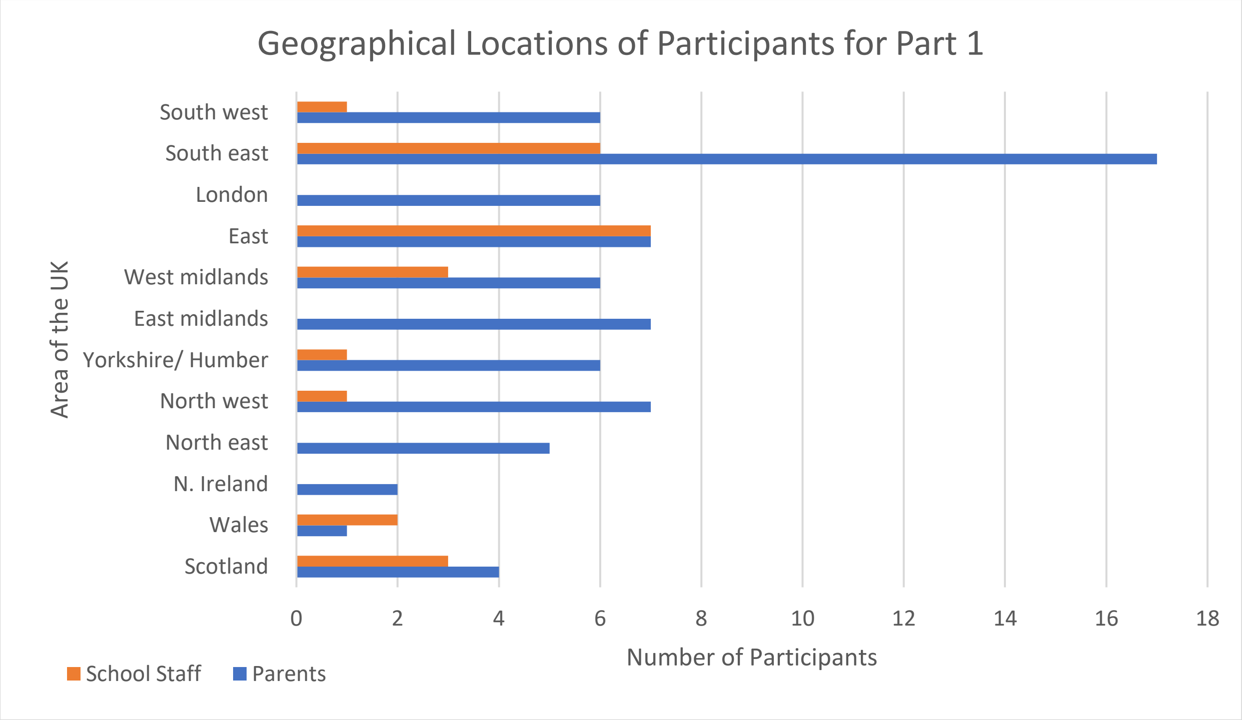
Participant Inclusion Criteria	
School Staff	**Parents of children with TS**
- Any member of school staff currently working in a mainstream school in the UK. - Experience of working with at least one pupil with a diagnosis of TS between the ages of 10-16.	- Parent/ carer of a child aged between 10-16 years with a diagnosis of TS. - Child with TS currently attends a mainstream school in the UK.

3.3.4 Part 1: Participants

Parent Questionnaire

Responses from 74 parents of children with TS were included in the analysis. A total of 102 parents responded to the questionnaire, however 28 of these were removed prior to analysis due to not matching inclusion criteria, not providing consent or not answering any questions beyond providing consent. The participants were parents of children with TS between 10-16 years old, with a mean age of 12.41 years; the mean age at which their child received a diagnosis of TS was 10.18 years (range: 4-16). Participants from across the UK participated, including responses from Wales, England, Scotland and Northern Ireland. Details of the proportion of participants from each area of the UK is shown in figure 3.

Figure 3 *Geographical locations of part 1 participants.*



The children with TS all attended mainstream schools; 32% attended primary schools, 57% attended secondary schools, the remaining 11% were reported to attend specialist classes within a mainstream setting or currently not attending their mainstream school. Diagnosis of at least one comorbid condition was reported by 70% of parents, with a mean of 1.57 co-morbid conditions reported per child. The most commonly reported co-morbid condition was anxiety, which 37% of parents reported their child had alongside TS. Other co-morbidities reported by parents are displayed in table 9.

Table 9 *Co-morbid conditions reported by parents of CYP with TS participating in part 1.*

Co-morbid conditions of children with TS as reported by their parents	Number (%)
Anxiety	27 (37%)
Obsessive Compulsive Disorder (OCD)	19 (26%)
Attention Deficit Hyperactivity Disorder (ADHD)	18 (24%)
Autism Spectrum Disorder (ASD)	17 (23%)
Depression	8 (11%)
Phobias	6 (8%)
Hypermobility	4 (5%)
Sensory Processing Disorder	3 (4%)
Sleep disorder	1 (1%)
Deficits in Attention, Concentration, Motor Control and Perception (DAMP) disorder	1 (1%)
Attachment disorder	1 (1%)
Dyslexia	1 (1%)
Language disorder	1 (1%)
Developmental Co-ordination Disorder (DCD)	1 (1%)

Staff Questionnaire

Questionnaire responses from 25 school staff participants were included in the analysis from a total of 47 responses to the questionnaire. Responses were excluded due to not meeting inclusion criteria or not answering questions beyond providing consent. A large proportion of the participants worked in secondary schools (72%) with 8% working in primary settings and the remaining 20% reported working in specialist provisions in mainstream settings (8%), boarding schools (4%) or did not specify the type of school (8%). For this research those working within specialist classrooms or resource bases were included only if they were considered to be a part of a mainstream school. Participants represented schools across the UK, including England, Wales and Scotland (figure 3). In addition, participants included a range of school staff, details of roles held in school are shown in table 10.

Table 10 *Roles in school reported by school staff participating in part 1.*

School staff roles in schools	Number (%)
Teacher	10 (40%)
Pastoral lead/ manager	5 (20%)
TA / LSA	4(16%)
SENCo/ ALNCo	1 (4%)
Senior Leadership Team	1 (4%)
Specialist teacher	1 (4%)
Admin role	1 (4%)
Supply teacher	1 (4%)
Access leader	1 (4%)

As stipulated in the inclusion criteria, all school staff included in the analysis had experience of working with at least one child with TS in school. 40% reported having worked with one pupil with TS, 36% reported working with two different children with TS, 8% had worked with three and 12% had worked with four or more children with TS.

3.3.5 Part 1: Data Analysis

Quantitative data from questionnaires was analysed using descriptive statistics to provide an overview of data from both participant groups. Qualitative questionnaire data was analysed using content analysis, using inductive category development as described by Hsieh and Shannon (2005). This process allows the researcher to gain direct information from the participants without imposing preconceived categories or perspectives (Hsieh & Shannon, 2005). Content analysis has been suggested to be a flexible approach that can be utilised for analysis of qualitative questionnaire data such as this (Robson, 2002). The steps used to guide the process of content analysis and examples of this procedure can be found in appendices 14 and 15.

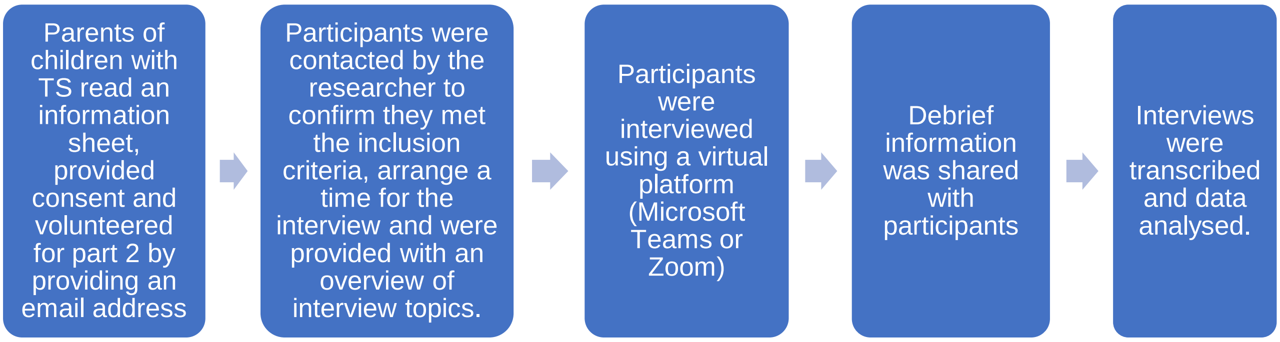
3.4 Part 2: Methods and Measures

Part 2 of this research involved semi-structured interviews with parents of children with TS to gain insight into their experiences and views of school support.

3.4.1 Part 2: Procedure

The procedure followed for part 2 of the research is outlined in figure 4.

Figure 4 *Part 2 Research Procedure*



3.4.2 Part 2: Measures

For part 2 of the research, semi-structured interviews were conducted with parents of children with TS. The interview schedule (appendix 16) was designed to gain insight into parents experiences related to schools support for their child with TS, a semi-structured approach was selected to allow for flexibility in exploring experiences (Kallio et al., 2016). The interview schedule was designed following the principles of IPA which is described as an approach to research rather than a tool for analysis (Smith et al., 2009). Interviews were arranged at a mutually convenient time for the participants and researcher and an outline of areas to be discussed was sent to the participant prior to the interview. Due to the ongoing COVID-19 pandemic and associated risks, all interviews were conducted using virtual platforms, using either Microsoft Teams or Zoom dependent on participant preferences. Interviews lasted an average of 48.02 minutes, there was additional time before and after the interview for rapport building, ensuring informed consent and opportunities for participants to ask questions.

With the participant’s consent the first interview that was conducted served as a pilot interview, utilising the field-testing method (Kallio et al., 2016). The participant was asked questions relating to: the interview schedule, how the participant felt about the interview being conducted over a virtual platform, whether there were any questions or topics of discussion the participant felt were too personal or difficult to talk about and if they felt they had been able to share their experiences effectively. The participant gave positive feedback about both the interview questions and the process of the interview and this interview was therefore included in the analysis.

Interviews used in part 2 of the research were assessed for validity and reliability using principles outlined by Yardley (2000), detailed consideration of these principles can be found in appendix 17.

3.4.3 Part 2: Recruitment and Inclusion Criteria

Participants for part 2 of the research were recruited through volunteer sampling from the parents participating in part 1 of the research. At the end of the questionnaire parents were given the opportunity to follow a link to read further information (appendix 18), provide consent (appendix 19) and contact information to volunteer for part 2 of the research. Following the link allowed participants to enter contact information without this being linked to their questionnaire responses. Following interviews participants were provided with debrief information (appendix 20) via email. The inclusion criteria for parents participating in part 2 was identical to that in part 1, including parents of children with TS between 10-16 years of age currently attending a UK mainstream school.

3.4.4 Part 2: Participants

Participants were contacted by the researcher following volunteering for interviews, and interviews were arranged on a first come first served basis. Although many participants volunteered for interviews, only six interviews were conducted, following guidance outlined by Smith et al. (2009) stating 3-6 participants being a suitable sample size when conducting IPA for a project of this size. Details of the interview participants and their children with TS are displayed in table 11. Pseudonyms have been used to protect the anonymity of families.

Table 11 *Part 2 participant details*

#	**Pseudonyms**	**Details of child**	**Additional relevant information**
1	Parent: Ann Child: Adam	12 year old boy (year 8)	Other siblings also have tics
2	Parent: Becky Child: Beth	10 year old girl (year 6)	
3	Parent: Carol Child: Chloe	14 year old girl (year 10)	

4	Parent: Diane Child: Daisy	12 year old girl (year 8)	Diane also has a 10 year old child with TS and ASD who is attending a specialist provision.
5	Parent: Emma Child: Ethan	14 year old boy (year 10)	Ethan is also diagnosed with ASD.
6	Parent: Fiona Child: Freddy	13 year old boy (year 9)	Freddy is also diagnosed with ADHD and a sibling with ASD.

3.4.5 Part 2: Data Analysis

Interviews were transcribed and analysed using IPA, following the steps of IPA as described by Smith et al. (2009) presented in table 12. IPA examines lived experiences of a homogenous group to explore the perspectives of participants who have lived through the same phenomena (Smith et al., 2009). With the goal of giving voice to the participants, IPA was considered an appropriate approach to explore the perspectives of parents of CYP with TS and how they make sense of experiences within school (Larkin et al., 2006).

Table 12 *Summary of IPA steps described by Smith et al. (2009)*

IPA steps described by Smith et al. (2009)
- Step 1: Reading and re-reading - Step 2: Initial noting - Step 3: Developing emergent themes - Step 4: Searching for connections across emergent themes - Step 5: Moving to the next case - Step 6: Looking for patterns across cases

With the view of minimising researcher bias the IPA process was checked using extracts from each of the transcripts by an independent peer with knowledge of the IPA process (see appendix 21 for additional details). A full description of the process as well as transcript extracts showing stages of the analysis are presented in the appendices (appendices 21, 22 &23).

Given the interpretative nature of IPA, the researcher plays a key role in the process. The double hermeneutic in which the researcher is entangled within the IPA process requires the researcher to interpret the participants sense making, this will however be influenced by the researcher’s own knowledge and experience (Smith et al., 2009). The researcher was also conscious that at times during the interview a triple hermeneutic would come into play as the parents discussed their interpretations of their child’s experience which would again be interpreted by the researcher. The researcher was also aware that their own knowledge and experience of working with CYP with TS meant they had their own preconceived ideas and views which could influence the process. Finlay (2008) describes the complexity of the role of the researcher in both remaining open and naïve during interviews while also recognising the value and insight that can be gained from previous experience and understanding of the phenomenon being researched.

3.5 Ethical Considerations

Cardiff University School of Psychology Ethics Committee granted ethical approval for this study in March 2021. An overview of ethical considerations can be found in appendix 24.

The British Psychological Society (BPS) code of human research ethics (BPS, 2021b) guided all decisions from the conception of the research project to writing up. Confidentiality and anonymity were key ethical considerations throughout both parts of the research, addressed by avoiding questions asking for personal information in part 1 and removing any identifiable information from interview transcripts in part 2. In addition, the interviews involved participants sharing their own personal lived experiences and it was therefore important that there were opportunities for rapport building to ensure that participants felt comfortable and confident to ask any questions they had. It was also vital that participants were properly informed and aware of how the experiences they had shared would be used as part of the research, comprehensive information sheets, consent forms and debrief information supported this. In addition to procedural steps to ensure the research was ethically sound the researcher followed principles of professional conduct from the BPS and HCPC in guiding all interactions with participants (BPS, 2021a; HCPC, 2016).

4.0 Results

4.1 Part 1: Questionnaires

Findings from questionnaires completed by school staff and parents of children with TS have been considered under three headings: school staff knowledge, difficulties in school and support in school. Findings from school staff and parents were analysed separately and combined to give an overview of findings. The relatively small sample size of parents of children with TS should be considered when interpreting these results.

4.1.1 School Staff Knowledge of TS

Table 13 *Summary of key findings: School staff knowledge of TS*

Summary of Key Findings : School Staff knowledge of TS
- Parents rated school staff knowledge of TS at 3.6/10 while school staff rated their own knowledge of TS at 5.4/10. - 41% of parents reported nothing had been done in their child's school to increase awareness and knowledge of TS. - 50% of school staff reported receiving no training related to TS. - Common steps taken to increase knowledge of TS in schools include parents providing information, charities providing information and training sessions for staff.

A measure of perceptions of school staff knowledge of TS using a 10-point scale (0=not at all, 10=extremely) was included in the questionnaire for parents and school staff. Parents reported a mean score of 3.6/10 (range 0-9) when rating how knowledgeable they felt school staff are of TS in their child's school. Similarly, school staff were asked to rate on a 10-point scale how knowledgeable they felt about TS, a mean score of 5.4/10 (range 1-10) was reported.

When asked about steps that the school have taken to improve staff knowledge of TS, 41% of parents reported that to their knowledge nothing had been done to improve knowledge of TS in school. 19% of parents reported that they had themselves provided information or resources to support development of knowledge of TS in school. Other responses included charities providing information or resources to school (11%), staff conducting their own research (4%) and assemblies to increase awareness (4%).

When asked about opportunities to increase their knowledge of TS, 50% of school staff reported receiving no training on TS, 29% had received in-school training, 9% had received some training on TS during their initial teacher training and 9% had other training through personal interest or experience.

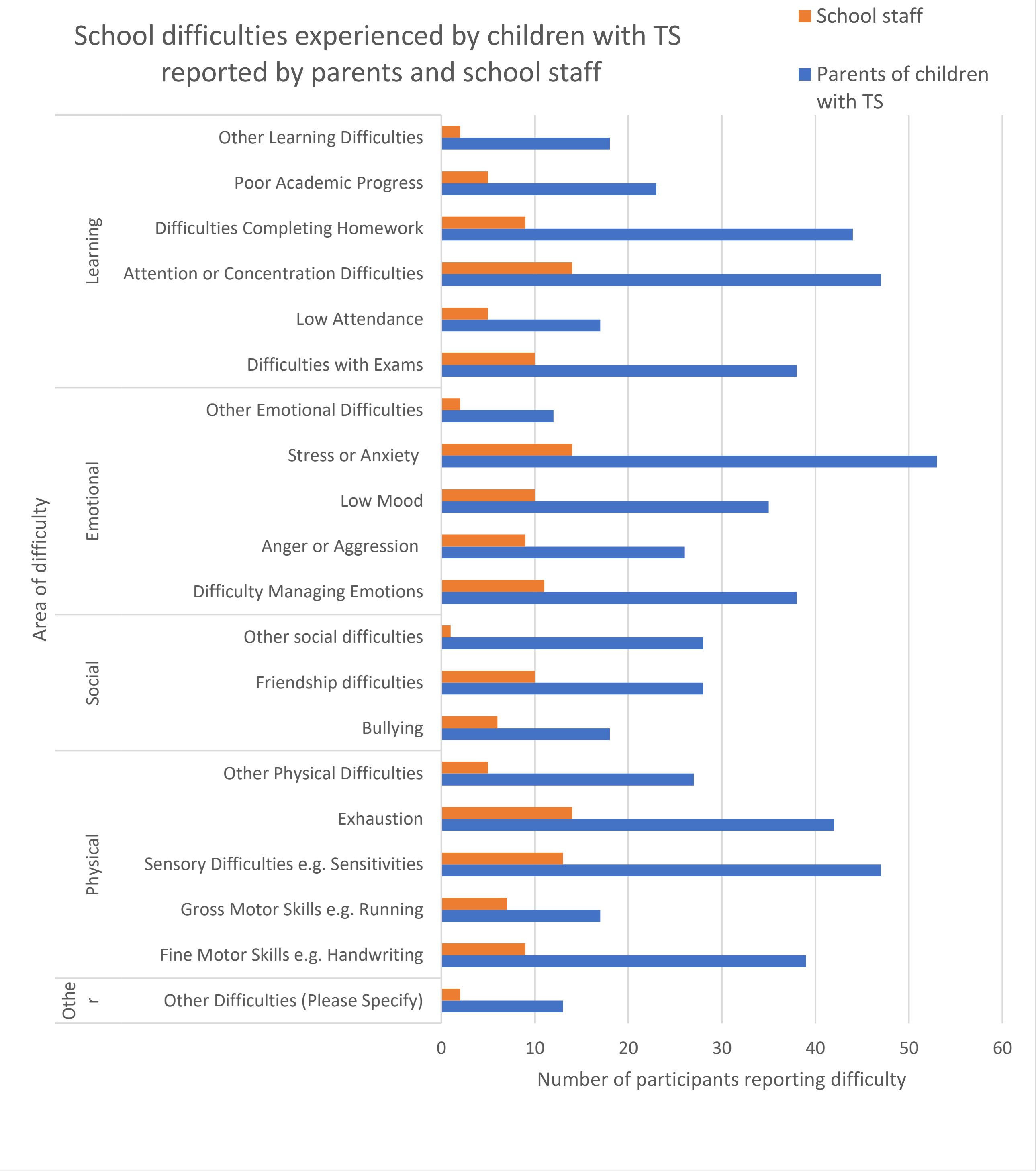
4.1.2 Difficulties for children with TS in School

Table 14 *Summary of key findings: difficulties experienced by children with TS in school*

Summary of Key Findings : Difficulties experienced by children with TS in school
- Most commonly reported difficulties by school staff and parents were stress or anxiety, attention/ concentration, sensory difficulties and exhaustion. - Physical difficulties were the most commonly reported category of difficulties with 81% of parents and 72% of school staff reporting at least one physical difficulty. - 58% of parents and 48% of school staff reported that their child with TS experienced at least one difficulty in each of the four categories; physical, social, emotional and learning.

Parents and school staff were asked about difficulties that children with TS experience in school. These were considered in four categories: physical, social, emotional and learning. Responses from both school staff and parents are shown in figure 5. Difficulties associated with physical functioning were the most commonly reported type of difficulty with 81% of parents and 72% of school staff reporting their child experienced some form of physical difficulty in school due to TS. Overall, 58% of parents and 48% of school staff reported that their child with TS experienced at least one difficulty from each of the 4 categories.

Figure 5 *Difficulties for children with TS in school reported by parents and school staff*



The most commonly reported specific difficulty was stress or anxiety, with 72% of parents and 56% of school staff reporting children with TS experiencing this in school. Other commonly reported difficulties by parents included: attention and concentration (64%), sensory difficulties (64%) and exhaustion (57%). Similarly, attention and concentration (56%), exhaustion (56%) and sensory difficulties (52%) were the most commonly reported difficulties for children with TS by school staff.

In addition to difficulties displayed in figure 5 school staff and parents reported additional difficulties for children with TS, these are recorded in table 15.

Table 15 *Additional difficulties reported by parents and school staff*

Other Difficulties Reported	Parents (number of participants reporting difficulty if more than 1)	School Staff
Physical	Pain from tics (6) Tic attacks (3) Clumsiness (2) Tiredness (3) Self-injurious behaviour (2)	Tic attacks Motor tics causing harm to self or others
Social	Coprolalia (2) Misunderstanding social situations (5) Feeling different from peers (3)	Low confidence
Emotional	Putting pressure on themselves Low self-esteem (2) Low self-worth (2) Feeling overwhelmed Embarrassment (3)	‘ADHD type behaviour’ ‘Won’t ask for help’
Learning	Slow to finish tasks (2) Difficulty following instructions (2) Reading difficulties (3) Low motivation Memory difficulties (3) Literacy difficulties (2)	Missing learning due to leaving lessons
Other	Difficulty with transitions Intrusive thoughts (2) Paralysis tics Planning and organisation Masking tics in school	Feelings of discomfort result in increase of tics

Parents also highlighted some difficulties which children with TS experience in school which were related to the actions of staff in school, these include: being told off or punished for TS symptoms, being sent out of class, lack of understanding from school staff and having attention drawn to tics.

4.1.3 Support for Children with TS in School

Table 16 Summary of key findings: support for TS in school

Summary of Key Findings : Support for TS in school
- Parents rate their satisfaction with support in school for TS at 4.8/10. - School staff report their confidence with supporting TS at 5.2/10. - 30% of parents report that there is no formal support in place for their child with TS in school.

- The most common support in place as reported by parents were: time out opportunities, a safe space and exam arrangements.
- The most common support in place as reported by school staff were: Additional service involvement and a safe space.
- In addition to practical support parents suggested some barriers to support, these included: lack of awareness of TS, lack of consistency in support, inappropriate responses and unwillingness to put support in place.
- External professionals that were involved in supporting children with TS were: Educational Psychologists (EPs), Children and Adult Mental Health Services (CAMHS) and Emotional Literacy Support Assistants (ELSAs).

Parents reported a mean score of 4.8/10 (range 0-10) when rating their satisfaction with support their child has received for TS in school. A mean score of 5.2/10 (range 1-10) was reported by staff in rating their confidence in supporting students in TS in school.

Content analysis was conducted on qualitative data collected related to school support in place to support children with TS. Categories identified and the frequency with which they were reported by parents are reported in table 17, supporting quotations for the categories are shown in appendix 25. The most common response from parents was the perception that no support had been put in place for their child with TS. Parents were also asked which of the strategies that had been put in place were the most helpful for their child with TS. Parents reported that the most helpful strategies were a time out card, TA/LSA support, quiet/safe space and exam arrangements.

Table 17 *Support in school for TS reported by parents of children with TS*

Parents of children with TS (n=74): Support in school		
Category	**Constructed definition of category**	**N**
No support	Reports of no support being in place in school.	22
Time out opportunities	Reports of opportunities for children with TS to leave the classroom/ lesson at any time.	20
Quiet/ safe space	Reference to access to a quiet or safe space in school that the child with TS can use.	15
Exam Arrangements	Reference to additional considerations and support in place for children with TS in exam circumstances – this included additional time, separate room, breaks and a scribe.	10
Specific interventions (social, anxiety)	Reference to the school providing any intervention for a specific area e.g. emotional literacy, social skills or anxiety.	9

Supportive staff	Reference to school staff being supportive and understanding to the child with TS.	8
Support with writing	Any support for the child with TS for writing, including use of a scribe or device for written tasks.	7
Fidget/ Sensory toys	Reference to school providing or allowing fidget toys, sensory toys or chewing gum in school for child with TS.	6
Information sharing	Sharing of information about the child with TS, including information shared from parents and information shared within school.	6
Support plan in place	Reference to a formal support plan or outline of support for child with TS	4
Access to facilities at school	Access to specific facilities in school which may provide additional support to child with TS.	3
LSA/ TA support	Reference to a teaching assistant (TA) or learning support assistant (LSA) in school providing any kind of support to children with TS.	3
Movement breaks	School providing opportunities to children with TS to move around during lessons.	3
External professionals	Reference to school providing access to additional external professionals to support children with TS.	3
Support from peers	Reference to support provided by peers and friends in school.	2
Reduced workload	Reference to reducing the workload or expectations on children with TS	2
Seating considerations	Consideration of where or with whom the child with TS sits within the classroom	2
Extra time	Provision of additional time to complete classwork.	2

Although this question related to support in place, several codes were conceptualised from the data which related to school staff attitudes or understanding of TS; these categories and their frequencies are displayed in table 18 .

Table 18 *Additional categories conceptualised from qualitative data from parents*

Additional Categories from Parents		
Category	**Constructed definition of category**	**N**
Staff lack of awareness or understanding of TS	Reports that school staff do not understand, recognise or know how to support child with TS	9
School responding inappropriately to TS	Reports that the support is incorrect, inappropriate or unhelpful for child with TS	3
Lack of consistency with Support	Reports that support was not consistent across years in school, not following through with plans.	3
School unwilling to provide support	Reports that schools are unwilling or not supportive in providing appropriate support	4

Similarly, school staff were asked to report the support that is put in place in their place of work for children with TS. The categories identified using content analysis and the frequency of each are shown in table 19. The most common support in place reported by school staff were: providing a safe space and involvement from additional services. Strategies suggested to be most effective by school staff were: Quiet/ safe space, understanding and awareness of TS in school and talking with a trusted member of staff.

Table 19 *Support in school for TS reported by school staff*

School staff (n=25): Support in school for children with TS		
Category	**Definition**	**N**
Safe/ quiet space	Provision of a safe or quiet space the pupil could access.	5
Additional service involvement	School referring to additional services, this includes school counsellors and services to support the family.	5
Pastoral support	Access to some form of pastoral support in school.	4
Reduced workload	Reduced workload through reducing timetable or class work or homework.	4
Time out card	Opportunities to leave classroom/ lesson when required.	4
Individualised pupil plan	Reference to existence of a specific support plan for individual student.	4
TA/ LSA support	Access to additional adult support in the classroom.	4
Staff awareness	Increasing staff awareness through training or sharing of information.	3
Lunchtime arrangements	Specific arrangements to support children with TS at lunchtime.	3
Use of technology	Laptop for writing or phone for music	3
Social skills	Support with development of social skills in school.	2
Exam arrangements	Arrangements for additional support in exams, including extra time, scribe or separate room.	2
Fidget toys	Sensory tools or fidget toys	2
Peer support	Providing training for peers or ensuring children with TS has access to a supportive peer	2
Emotional support	Support from staff with emotions	2
Flexibility in rules	Allowances to behaviour policy	1
Academic support	General support with learning	1
Reduced reading	Avoiding asking child with TS to read aloud	1
Memory support	Chunking or recaps	1

Parents and school staff both reported which professionals, if any, had been involved with the children with TS that they knew of (table 20). 35% of parents and 16% of school staff reported no external professional involvement. Other responses recorded by participants included medical professionals, local services and therapists.

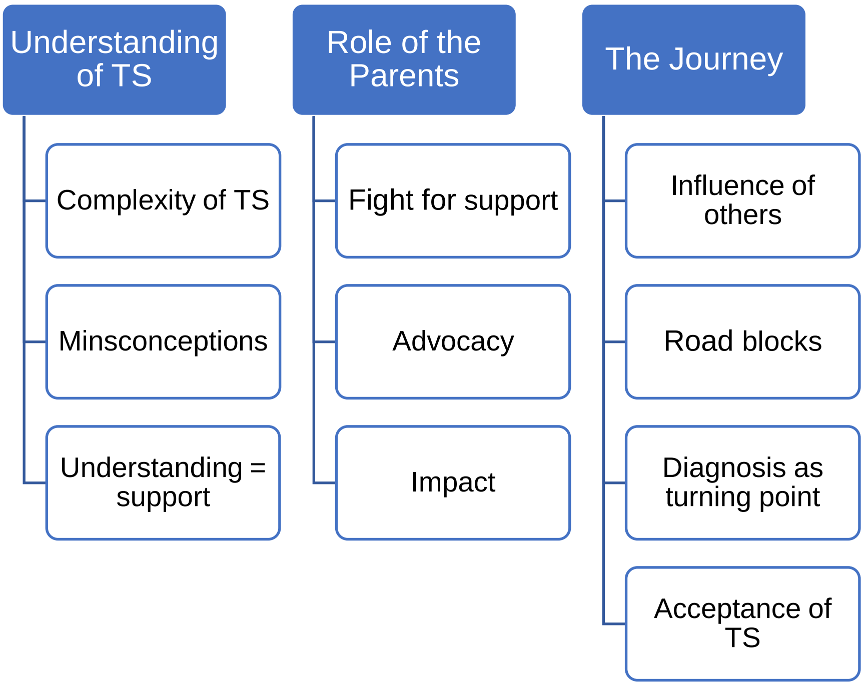
Table 20 *Involvement of external professionals to support TS in schools, reported by parents and school staff*

External Professionals involved in supporting CYP with TS	Parents		School Staff	
	N	**%**	**N**	**%**
Educational Psychologist (EP)	16	22%	6	24%
Occupational Therapist (OT)	8	11%	0	0%
Speech and Language Therapist (SaLT)	6	8%	1	4%
Emotional Literacy Support Assistant (ELSA)	8	11%	4	16%
School nurse	5	7%	5	20%
Children and Adolescent Mental Health Services (CAMHS)	9	12%	3	12%
None	26	35%	4	16%
Other	14	19%	2	8%

4.2 Part 2: Parent Interviews

Part 2 of the research involved interviews with 6 parents of children with TS. Analysis was guided by the IPA procedures outlined in appendix 21. Initial themes were conceptualised from each transcript before themes were mixed, transformed and arranged into superordinate and subordinate themes. Finalised superordinate and subordinate themes conceptualised from the 6 interviews are displayed in figure 6. Example quotations associated with each of the themes can be found in appendix 26.

Figure 6 *Thematic map of superordinate and subordinate themes conceptualised from interview data.*



4.2.1 Understanding of TS

The superordinate theme of ‘understanding of TS’ includes the subordinate themes of ‘complexity of TS’, ‘misconceptions’ and ‘understanding = support’. The understanding of TS as a complex and ever-changing condition was highlighted by all parents in interviews with many discussing the misconceptions around it and the importance of understanding in facilitating support for TS in schools. Each of the subordinate themes are discussed individually below.

Complexity of TS

Parents talked of the complexity of TS from their own experiences of having a child with the condition. There was a sense that TS was often seen as tics alone, particularly in schools, and that in their experiences there is more to TS than tics, as described by Ann:

> *“they don't realise about all the other things that would stop them from learning, you know, trying not to tic, you know, or it taking away their focus and stuff like that so”* (Ann)

Becky used a powerful analogy of an iceberg which she used to understand the range of symptoms and traits that might occur for her child with TS, some of which appeared to be congruent with other conditions.

> *"On the top of the iceberg, you've got motor tics and vocal tics … you've got the rest of the iceberg, and that icebergs got like 10 or 15, lots of different symptoms like OCD, ADHD, anxiety, rage, etc."* (Becky)

Conversations with all the parents suggested there was a need for TS to be better understood as a whole condition, beyond the tics that were on the surface. Parents talked of a wide range of TS symptoms, visible and invisible, that they noticed in their children and the impact these had on their child, which may not be recognised, as often only the visible tics appear to be noticed by those less familiar with the condition.

In addition to the range of symptoms, the context dependent nature of TS adds to the complexity of the condition, particularly in considering the school context. Diane and Emma both shared experiences of seeing their child with TS experiencing extreme tic attacks upon arriving home from school, often as a result of supressing tics.

> *"then when they come home. It's like a boiled pot just spilling over"* (Diane)
> *"the way he is at school is different to what he's like at home"* (Emma)

This suggests that the school environment may not feel safe for the children and lead to suppression of tics to avoid social judgement, however this often resulted in pain or exacerbating tics at home. The differing expression of TS at home and at school led to some challenges for parents in seeking to secure support for their child in school. Conversations around this gave the impression that suppression of visible tics in school would lead to school staff assuming that the child didn't need support or was managing well and may therefore reduce the support that is offered.

> *"people think that because they don't see tics if you're suppressing them in school, then he's okay"* (Fiona)

The complexity of each individual experiencing TS differently was also clear, with Ann highlighting:

> *"it's not a one rule for everyone. It's so completely different for every single child that has Tourette syndrome"* (Ann)

In addition, Diane, who has two children with diagnoses of TS, shared her experiences of both children presenting very differently in terms of symptoms and behaviours related to TS.

“My son and daughter are chalk and cheese, like, they're completely different. Yet, they've both got Tourettes” (Diane)

Parent’s experiences suggested that there is a need for this variability of TS to be understood and support to be individualised on a needs-led basis rather than a standardised package of support for all children labelled with TS.

Misconceptions

Parents shared experiences of people’s understanding of TS as a condition often being based on or influenced by existence of stereotypes of TS and misconceptions. Becky shared experience of her own exposure to stereotypes through TV and showed an understanding that these stereotypical views of TS may be difficult to avoid as this are often the only visible portrayals of TS to those who do not have direct experience.

“I think people like we did when we first found out know what they know from the, from the TV and the press and you think Tourette's and you think of swearing, because that's what you think and it's very naive and very stereotypical, but we all do it” (Becky)

In some cases parents took it upon themselves to support the understanding of school staff and address the misconceptions, as described by Fiona. Fiona, and other parents were involved in supporting school staff to understand that TS is more than and different to stereotypical representations of the condition.

“I've sent every teacher he’s had, I send the stuff from [charity name] and say this is, this is more, there's more to this than you think” (Fiona)

It was also suggested that the views held by others based on stereotypes can lead to school staff not believing a child has TS, as symptoms seen do not match expectations based on stereotypes. This highlights the importance of increasing understanding of the condition to ensure that parents and children with TS are believed and difficulties are supported appropriately.

“it’s that, that stereotype and he does, but the fact now they don't actually believe he's got it because of the fact that he doesn't do the things that they think he should be doing” (Emma)

Emma also described how peers holding stereotypical views of TS led to them not believing her son had the condition.

“he said well the people that I have sort of shared it with they say ‘ohh, you ain't got Tourette’s, you don't swear” (Emma)

This suggests that parents have experienced knowledge of TS being based on stereotypes which misrepresent the condition, often also suggesting their own understanding of TS was based on stereotypes prior to developing a deeper understanding of the condition following their child's diagnosis. The existence of stereotypes and media portrayals of TS suggest that many school staff may feel they are familiar with the condition, however their understanding of the condition may be skewed by these misrepresentations. Parents may play a role in addressing these misconceptions in order to increase understanding, acceptance and provision of appropriate support for children with TS in school.

Understanding = support

There was a sense from parents that an accurate and complete understanding of TS as a condition was necessary in schools in order for the appropriate support to be put in place. Understanding of TS as a whole appeared to act as a facilitator to support being provided and was important to parents. Overall, there was a sense that parents felt the general understanding of TS in schools was not adequate it was important to them for steps to be taken to increase this understanding.

> *"I don't think there's enough of an understanding from school, as to actually what those hidden disabilities mean for a child with Tourette's"* (Becky)
> *"really important to us that anyone that works with Adam should have a knowledge of Tourette's"* (Ann)

Parents shared negative experiences of lack of understanding of TS leading to inappropriate or unhelpful responses to tics or other symptoms related to TS, such as being told off for tics as described by Carol.

> *"we're having far too many days where she was coming back and saying I was shouted out for whistling or I shouted out for this [tic]"* (Carol)

There was a sense of injustice that appeared to be experienced by parents, in discussion of the way in which schools supported other, sometimes co-morbid, conditions, it was felt that these were better understood and perhaps taken more seriously by school staff. This was discussed in a general sense by Ann suggesting school are better equipped and show more willingness to support other conditions:

> *"for people with Tourettes they don't seem to get the same acknowledgement, level of care, as other things."* (Ann)

In addition, Fiona shared experiences of her Son, who has both TS and ADHD, receiving more support for ADHD symptoms than TS based difficulties.

> *"We've certainly had more support [for ADHD], there's certainly more recognition that, that, of what he's struggling with. So, the recognition that, yeah he is going to be struggling to sit still, which was never, never came into play with, with Tourette's diagnosis."* (Fiona)

This suggests that parents believed that schools may feel more confident and knowledgeable in supporting ADHD or other co-morbid conditions than TS, which appears to be less understood. It was also considered that levels of understanding or familiarity with a condition may be linked to the support offered and increasing understanding of TS in schools may lead to more acceptance and appropriate support.

4.2.2 Role of Parents

The ‘role of the parents’ superordinate theme represents parents experiences of the responsibilities and roles they have taken on as parents of children with TS in relation to seeking support in schools. This was captured in three subordinate themes; ‘fight for support’, ‘advocacy’ and ‘impact’.

Fight for support

Parents use particularly emotive language in describing some of the steps that they had taken in fighting for support for their child with TS. This experience was framed as a ‘fight’ with parents describing their role as having to ‘push’ or ‘struggle’ for support. While explaining the process parents used terms such as “fight for justice” (Becky) and “take drastic measures” (Diane) to explain the steps they had taken to ensure support for their child was in place at school. Language used at times suggested that parents felt they were fighting against school rather than feeling they were on the same team with shared goals in providing support for their child with TS. Parents talked of the effort required to secure the support in school and the confidence and persistence needed, as described by Diane and Ann.

> *“all these things as I said it took a bit of a fight, but, as I said, I think because I've been there and done that knew that you have to put your foot down.”* (Diane)
> *“we've had to push for everything that we've got basically, you have to be on the ball and, making sure that they are doing that all the time.”* (Ann)

Diane described feeling as though she needed to prove that her daughter was struggling in order to secure support. This suggests parents may experience some reluctance from school to provide support for TS symptoms, particularly if symptoms are not visible or obvious in school.

> *“I felt as if they were saying well we don’t believe you, So prove it. Prove it. And we're not, or we're not giving her the support”* (Diane)

Advocacy

Parents of children with TS had a shared experiences of taking up the role of an advocate for their child with TS. It was suggested that parents were often the only source of advocacy for their child and it was therefore important that parents advocate for their child both in school and in other settings. It was felt that parents didn't have a choice and that advocating for their children was an important aspect of their role as a parent, as summarised by Ann.

> *"You have to advocate for your son, because no one else is going to"* (Ann)

In advocating for their child, there was a sense of frustration for some parents with feeling that their voices weren't heard. Diane shared her views on the voice of parents of children with TS.

> *"I think, they need to listen to the parents more, because the, the school seems to be very focused on what the professionals thought what support the professionals wanted to put in place. But the parents are the ones that deal with the children, every single day, they're the ones that see the child, and what helps them, what doesn't help them and you know as much as the professional side is invaluable. I think sometimes parents can get kind of pushed to the side a bit."* (Diane)

This suggested that the parents should be seen as the expert on their child in advocating for them and that their voices should be listened to. There was a sense of bias in the professional voices being taken more seriously or given a greater value compared to parents. Advocating for their children was an important role discussed by parents which takes a commitment of time and attention, however the value others give to their voice and experiences appeared to be questioned at times.

Impact

The role that parents of children with TS take on appears to have a significant impact on the parents and family as whole. TS as a condition goes beyond impacting the diagnosed individual, with parents describing the whole family being involved. Becky described this:

> *"actually the diagnosis isn't just for the person it's for the whole family. It's a family diagnosis"* (Becky)

The impact on the parents was evident with Ann describing the impact of her role as a parent.

> *"it's quite an emotional ride, you know, going through something like this"* (Ann)

This ‘fight for support’ which parents found themselves in clearly had an impact on parents as they described feelings of guilt, dedicating time and attention to the fight and stress involved in the process.

> *“I just feel like just such a horrible person constantly haranguing the school. But you, you just have to.”* (Fiona)
> *“Yeah, yeah, I sent a lot of emails, I’m very annoying.”* (Carol)
> *“you feel like you're a pushy parent”* (Ann)

There was a sense that parents experienced feelings of guilt for continually contacting school to discuss support for their child and that they in some ways were made to feel that they were not fully supported by school in taking up this role to secure the best support for their child.

Additionally, the financial impact on the family in taking up their role to support their child with TS was discussed in the context of parents paying for tutoring and external professional input.

> *“we paid for him to have a tutor for four I think it was about for four years”* (Ann)
> *“so yeah that [EP] was from myself. Yeah, cost a fortune”* (Fiona)

In addition, the time and attention dedicated to securing school support was described by Ann, who felt a sense that this role took her time and attention away from work and family and adding additional stressors to her life. Again, there was a sense of guilt from Ann in not being able to give her full time and attention to other aspects of her life.

> *“I know it sounds terrible but you know we've all got life and work and family, and it's quite stressful when you're chasing something all the time.”* (Ann)

4.2.3 The Journey

Throughout discussions of parent’s experiences it was clear that each parent of a child with TS has undertaken a journey in securing support for their child with TS. Each of the parents were at different stages on their own individual journeys and had taken different roads along the way, however there was a shared experience of a long road to support for their child with TS in school. Each of these journeys included various individuals influencing the process, roadblocks which created challenges, turning points and a path to acceptance along the way.

Influence of others

Many of the parents discussed key individuals which had a strong influence on the journey to seeking support for their child with TS. For example, Fiona talked positively about a specific teacher who had been particularly supportive to her son and made had a positive influence.

> *"He had an amazing teacher when he got his diagnosis, and, you know, was, was very supportive"* (Fiona)

Likewise, Becky talked of a teacher who themselves has TS, and this personal experience was valued as it was felt that the teacher truly understood what the child would be going through, which previous teachers had found difficult to understand.

> *"she's had somebody that actually understands how it feels on the other side which has been amazing."* (Becky)

There appeared to be a range of experiences with different school staff, suggested there were not consistent levels of understanding or support in schools. However those individuals that were understanding or supportive stood out to parents and made a difference to their experiences.

> *"In terms of the teachers. That's been a bit hit and miss, some have been more supportive than others,"* (Emma)

The influence of peers was also discussed, in some cases peers led to challenges for the child with TS due to lack of understanding, name calling and teasing. For example Carol talked of peers deliberately trying to trigger tics from her daughter.

> *"when they [peers] realised that she, she was swearing that would be, they would try and set that off every lesson, it's what do we have to do to make her swear."* (Carol)

However, friends in school were seen to be a positive impact and act as a source of support, particularly for Carol and Diane's children.

> *"she's usually sat next to one of her friends so they understand what's going on. And they can support her and calm down and tell her to leave if she needs to, which has been really useful for her,"* (Carol)
> *"So they've been absolutely fantastic, so they have and she's, she's got some really good friends there."* (Diane)

Individual professionals were also discussed to have a key influence on the journey of these families, some in the medical field, as described by Becky talking about a doctor she had encountered.

> *"he was an absolute superstar. We had two meetings with him, and he just made us instantly feel better about the diagnosis talked us through what it was how we*

could support her, gave us all some family education which is what we needed." (Becky)

In addition, Ann talked of an Educational Psychologist who made a key difference through listening to parents.

"she was really good, really sort of listened to us and what how Adam was and, and what sort of things he needed." (Ann)

In discussion of various individuals that had influenced the journey to support for these families, the themes of being listened to, understanding and acceptance came through as important to parents of children with TS. In contrast, lack of understanding, not being taken seriously and teasing from individuals had a negative impact on school experiences. It was clear that even one individual at school could make a significant impact on the experiences that the child with TS and their parent have in ensuring they are comfortable and supported at school.

Road blocks

In talking of their journeys and experiences parents of children with TS shared several roadblocks that they had faced along the way. As well as limited understanding creating a barrier to support as previously discussed, there were several practical elements which appeared to create challenges for parents along their journey to support. Many of these roadblocks were based on processes and policies which made support of TS more challenging. These included funding difficulties in school as described by Fiona.

"there's lack of staff and it's lack of resources and or there's lack of funding" (Fiona)

In addition, lack of provision was discussed by several parents, suggesting that there were limited support options for children with TS, and that they were often turned away from services when seeking support. There was again a sense of injustice in discussions regarding provision and support services, with parents feeling children with other conditions had better access to services than those with TS.

"like many others around the country [place name] doesn't have provision for children with Tourette's" (Becky*)*
"And it feels like there are just so many roadblocks to getting them help, and being sort of flatly turned down by agency after agency" (Carol)

Ann demonstrated a sense of frustration that these roadblocks created barriers to support for her child in school.

> *“Yeah I think that's the hardest thing is, you expect your child to go to school, and if they need help, that they'd get it, not to be told, “oh we haven't got the budget for that”, Or, “oh they need to be two years behind to get any help”.* (Ann)

Parents also described experiences of going backwards when circumstances changed in school and lack of consistency. Changes between year groups seemed to disrupt continuity of support, with parents often feeling they needed to re-negotiate support with new, unfamiliar members of staff. For example, Emma shared experiences of having to build up support each school year when her son encountered different members of staff.

> *“we've got different staff, one is the same as last year but the rest of them seem to have changed. So feel a little bit, not necessarily back to square one. But back to say square three, or something”* (Emma)

Similarly, Fiona talked of support being withdrawn after summer holidays having previously been in place.

> *“we are week three in term, and there is no SEN provision plan in place, all his supported learning has been withdrawn, just from summer holidays to now”* (Fiona)

The unique context of a global pandemic was also discussed as a roadblock to support in schools for children with TS. Schools have been significantly impacted by the pandemic with uncertainty related to school closures, changes in school routines, classes and staffing. These changes have led to challenges for children with TS, many of whom can find change difficult. Parents reported difficulties particularly with staff changes and lack of awareness or consistency in support strategies for TS in school.

> *“it's [the pandemic] been really hard for the kids, because they sort of adapted and then adapted again and then come back in and half their teachers still aren't there.”* (Carol)
> *“So it [COVID] means there's a lot of supply teachers working and the supply teachers don't get that information unless it's put on the sheet, specifically by the class teacher they won't know”* (Carol)

Diagnosis as a turning point

While talking of their journey to support parents discussed various notable turning points of significance, their child receiving a diagnosis of TS was often seen as a key event on their journey. Parents shared a range of experiences upon receiving a diagnosis, with some describing feelings of relief and being able to move forward while others found this a difficult process of acceptance and a sense of the unknown.

> *“we found that [diagnosis] that was the best thing for us is to know what was wrong”* (Ann)
> *“It was a kick in the teeth to get that diagnosis”* (Becky)

Parents shared that in some cases, as described by Emma, receiving a diagnosis was a positive step in accessing support:

> *“And once that [diagnosis] happened, that seemed to kind of open a few more doors and the fact that the school is like, they actually believed him then.”* (Emma)

This suggests that without a diagnostic label schools may be reluctant to provide support, and that the label of TS appears to be vital in school staff recognising difficulties that Emma's son was experiencing. In contrast to Emma’s experience, Fiona described a lengthy journey to diagnosis and appeared to show disappointment with the lack of support following the diagnosis, feeling that it was left up to parents to secure support with school.

> *“yeah, you just presume it's at the start of doors opening, and actually, it's the end, if that makes sense, right, [service name] go: ‘Okay, so here's the diagnosis, thank you very much and get in touch, you know, in the future if there's any anything else’ and you're going, Well what happens next? Go, just go, tell school. So yeah so that whole thing is a bit of a shock.”* (Fiona)

Conversations relating to diagnosis as a turning point led to reflections about the purpose of diagnosis, for some this led to feeling believed and additional support in schools while others appeared to experience disappointment with a long journey to the diagnosis to find that it would not change support offered in school.

Acceptance of TS

The subordinate theme of acceptance of TS came through from parents, there was a sense that along their journey there was a process of learning to accept TS. This included their own acceptance of what it means to have a child with TS, which some found challenging as described by Fiona.

> *“It's that acceptance process. It, it, basically saying your child has a disability. That's really tough.”* (Fiona)

In addition, the process of supporting their child to accept TS as part of them was important to parents. Ann and Becky described difficulty their children have faced with accepting TS.

“He's always been a bit, umm, even now sort of in denial about it all.” (Ann)
“She wants to know why she's got it [TS] and nobody else has got it” (Becky)

Similarly, Emma talked of the challenges her son faced in accepted some of the tics he experienced and challenges of a parent watching their child facing these challenges.

“He gets really down with it, he like, ‘Ohh Mum lets just chop my brain out, I just hate having these’. It is really, Yeah It’s heart-breaking really sort of when he’s getting when he has quite bad, sort of episodes of them.” (Emma)

Overall, the journey to accepting and understanding TS as a condition and specifically what it means for each of the children and families in this research appears to be a long and challenging process. There was also a sense that parents felt they had limited support or information provided to them to support this process but instead it fell to them to accept and work to support others including school communities to accept and understand TS and how it impacts their child. In addition, parents found it challenging to see their children struggling to accept TS, feeling a sense of injustice and frustration that they have the condition.

5.0 Discussion

This research aimed to explore current practices for supporting CYP with TS in mainstream schools in the UK and parent's experiences and views of this support. Key findings related to both research questions will be discussed, alongside implications of the research, strengths and limitations and considerations for future research in the area.

5.1 Discussion of Findings

Findings from this research were consistent with those in previous literature in recognising the vast range of difficulties which CYP with TS may face in school. Commonly reported difficulties associated with TS were similar to those previously reported, including exhaustion, stress, anxiety and attention and concentration difficulties (e.g. Christie & Jassi, 2002; Edwards et al., 2017; Wadman, Glazebrook, Beer, et al., 2016). One finding in this area that was less prominent in the previous literature was the sensory difficulties experienced by CYP with TS. These types of difficulties were reported by 64% of parents and 52% of school staff in the questionnaires, suggesting sensory difficulties may impact many CYP with TS and this should be considered in ensuring environmental adaptations are made where possible to accommodate for specific sensitivities or difficulties. Overall, despite having different perspectives on the situation, parents and school staff completing the questionnaire reported broadly similar difficulties and appear to be in agreement on the key challenges for CYP with TS in schools. It is important to note that, as found from parental interviews, TS symptoms are reported to be context dependent, often presenting differently at home and at school. Recognition of the specific difficulties that each individual with TS experiences in school is key to ensuring that appropriate support can be tailored to their needs. In addition, consideration should be given to why TS symptoms present differently, for example, parents in interviews shared experiences of their children supressing tics in school, which may suggest that CYP with TS do not feel accepted or comfortable in school. The effort required to supress tics in order to avoid attention was described as having a detrimental impact on CYP in schools, and led to missed learning opportunities and implications for their mental health. Suppression of tics or modification of behaviour in the classroom may act as a social defence for CYP with TS in order to avoid attention or negatives reactions to tics (Krantz, 2010). Addressing this would require systemic changes to ensure the school environment is one that nurtures a sense of belonging and acceptance for CYP with TS.

Findings relating to current practices in supporting CYP with TS in mainstream school in the UK are fairly unique to this research as there is limited literature in this area. Overall, 18 categories were conceptualised from parent's qualitative questionnaire responses and 19 from school staff, suggesting there are a range of support strategies in place, which is unsurprising given the variety of difficulties that may require support in schools. There was, as expected, some commonality between parents and school staff responses with 'safe/quiet space' being suggested as a common support strategy by both groups of participants, this was also suggested as one of the most effective strategies by both groups. Many of the strategies reported to support CYP with TS align with the previously discussed reported difficulties. For example, attention and concentration difficulties may be managed by providing adjustments in exams, seating considerations and TA/LSA support. Feelings of exhaustion and anxiety may be managed by provision of a safe quiet space and opportunities to take time out of lessons. In addition, specific tools and strategies such as sensory toys and specific interventions/ groups would be beneficial for CYP with sensory and specific emotional or social needs.

Reference to individualised support plans or pupil plans were also among current practices reported, this is key to ensuring a person-centred approach is adopted in schools to consider each pupil with TS and their specific needs. This is important given the heterogenous nature and complexity of TS as described by parents in part 2. Findings related to current practices were aligned with findings from Wadman, Glazebrook, Parkes, et al. (2016) which utilised hypothetical scenarios for school staff to suggest strategies. School staff reported additional service involvement as one of the most common strategies used to support CYP with TS, suggesting that schools may not feel they have the expertise to support TS without this additional input. However, it would be beneficial to further explore the nature of this support as to whether external professionals support CYP directly or work to upskill school staff to support CYP with TS in schools. School staff rated their own confidence in supporting CYP with TS at an average of 5.2/10, suggesting additional support to increase staff confidence in this area may be beneficial.

Interviews with parents gave insight into the processes involved in arranging for support to be put in place to support their children in school. Experiences of parents highlighted their role in ensuring support was in place, language such as ‘fight’ and ‘push’ were used to describe the journey parents went through in securing support for their child. Parents felt that they had a role in providing information to school, advocacy and following up support. This process clearly took a toll on parents who described the impact this had on themselves in feelings of guilt, financial costs, consuming their time and attention and their mental health. However, parents felt that they didn’t have a choice and that this was part of the role of being a parent of a child with TS. This role of the parents highlights the importance of communication between systems and these relationships within the mesosystem of the Bronfenbrenner model (Bronfenbrenner, 1979) appear to play a key role in supporting CYP with TS in school.

Overall, in ratings of satisfaction with the support their child with TS receives in school parents gave an average rating of 4.8/10, this suggests that there are opportunities for this support to be improved. However, the range of these scores (0-10) suggests that there is considerable variation in the levels of satisfaction of parents based on support offered in different schools. In addition to the many support strategies reported to be in place, 30% of parents reported that no support was in place for their child with TS. This may suggest that some CYP with TS do not require support in school. However, comments that often accompanied reports of lack of support in school suggested that in some cases there was a reluctance to provide support, inconsistency in support provided and that school staff were unaware of which support would be appropriate due to lack of understanding of TS, this is consistent with findings from previous literature (e.g. Ludlow et al., 2018).

School staff knowledge of TS was a key area that parents felt acted as a barrier to provision of appropriate support for their children with TS. Questionnaire participants gave mean scores of 3.6 and 5.4/10 from parents and school staff respectively for school staff knowledge of TS, suggesting this is an area which may require some improvement. In interviews, parents were passionate about the importance of the school community understanding TS in avoiding stereotypes, understanding the complexity of TS and reducing the injustice felt by parents in TS being less of a priority compared to other conditions. In contrast, the positive impact that one member of staff can have in facilitating school support was highlighted by parents experiences and the effort from school staff was also recognised as an important and valued factor for parents. School staff in the questionnaire also recognised the value of awareness and understanding of TS amongst the school community as this was reported as one of the most effective support strategies. Therefore, it seems that there is agreement in the value of increasing awareness and understanding of TS in school communities, particularly in school staff. However, as recognised by parents in the interviews, there are challenges to overcome in budget, policies, staff shortages and an already increased workload on school staff.

Limited knowledge of TS appears to be a systemic issue both within schools and extending into the community. Parents shared experiences of peers, school staff and members of the wider community holding stereotypical views or misconceptions about TS, often linked to media portrayals of the condition. This is consistent with literature reporting on media perpetuating stereotypes of TS (Calder-Sprackman et al., 2014) and also highlights the influence of society, in the exosystem and macrosystem of a child’s world having an influence. This suggests that in order to support individual CYP with TS a wider systemic shift in the portrayal of TS in the media and society as a whole may be necessary.

5.2 Implications for Educational Psychologists

As demonstrated both in existing literature and the current research, CYP with TS can experience a range of difficulties in school which may require support. This research found that nearly a quarter of CYP with TS had received some EP involvement, and that EPs were the most common external professional involved in supporting CYP with TS. This section therefore considers implications for EPs that may arise from this research.

On an individual level, EPs may work directly with school staff, utilising skills in consultation, to understand how specific individuals with TS experience school and discuss appropriate adaptations and support. Encouraging staff to adopt a person-centred approach and promoting understanding of how individuals experience TS and how this may change will be important to ensure that school staff are adaptable in their approach and seeking the views of CYP with TS.

Given the TS incidence rate of 1% (Robertson et al., 2009) and the relatively low ratings of staff knowledge and the impact that lack of understanding is suggested to have on school support, it may be important to proactively increase awareness of TS in schools. Findings from this research suggested that only 29% of school staff participating had received in-school training on TS, with 50% reportedly receiving no training at all, suggesting a gap in provision of training to increase knowledge in this area. Working in a systemic manner EPs may have a role in providing training, signposting and bridging the gap between TS research and practice in schools, this may include collaboration with services or charities that are already offering training packages to ensure these are based on relevant research. EPs may also be able to support schools with peer education to increase acceptance of TS within the entire school community. However, it may be necessary to consider the confidence levels of EPs in doing this and where necessary, build knowledge of TS amongst the EP community, utilising existing research and information sources such as charities.

In addition, with regards to findings about the role of parents in securing support for their children in school, there could be a role for EPs in mediating interactions between parents and school staff to ensure appropriate actions are taken and the child is remaining at the heart of the process. This may benefit parents in supporting them to feel that their voice is heard, which was highlighted as a barrier for parents in the current research. Supporting schools to understand the impact which TS can have on a whole family may allow for increased empathy and understanding from school staff and encourage strong communication and relationships between home and school.

5.3 Strengths and Limitations

The strengths and limitations of the current research are outlined in table 21.

Table 21 *Strengths and Limitations of the current study.*

Strengths	Limitations
A large sample of parents of children with TS participated in the questionnaire (part 1).	In comparison to the number of parents, relatively few school staff participated in part 2 of the research. Small staff sample size limits the generalisability of these results.
Participants for both part 1 and part 2 came from across the UK, increasing the extent to which results may be generalised.	The views and experiences of school staff were not explored to the extent that parent's views and experiences were, overall results may therefore be biased towards the views of the parents.
School staff and parents of children with TS reported experiences from a range of mainstream school settings, including primary and secondary, this increases the extent to which findings may be generalised across settings.	Parents of CYP with TS were recruited through a charity supporting TS, they may therefore have some support through the charity, both at home and in school – this may bias results.
The number of parents interviewed in part 2 is suitable for a small scale research project using IPA (Smith et al., 2009).	Participants volunteering for interviews may have been more likely to do so if they had particularly negative or extreme experiences to share regarding support for TS in schools, this may have biased results.
Parents interviewed in part 2 of the research represented children with TS of various ages, in different school settings, with various co-morbidities and of different genders, increasing generalisability.	The researcher had fairly limited experience of conducting research interviews and using IPA procedures.
Use of semi-structured interviews allowed for flexibility in the interview schedule to explore specific experiences of parents being interviewed.	IPA is most successful with a homogenous sample, given the heterogenous nature of TS, this was not possible. In addition, interviews with parents whose children attended primary and secondary school also limited the homogeneity of the sample.
Conducting interviews online, using virtual platforms allowed flexibility in arranging a time for the interviews, there were also no requirements for parents or the researcher to travel. Being interviewed in their own home may have allowed participants to feel more comfortable than they might have done in an unfamiliar environment.	Conducting interviews using virtual platforms meant the researcher was more restricted in terms of interpreting body language or gestures made by participants. In addition, having participants interviewed from their own homes meant there were opportunities for distractions and background noise. Parents may also have been wary of sharing their experiences or views if other family members (such as their child with TS) were within hearing range.
Triangulation of data from different sources allows for inclusion of multiple perspectives (Krahn & Putnam, 2003) and triangulation	

from different data collection methods balances out limitations of individual methods of data collection (Todd et al., 2004).	
IPA coding and themes were checked by an independent researcher, familiar with the IPA process to reduce opportunities for researcher bias in analysis of interviews.	

5.4 Future Research

Future research directions in this area could include:

- Exploration of the views of CYP with TS with regards to their experiences of school, support they receive and how TS impacts their schooling.
- Exploration of the knowledge and experiences that EPs hold of TS as well as their views on the role of the EPs in supporting TS.
- Evaluation of the impact training has on school staff’s knowledge of TS and practices.
- In depth comparisons of practices to support TS across a range of settings, including specialist provisions, primary settings and secondary settings.

6.0 Conclusion

This study explored the current practices for supporting CYP with TS in mainstream schools in the UK and parents' experiences and views of school support for their child. CYP with TS were found to experience a range of difficulties in school; the most common of which were reported as being sensory difficulties, stress or anxiety, exhaustion and attention and concentration difficulties. Schools are reported to support CYP with TS in various ways, the most common of these are: providing a safe quiet space, opportunities for time out of lessons, involvement of external professionals and exam arrangements. It was also reported by many parents that their child's school had little or no formal support in place for TS. Interviews with six parents of children with TS gave insight into their experiences and led to the conceptualisation of three superordinate themes. Parents talked of the complexity of TS as a condition, misconceptions and the limited understanding that others, including school staff have of the condition. The role that parents of CYP with TS play in securing support was often discussed, with parents feeling they are 'fighting' for support, advocating for their child and that taking up these roles can have significant impact on parents. Finally, each parent talked of the journey that each family has taken to get to where they are today which including a range of facilitators and barriers. Of the parents interviewed each had unique stories, however the themes that emerged represent some shared experiences for parents of CYP with TS. This research highlights the range of difficulties that CYP with TS may experience in school and the range of support that is currently in place in schools for supporting TS. However, findings suggest that from a parental perspective they are not completely satisfied with support offered and feel there are opportunities for improvement in schools. Knowledge of TS in schools, both in school staff and peers, is reported to be based on stereotypes and this is an area in which systemic change would be beneficial to increase acceptance of CYP with TS. Implications for EPs following this research may involve a role in training school staff to increase knowledge of TS, mediation between parents and school to clarify roles and manage potential conflict and supporting CYP with TS directly with their difficulties in school utilising a person-centred approach.

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An Exploration of Support for Children and Young People with Tourette Syndrome in Schools

Part C: Critical Appraisal

Word Count: 7,405

1.0 Overview

This critical appraisal will aim to evaluate the current study and the decisions made in a reflexive manner. Reflexivity is suggested to be important in research and practice in the field of Educational Psychology to recognise and understand our own assumptions, beliefs and social constructions and utilise skills in reflection to inform future practice (Moore, 2005). This account has been written in first person to allow opportunities to explore and present my own experiences as the researcher as well as recognising my role and influence as part of the research process. Pellegrini (2009) recognised the importance of use of first person in reflexive writing to consider the researcher as an embedded part of the system rather than an outsider looking in.

This critical appraisal is presented in two sections. The first section gives an overview of how this research contributes to the existing knowledge in the area and considers dissemination of findings. This section will include discussion of: the origins of the research topic, discussion of the literature review, how the current study relates to existing literature and consider dissemination of research findings. The second section will consider decisions made during the research, including discussion of methodology, recruitment, analysis and ethical considerations. My own position as a researcher will be discussed alongside reflections of the process.

2.0 Contribution to Knowledge and Dissemination

2.1 Development of the research topic

My areas of interest as a Trainee Educational Psychologist (TEP) have been varied and thus I found the process of selecting only one topic as a focus for a thesis incredibly challenging. Through my practice as a TEP I recognised the wide range of difficulties that Children and Young People (CYP) in schools experience which may lead to additional support in schools. Having worked with CYP with Tourette Syndrome (TS) in a previous role I was aware of some of the misconceptions that can be held in relation to this as well as some of the difficulties that CYP with TS may face in school. In my experience TS was often an area that school staff were not as knowledgeable about compared to other conditions/ disorders. This was reinforced while working as a TEP with experiences of school staff being unsure how to support CYP with TS in schools. This led to a curiosity about the support that is currently in place in schools for CYP with TS.

2.1.1 The current context

The context and the ongoing impact of the COVID-19 pandemic cannot be ignored in any current research considering the education system. The unprecedented disruption to daily life over the past two years has included school closures, national lockdowns and restrictions. The impact of the pandemic on both adults and children included increased stress, reduced support, reduced access to coping strategies and challenges in accessing resources (Clemens et al., 2020). It has been suggested that the largest impact of the pandemic, including on mental health, will be on the younger generation (Racine, Korczak, et al., 2020). Considering this context for CYP with TS, research suggests that symptoms of TS often increase with anxiety and stress (Eapen et al., 2004), and given the increased levels of anxiety and stress in CYP during the pandemic (Racine, Cooke, et al., 2020), it could be expected that TS symptoms may worsen. Research has supported this with findings suggesting that there has been an increase in symptoms in CYP diagnosed with TS and other tic disorders (Heyman et al., 2021). In addition to existing TS symptoms worsening, there is an emerging body of literature suggesting that there are increasing numbers of CYP experiencing initial onset of tics and TS. Pringsheim et al. (2021) reported an increase in rapid onset of motor and vocal tics, termed Functional Tic-Like Behaviours, particularly in adolescent women since the beginning of the COVID-19 pandemic. During interviews in my own research some parents explicitly mentioned an increase in TS during the COVID-19 pandemic, referring to either personal experiences or articles they had read. These findings, although in the early stages of research, may suggest that cases of tic disorders may be increasing and the difficulties CYP with TS face may become more salient, suggesting appropriate support in school is particularly important in the current context. It is therefore timely to explore the support these CYP are receiving in school and how this support is perceived by their parents.

2.2 Exploration of the Literature

Upon deciding on a general topic area, a literature review was conducted to explore the existing literature about TS in schools, to be able to construct research questions. When defining search terms for the literature review I chose to use broad search terms with the aim of not missing any relevant research, this also included considering terminology that may be present in literature from different fields. As there was limited research conducted in the UK, the decision was made to include research extending beyond the UK. This was deemed appropriate as criteria for diagnosis of TS are consistent internationally using the Diagnostic and Statistical Manual of Mental Disorders (5th ed; DSM-5; American Psychiatric Association, 2013) and International Classification of Diseases and Related Health Problems (11th ed; ICD-11; World Health Organisation, 2022). However, I did recognise that school systems would vary between countries and this would need to be considered when interpreting findings. In addition, literature related to involvement of Educational Psychologists (EPs) with TS in the UK was limited and international research considering School Psychologists (SPs) was useful in providing insight into the role of practitioner psychologists supporting TS within school contexts. To supplement research found through searching of relevant databases, I found additional literature through grey literature searching, reference chaining and hand searching of relevant journals. These techniques are suggested to be effective in identifying literature missed from searching of databases (Dixon-Woods et al., 2006). The search stage of the literature review returned considerably more results than expected, this led to a lengthy process of screening results (appendix 2), which I felt was necessary to ensure important research was not missed.

Reviewing the literature presented challenges in identifying relevant literature from a large body of research from various fields. The various aetiological theories and treatment routes meant that there were many areas to explore and it was challenging to select only the most relevant to consider within the literature review. In particular, the large amounts of medical research in the field of TS created challenges as I spent a lot of time aiming to understand the research in order to summarise findings or theories. Initially in reviewing the literature I found challenges in finding balance between the range of theoretical perspectives and reviewing only findings that were key to providing an overview without too much detail.

The decision to conduct a narrative literature review was made as this provided opportunities for me to include literature from a range of fields and with diverse methodologies to suit the breadth of my topic (Siddaway et al., 2019). There are however some limitations of narrative reviews, including lack of reproducibility and potential researcher biases (Siddaway et al., 2019). I was aware of potential bias, particularly given my previous experiences in the field, a common difficulty in conducting narrative reviews presented by Green et al. (2006). I aimed to avoid this bias by presenting research critically and objectively. I felt that these limitations were outweighed by the opportunities a narrative review provided in offering an overview of the field in a readable format as suggested by Green et al. (2006). As highlighted by Baumeister and Leary (1997) there is little guidance for researchers around writing narrative reviews, and having limited experience of this myself it was important I spent some time understanding the process of conducting a narrative review. The Scale of the Assessment of Narrative Review Articles (SANRA) (Baethge et al., 2019) was considered throughout, with the aim of producing a quality review based on the elements of SANRA.

2.3 Development of the Research Questions

Following an extensive review of the existing literature, the following research questions evolved:

- What are the current practices for supporting CYP with TS in mainstream schools in the UK?
- What are parent's experiences of school support for their child with TS?

It was clear that there was limited literature exploring the practice of UK schools in supporting CYP with TS. Previous research in this area (e.g. Wadman et al., 2016) had presented hypothetical situations to school staff and asked how they would support a CYP with TS in school rather than asking about the support they actually have in place. In addition, investigation of parents' experiences of the support school put in place for their child with TS was a limited area of research and I felt this exploration of experiences would provide increased depth to the findings about TS support in schools.

2.4 Contribution to the field

Many findings from this research are consistent with those reported in previous literature, including findings from international research. Difficulties experienced by CYP with TS in school, reported by parents and school staff, were consistent with existing literature in reporting; maintaining attention and concentration, anxiety, stress and exhaustion as common challenges. This study also reported sensory difficulties for CYP with TS, this was not commonly discussed in previous research, and presents implications for raising awareness of this in schools in order to provide support where necessary. This research highlighted a range of support strategies that are currently in place for CYP with TS, many of which were consistent with previous literature. Support often in place for CYP with TS in schools included provision of a quiet space, opportunities to leave the classroom and specific exam arrangements. School staff also suggested CYP with TS may be referred to receive support from external professionals.

In this research, school staff's knowledge of TS was reported to be fairly low, this is consistent with previous findings and suggests that despite previous research highlighting a need for school staff to be more aware of TS, there still seems to be limited knowledge of TS in mainstream schools. Findings from parents perspectives suggest that support in place for CYP with TS appears to be, at least to some extent, mediated by the understanding and knowledge that school staff have of TS. It was suggested the lack of knowledge led to inappropriate or unhelpful interactions which exacerbated difficulties for CYP with TS. Parents also shared experiences of specific members of staff with knowledge of TS being facilitators of support for their child and highlighted the importance of the whole school community understanding TS. This research therefore suggests that improving knowledge of TS in schools is an important step in improving support.

Findings related to parent's experiences gave insight into the 'journey' that families face in securing support in school for a child with TS. The process of securing support was framed as a 'fight for support' in interviews and the impact of this on the parents, CYP with TS and wider family were clear. This finding presents implications for schools, professionals and other services to be aware of the impact that these experiences can have on the family of a CYP with TS and ensuring that support is available for the wider family system.

2.5 Implications for Practice

Findings of this research may have implications for the practices of mainstream schools in the UK as well as professionals working with these schools such as EPs. Given that TS is suggested to affect 1% of school-aged children (Robertson, 2008), it is fairly likely that schools will encounter CYP with TS, and may be required to provide support in school. The insight provided by this research into current practices highlighted some potential areas for improvement, such as increasing school staff and peer knowledge of TS, support for the wider family and considering every child with TS as unique with individualised needs. EPs may be in a position to support schools with increasing knowledge of TS for school staff and pupils and supporting schools to consider appropriate person-centred support for individual CYP. Inclusion of parents of CYP with TS in decisions related to support is also an important implication for schools to consider. Parents shared experiences of advocating for their child, sharing information with school and continually 'fighting' to secure support, actively including and valuing parental contributions may alleviate feelings of guilt that parents reported from chasing up support from school and support them to feel that their voices are heard. In addition, challenges associated with the heterogeneity and changeable nature of TS, may be supported by schools actively engaging with parents to support each CYP with TS in a person-centred way, with the view to understand what TS means for each CYP and their family individually, as described by Smith et al. (2015). EPs may also be asked to support schools with this, utilising skills in consultation and mediation to enable dialogue between the home and school systems to ensure all perspectives are valued and communication between systems is ongoing.

2.6 Dissemination

Dissemination is key to ensure that research such as this can be useful in practice and changes can be implemented, however this process requires careful consideration and can present challenges (Fox et al., 2007). Sharing findings of this research may support to build understanding of difficulties that CYP with TS and their families experiences and how schools may be able to support CYP with TS most appropriately. One way to share this research may be through charities aimed at supporting CYP with TS and the systems around them. However, it is acknowledged that these charities are mostly used by parents and families of CYP with TS, therefore, although findings may be interesting and provide information to share with schools, this method of dissemination may not have the intended impact across schools and the education system. A lay summary of this research will be shared with the charity that supported recruitment to be disseminated through their website and social media. Consideration will also be given to how this research may be used by the charity to support development of their work within schools, this may include collaborating to develop their training offer to schools and ensuring information shared is utilising relevant research findings.

Another method of dissemination may involve EPs and their role in supporting schools. EPs often support schools through training in specific areas to improve the skills of school staff and consequently improve the provision of support for CYP. By sharing findings with EPs this may encourage discussions about TS within schools that EPs work with and lead to implementation of more appropriate support for CYP with TS in schools. Personally, I would like to ensure that this research is impactful by sharing information with schools that I may work with in the future, this may involve producing a training package about TS, leaflets or specific advice in consultations.

2.7 Future research

As highlighted in part B there are various opportunities to expand on this research. One area which will be particularly valuable would be to research the views of CYP with TS in relation to their school experiences and support received. Careful consideration as to how views may most appropriately be gathered would be required, tools from Personal Construct Psychology (PCP) (Kelly, 1955), such as ‘the ideal school’ may be valuable in gathering CYP’s views about school without putting pressure of interviews or focus groups on the CYP with TS. In addition, consideration as to effectiveness of current support practices in supporting CYP with managing TS symptoms may be valuable. This may involve CYP and school staff rating the effectiveness of support strategies used in schools. Considering the ease and cost of implementation alongside effectiveness may be valuable in considering efficiency of provision for CYP with TS in schools.

Alongside implications for EPs highlighted from this research, it may be valuable to further explore the role of the EP in working with CYP with TS, this might include gathering information about EP’s experiences of working with TS, their knowledge of TS and confidence in supporting schools with supporting CYP with TS.

3.0 Critical Account of the Development of the Research Practitioner

3.1 Development of the Research Paradigm

The paradigm used in research represents the basic beliefs and the way in which a researcher views the world (Guba & Lincoln, 1994). Prior to any considerations related to design of the research it was vital that I spent time considering the ontological and epistemological position with which I would approach this thesis. The concepts of ontology and epistemology were fairly new to me at the beginning of the doctorate, having previously only conducted research from a positivist stance with quantitative designs during undergraduate studies. Exposure to and increased familiarisation with a social constructionist stance through use of the Constructionist Model of Informed and Reasoned Action (COMOIRA) (Gameson & Rhydderch, 2008) in my practice as a TEP opened my eyes to different ways of viewing the world.

Through consideration of a spectrum of research paradigms I decided that a critical realist ontology with a contextualist epistemology was the most suitable approach to adopt. Consideration was given to a range of ontological and epistemological positions. In terms of ontology, a realist ontology, which considers a single truth to be accessible through research (Braun & Clarke, 2013), was considered, however as this research aimed to gain insight into the perspectives and experiences of participants rather than a single truth, this did not appear to align. In contrast, a relativist ontology, which recognises multiple constructions of the truth (Braun & Clarke, 2013), may not account for the truth of TS existing as a diagnosable condition. Therefore, a critical realist ontology which recognises the existence of truth which can only be accessed through socially-constructed knowledge, was decided to be the most suitable. In considering epistemology, a positivist stance, which assumes an observable truth exists to be researched (Braun & Clarke, 2013), limits opportunities for participant's own constructions to be included in the research. On the other hand, the constructionist view, which considers all knowledge to be socially influenced (Braun & Clarke, 2013), does not account for a shared truth. However, in aiming to gain insight into the current support for CYP with TS, it was felt that there was, to some extent a truth to explore, whilst recognising the impact of context, leading to a contextualist epistemology.

3.2 Development of Research Design

The ontology and epistemology led to the development of the research design, utilising a mixed-methods approach. Methodological triangulation was selected with the view to increase completeness of data as described by McEvoy and Richards (2006). Madill et al. (2000) describes triangulation for completeness as a strength of contextualism in retaining novel perspectives related to the same topic, in this case school support for CYP with TS. I considered focussing on interviews alone, with parents and school staff with the view to understanding support in place for CYP with TS in schools, however, I felt that this would limit opportunities to gain a broad understanding of the support that schools put in place by being limited to smaller samples. In addition, I considered only using questionnaires, however the limited depth of information that can be gathered using questionnaires meant that I would not be able to explore the parents' experiences in depth to be able to discover their views of support for CYP in schools. Utilising a mixed-methods approach can, to some extent, balance limitations of individual methods (Todd et al., 2004).

3.2.1 Part 1

Questionnaires provide an opportunity for a large sample of participants to share their own experiences of their 'truth' relating to current practices for supporting CYP with TS as well as sharing their views of support. Use of questionnaires therefore create a more extensive picture of current practices across the UK than would have been possible through methods with smaller samples, such as interviews or focus groups. In this research the broader information gathered in questionnaires could be used in conjunction with data gathering from in depth parent interviews. Use of an online rather than paper questionnaire increased the opportunity for the questionnaires to reach participants in a range of geographical locations, were quick and easy to share and complete and enable anonymity (Wright, 2005). It is however acknowledged that the use of online questionnaires required participants to have and be confident in using a smart phone or computer to access the questionnaires and therefore may have excluded participants on this basis, thus potentially biasing results. Consideration around the depth of data that could be gathered through use of a questionnaire was important, I recognised that questionnaires limited my opportunities to gather in-depth views and experiences from participants, however, I aimed to overcome this by using open-ended questions and providing occasions to enter additional qualitative information at various points in the questionnaire. In addition, I used an open-ended question to gather information about the support in place in schools, with the aim of avoiding influencing results by providing examples of support, as this may have led to school staff selecting responses based on the view that these might be appropriate support strategies rather than responding with strategies that are actually in place.

I created different versions of the questionnaire for parents and school staff to ensure that the wording of the questions was appropriate (appendices 3&4). However, in order to triangulate results I aimed to gather data on the same areas from the two sources. I recognise that school staff responding to the questionnaire may have been answering questions in a more general sense from experiences with more than one child with TS while parents were specifically answering about their child with TS. However, considering the purpose of the questionnaire to gather a general overview of support for TS, this was not seen as a problem.

3.2.2 Part 2

Part 2 of this research involved interviews with parents of CYP with TS to explore their experiences of the support their child's schools provides for TS. I decided to use an Interpretative Phenomenological Analysis (IPA) approach to this part of the research to explore the experiences of participants in-depth. IPA, as an approach, fits with the critical realist ontology adopted as it recognises individual's interpretations of a specific phenomenon or truth (Alase, 2017), in this case support for CYP with TS in schools. Use of semi-structured interviews was determined as the most appropriate method for this part of the research as the semi-structured nature allows for flexibility to explore individual experiences. I created an interview schedule with prompts as a guide during the interviews (appendix 16), and also emailed the participant prior to the interview with an overview of topics that would be discussed. As I moved through the interviews, and gained confidence in my role as the interviewer, I found myself relying on the interview schedule less and the interviews flowed as more natural conversations which allowed the participant to share their experiences, being gently guided by my prompts. I found that having already told the participants the areas that would be discussed in the interviews helped to guide them to share their experiences relevant to the research questions. Alternative methods such as focus groups may have been used, however as a key feature of IPA involves exploring individual experiences, interviews were considered more appropriate. Individual interviews also avoided biases associated with the phenomenon of ‘groupthink’ which can occur in groups such as focus groups (Carey & Smith, 1994).

As this research was conducted during the COVID-19 pandemic, the interviews were conducted using virtual means, using Microsoft Teams or Zoom. Participants were informed of this prior to volunteering to be interviewed, it is acknowledged that this may have acted as a barrier for some participants in volunteering as they may not have felt confident in using, or had access to these services. Conducting the interviews virtually rather than in person presented a range of advantages and challenges from my perspective, these are presented in table . In aiming to overcome some of the challenges of virtual interviews I ensured there were opportunities for building rapport prior to starting the interview. Many participants were familiar with virtual meetings through their own work and therefore were confident and comfortable in accessing and participating in virtual meetings which was helpful to the process.

Table 22 *Advantages and challenges of virtual interviews*

Advantages of virtual interviews	Challenges of virtual interviews
- Flexibility in arranging a time for interviews. - Less time required from the participants (eliminating travel time etc.) - Participants able to be interviewed in a familiar and comfortable place for them, which may have made them feel more relaxed and comfortable.	- Rapport building was more difficult using virtual means. - Participants were occasionally distracted by children, pets or other things around the home. - Limited view of body language or gestures used.

- Opportunity to access participants across the UK – this may not have been possible in person.	- Difficulties with internet connection occasionally interfered with sound quality. - Participants may have been reluctant to share some details with other family members within hearing distance, including the CYP with TS.

3.3 Selection and Recruitment of Participants

3.3.1 Participants

This research gathered data from school staff with experience of working with CYP with TS and parents of CYP with TS. In my work as a TEP I strive to work in a person-centred way and endeavour to ensure the child's voice is heard in any situation which may relate to them, however felt that in this research it would be most appropriate to gather data from school staff and parents of CYP with TS. Given that this is an area with limited existing research I felt that perspectives from parents of children with TS and school staff would give an overview of the topic, this could then be built upon in future research involving CYP. Parents and school staff were able to provide an overview of difficulties and support from the perspective of both the home and school systems. This may have been challenging to explore with CYP as I wondered how much awareness of the policies and processes involved in support them in school they might have. In addition, the context of the COVID-19 pandemic meant that data gathering online may be necessary, which may have presented additional challenges and anxieties for CYP with TS at what research has shown to be a time of increased anxiety (Racine, Cooke, et al., 2020).

The questionnaire phase of the research gathered views from both school staff and parents of CYP with TS. Gathering information from different sources allowed for triangulation of data based on different perspectives (Krahn & Putnam, 2003). I felt that utilising information from school staff alone about practices in school may present a biased representation of findings in part 1 of the research. School staff questionnaires may be subject to social desirability bias, with staff aiming to present their school and the support they put in place in a more positive light, it was hoped that this was minimised by encouraging staff to share experiences of current practices rather than their views on support that should be offered for CYP with TS. In recruiting school staff for part 1, only school staff with experience of supporting CYP with TS in schools were recruited to ensure that data reflected real practice of support for TS in schools, however it is recognised that staff who have been involved in putting support in place may have been more likely to respond to the questionnaire than those that have worked with a CYP with TS where no or little support is in place, thus potentially biasing results. In addition, research has shown that participants are more likely to provide responses to questionnaires when they have an interest in the topic, suggesting school staff with a specific personal or professional interest in TS may have been more likely to respond to the questionnaire, this may have biased findings (Saleh & Bista, 2017). It was decided that school staff would be recruited for part 1 but not part 2 of the research as the focus of research question 2 was on the perspective of parents, it would however also be interesting to further research staff perspectives and experiences of school staff in supporting CYP with TS in future research.

Recruiting parents as participants for both part 1 and 2 of the research allowed for a different perspective on the situation and also gave a wider systemic overview of experiences related to supporting CYP with TS in schools, beyond what may be visible to school staff. Fox et al. (2007) highlights the importance of parental participation in education research as they are key stakeholders. Parents are often viewed a experts on their child, and research related to TS suggests that parents have a good understanding of their child's needs in school (Shady et al., 1988). This suggests that parents can provide valuable insight in this research and their contribution is useful. It is recognised that in recruiting parents, those with extremely positive or negative experiences of school support for their child with TS may have been more likely to participate in the questionnaire and also volunteer for the interviews. A relatively large number of parents completed the questionnaire (n=102), and over a third of these parents volunteered to be interviewed (n=37), although the design of the research allowed for only six of these to be interviewed. The number of volunteers for interview surprised me as I had expected very few parents would want to give up their time for the research, particularly after already completing the questionnaire. This high level of parental interest in the research suggests that parents are motivated to be involved in research about TS and have experiences that they want to share. This was reflected in conversations during interviews with parents sharing their enthusiasm to be involved in order to encourage changes to support for TS and to ensure that their voices and stories are heard. I was initially disappointed that I was only able to interview a small proportion of the parents that volunteered as I recognised that each of these parents had a story they wanted to share with me. I utilised a ‘first-come first-served’ approach to select which participants would be interviewed, feeling that this would be the most appropriate method to ensure a random sample of parents were interviewed rather than selecting specific participants based on characteristics. However, I could also have selected to interview participants to represent a range of ages of CYP, geographical locations or type of school to ensure these were included in the sample.

Recruitment of parents of CYP with TS was assisted by a charity supporting families with TS sharing the research poster (appendix 12). It is recognised that this method of recruitment may have led to bias, as the families accessing the charity, and therefore being exposed to the research poster, may be those with more extreme or negative experiences that have required support from this charity. Parent’s accessing charity support may also have been more proactive and knowledgeable in working to support their child which may not be representative of all parents of CYP with TS.

As previously mentioned there were fewer school staff compared to parents recruited for part 1(n=47) with only 25 of these being included in the analysis. It is recognised that this relatively small sample size limits the generalisability of findings. One possible reason for the smaller number of school staff may have been the challenges with sharing the research poster. The research poster and questionnaire link for school staff were shared by a TS charity, which does have some resources for school staff and therefore may have reached some school staff in this way, however as the charity’s main focus is families, any school staff accessing the research through the charity would be likely to be accessing the charity website or social media channels based on a specific interest in TS and therefore may have biased responses. In addition, school staff recruitment utilised social media, and specific education hashtags to share the research, although this did lead to questionnaire responses, the pressures on school staff, particularly during the COVID-19 pandemic, may have limited engagement with the research. I also considered sharing the research via Educational Psychology Services (EPSs), with the hope they could share the research to schools within their local authorities, however, I wondered if school staff may have felt the research would be evaluating their practices if it came via their local authority. In addition to challenges of sharing the research widely, school staff viewing the research poster could have been less motivated than parents of CYP with TS to participate. Parents may have seen the research as an opportunity to influence change for the benefit of their child and others with TS, while school staff may not have been as motivated to contribute.

3.3.2 Inclusion and Exclusion Criteria

Inclusion criteria for school staff in part 1 of the research was defined as any member of school staff that had experience of supporting/teaching at least one child with TS, between 10-16 years-old, in a UK mainstream school. I decided not to limit the member of staff to teachers alone as I felt that any member of staff that viewed themselves as having experience with supporting CYP with TS would have a valued insight into how their school provides support. I was aware of the ambiguity of the term ‘supporting/teaching’ in the research poster, however, I hoped that by using the words supporting and teaching this would allow support staff with valuable insight to feel that they could contribute. Similarly, inclusion criteria for parents in part 1 and 2 of the research was defined as any parent or carer of a CYP aged between 10-16 years with a diagnosis of TS currently attending a mainstream school in the UK.

For the inclusion of school staff and parents of CYP with TS, it was stipulated that they should have experience working with or be the parent/carer of a child between the ages of 10-16 years with a diagnosis of TS. The age range of 10-16 years selected based on evidence that symptoms of TS tend of be at their most challenging at age 10 years (Leckman et al., 1998), suggesting that this may be the age at which school support may be most necessary. The cut-off of age 16 years was included to ensure that experiences shared were based on mainstream school-aged years rather than additional experiences at further education institutions which may have differences in the support offered. This age range allowed for inclusion of discussions related to both primary and secondary school experiences. It was also stipulated that only school staff and parents of CYP with TS in mainstream schools within the UK would be included, this was decided as specialist provisions would be likely to have additional knowledge of Additional Learning Needs (ALN)/ Special Educational Needs (SEN) and TS and therefore support for CYP with TS may look very different in these settings. The UK as a whole was included in the research, although it is recognised that education systems within the UK differ across the nations, it was felt that there were sufficient similarities in ALN/SEN practices, inclusion and person-centred practices to explore TS support across the UK. I decided to focus only on support for CYP with a diagnosis of TS, rather than being on the pathway to diagnosis or having a diagnosis of other tic disorders. The focus on diagnosed TS allowed for a more homogenous group, which is important for the IPA process, although the heterogeneous nature of TS as a condition is acknowledged. I do however recognise that there may be many similarities between CYP with other tic disorders and TS.

3.4 Data Analysis

Data analysis in this research was completed in two phases. The first phase involved IPA of the data gathered from interviews with parents of CYP with TS and the second phase involved analysis of parent and school staff questionnaires using descriptive statistics and content analysis. The decision to conduct the analysis in this way was deliberate to aim to reduce the data from questionnaires influencing my interpretation of interview data, particularly as IPA relies heavily on researcher interpretation. I felt that the analysis of the questionnaire data would be less easily influenced by already having analysed the interviews as the data analysis procedures for this is more prescriptive and required less of my own interpretation.

3.4.1 IPA

The process of IPA was new to me as a researcher and I was initially apprehensive about the interpretative nature of the process and the part I would play in the analysis, fearing that I may in some way misinterpret or misrepresent the stories and voices of my participants. I felt that, as a researcher, it was my responsibility to share these individual’s experiences as accurately as possible. During the analysis process

I considered that I would have liked to have been able to discuss my interpretations of the participant's words with the participants themselves, however in considering the IPA process described by Smith et al. (2009), this would have interfered with the interpretative nature of the analysis. I had also considered using Thematic Analysis (Clarke et al., 2015) to analyse the interview data, however as I transcribed the interviews and recognised that participants were sharing their experiences and how this made sense to them, I was confident the data aligned with the IPA approach. In addition, it has been suggested that within the field of TS research there is value in conducting phenomenological research, using approaches such as IPA, to gain insight into personal experiences (Curtis-Wendlandt & Reynolds, 2021). Use of peer support from other TEP researchers using IPA was beneficial to support my understanding of the process, discuss challenges and allow increased reflexivity.

In the design of the research I considered how the IPA approach fits within mixed method research as IPA is often described as an approach which influences the entire research process rather than simply a method of data analysis (Smith et al., 2009). In exploring other research using IPA, most research utilised interviews only which were analysed using IPA, I was therefore unsure whether the IPA approach could fit within a research project which utilised other methods of data collection and analysis. However, there is some literature which supports the use of IPA as part of mixed methods research. Mayoh and Onwuegbuzie (2015) argue that "phenomenological research methods work extremely well as a component of mixed methods research approaches" (p. 92). In addition, different models of mixed-method phenomenological research are suggested, which include the concurrent approach that was utilised in my research. This approach describes qualitative data, analysed using a phenomenological method, such as IPA, being used alongside additional qualitative and quantitative data in validating and confirming findings (Mayoh & Onwuegbuzie, 2015). In addition, Taylor (2015) highlighted two key benefits of utilising IPA within a mixed method design as: strengths and weaknesses of different approaches compensating for each other and different methods of data collection increasing engagement and willingness to share experiences from participants. I related to both of these benefits from experiences of my research, firstly in that the limitations of questionnaire use such as limited depth of data and lack of opportunities to follow up responses were minimised by interviewing some parents.

In addition, I found that it was a benefit that parents being interviewed had already answered the questionnaire: Participants were already aware of the focus of the research and therefore were more prepared to answer questions on the topic and had put some thought into specific experiences to be able to provide examples. It is, of course, impossible to draw conclusions on the influence the questionnaire had on the interviews as it is not possible to know how interviews with participants who had not completed the questionnaire would have differed. A key consideration for researchers using IPA within mixed methods research suggested by Taylor (2015) is the usefulness of this approach in answering research questions and whether mixed methods would improve the quality of research. In my view the use of IPA within a mixed methods design was valuable in answering my research questions and improved the strength of the research.

One of the challenges I encountered in my use of IPA was the phenomenon on hermeneutics. Hermeneutics is the theory of interpretation and within IPA a double hermeneutic, in which the researcher is interpretating the participants interpretations of their experience exists (Smith et al., 2009). I was aware that by asking parents about their experiences there were risks of creating a triple hermeneutic in which I would be interpreting the parent’s interpretations of their child’s experiences. This was challenging for me and an area in which I believe the research could be improved through more explicitly asking parents about their own experiences when they began to talk about their child’s experiences.

3.4.2 Questionnaire Analysis

The questionnaire data included quantitative and qualitative data. The quantitative data was analysed using descriptive statistics. Although I was aware that reporting descriptive statistics, such as mean scores, limited opportunities to represent the individual experiences of participants, they do provide a clear overview of data for the reader. I felt that it was important to present range scores alongside means to ensure that the variability that was present in responses was evident to the reader. Content analysis was used to analyse responses to the qualitative questionnaire questions. I felt that content analysis presented the opportunity to summarise the results while maintaining some of the richness of this qualitative data. Use of the inductive category development as described by Hsieh and Shannon (2005) allowed the participants perspectives to be presented with minimal influence from my own preconceived ideas or perspective. Content analysis also allowed me to consider the number of participants alongside the categories conceptualised which gave a clear overview of the most commonly reported support strategies.

3.5 Ethical Considerations

Ethical issues were carefully considered during the design and throughout the process of the research. Steps taken to ensure ethical practices are explored in part B and appendix 24. I recognised that discussion of their child’s TS may be a potential emotive issue for parents and this required sensitivity. This presented a challenge for me in the interviews, as I was aware of the importance of avoiding over-empathic questions in the IPA process (Smith et al., 2009). In order to overcome this I used general prompts such as “could you tell me how that was for you?” rather than what would have been my natural response to recognise and accept how the participant was presenting difficulties, e.g. “that sounds like it was really difficult for you”. It was however important that I maintained some empathy and sensitivity in my responses to build rapport and trust.

I gave all participants opportunities to discuss any difficulties or questions after the interviews to ensure that they had the opportunity to discuss any challenging themes or emotions that had occurred during the interviews. I also spent some time talking casually with the participant about non-emotive topics (e.g. their plans for the rest of the day or weekend) after the interviews with the aim to avoid them leaving the interview directly after emotive discussions. All participant shared their gratitude in being part of the research following the interviews, suggesting this was a positive experience for them and none of the participants contacted me with any concerns after receiving the debriefing information which included an invitation for any concerns to be discussed (appendix 20).

3.6 Researcher’s position

Throughout the research process I have been aware of my own position and my previous experiences of working with CYP with TS both as a TEP and in a previous role. My own experiences in working with CYP with TS have shaped the way I view this research topic and it was important to aim to put that to the side, approaching the research from a position of curiosity and openness rather than looking for information and data that might be congruent with my own views. I was also aware that as I had previous experience of working in a school with CYP with TS this might be seen as being part of an 'in-group' of the school staff participants, while, having no experience of being a parent of a child with TS I could be viewed as being on the 'out-group' of this group of participants. I wondered how participants might view this and that I may be considered biased toward the school staff participants views and give their perspective more value in my analysis. However, as I reflected on this, my previous experience was not disclosed to participants and as I was approaching the research as a TEP, I would be seen as an 'out-group' member to both participant groups. I was also aware that in my role as a TEP, both parents and school staff may have had experiences of working with TEPs or EPs and this may impact the research process. This was unlikely to have an impact on part 1 as participants did not have direct contact with me as part of the questionnaire. However, during the interview part of the research participants were more aware of my role as a TEP, this was made particularly salient during an interview when a participant asked me a specific question related to TS in schools. In this situation I was aware that I may be seen as an expert or as having knowledge on the topic, rather than as a researcher seeking to gain the participants experiences. I was careful in answering this question only by signposting the participant to other sources of information and avoiding providing any advice or answer based on my own knowledge, as suggested by the BPS code of research ethics (BPS, 2021).

The process of conducting this research has developed my personal skills as a researcher in many ways. Firstly, I have been able to gain confidence in using a variety of methods to conduct research, such as interviews and questionnaire as well as exploring new data analysis techniques of content analysis and IPA. In addition, I have been able to further my knowledge of TS and the range of difficulties that CYP with TS might experience in school, which may be beneficial for future practice as a TEP and EP.

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Appendices

Appendix 1: Search Terms for Literature Review

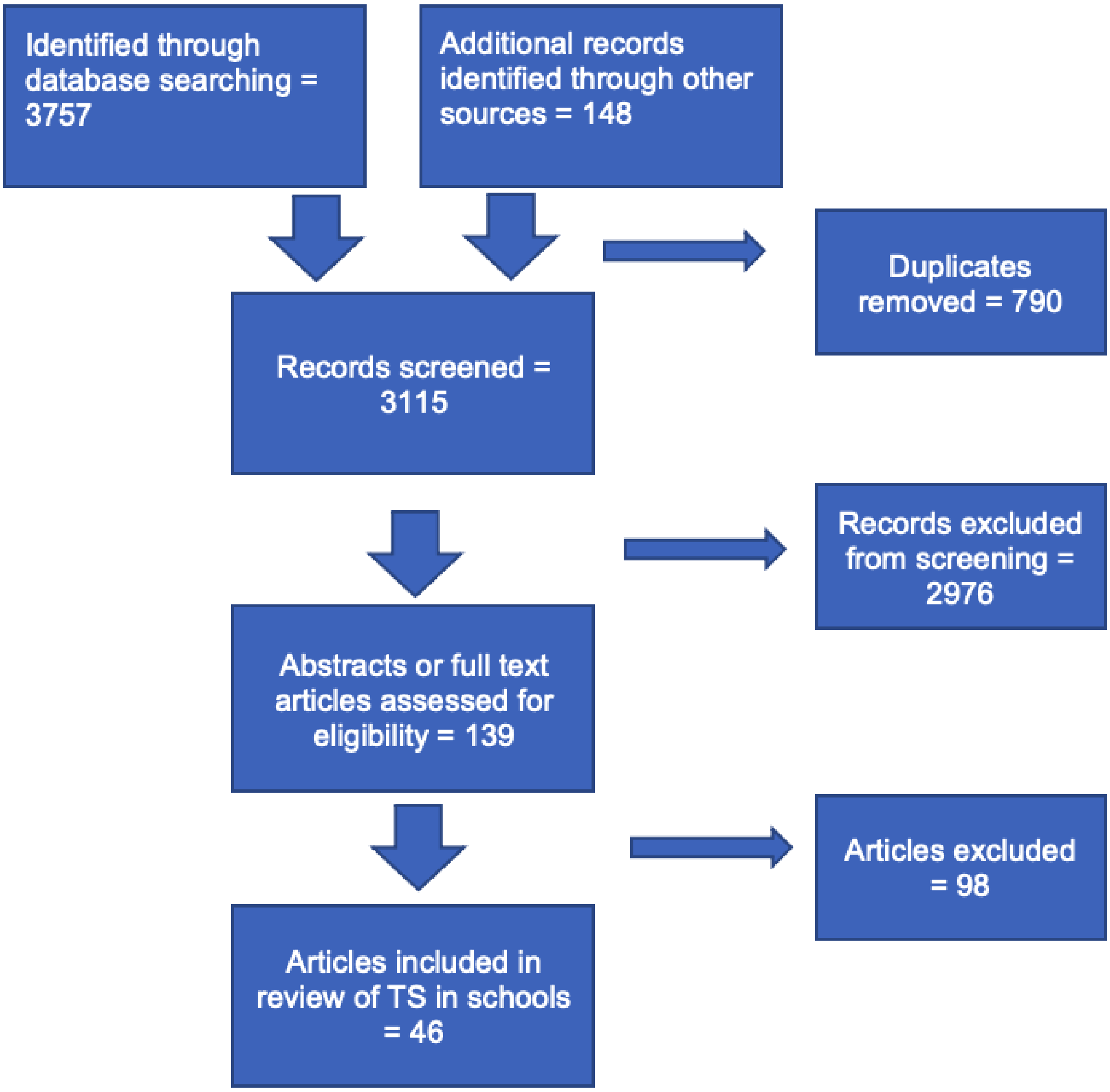
Key concepts of ‘tourette syndrome’ and ‘school’ were decided on. Additional terms which may be used for each of these concepts were consider to avoid missing important research due to different terminology. Final search terms used for searches in Psycinfo are shown in the table below. These search terms were combined and subject headings were used to ensure that research relevant to school and TS was being identified.

Search Terms	
Tourette*	School*
Tic syndrome*	Education*
Tic disorder*	Teach*
Tourette Syndrome (subject heading)	Pupil*
	Student*
	Learn*
	Education (subject heading)

Search strings for additional databases are presented in the table below:

Database	Search String
Scopus	((TITLE-ABS-KEY (tourette*))) AND (((TITLE-ABS-KEY (school*)) OR (TITLE-ABS-KEY (education*)) OR (TITLE-ABS-KEY (teach*)) OR (TITLE-ABS-KEY (pupil*)) OR (TITLE-ABS-KEY (student*))))
Web of Science	TS=(education* OR school* OR teach* OR student* OR pupil* OR learn*) AND TS=(Tourette* OR “tic syndrome*” OR “tic disorder*”)
ERIC	(education* OR school* OR teach* OR student* OR pupil* OR learn*) AND (Tourette* OR “tic syndrome*” OR “tic disorder*”)
British Education Index	(Tourette* OR “tic syndrome*” OR “tic disorder*”) AND (education* OR school* OR teach* OR student* OR pupil* OR learn*)
ASSIA database	noft(Tourette* OR “tic syndrome*” OR “tic disorder*”) AND noft("education* OR school* OR teach* OR student* OR pupil* OR learn*)

Appendix 2: Flow Diagram of literature identified through searches



Inclusion Criteria for screening process:

- Reference to TS or tic disorders
- Focus on a school context
- Published in the English language

Appendix 3: School Staff Questionnaire

1	What type of setting do you work in?									
	Mainstream primary school	Mainstream secondary school	Specialist provision	Other:_______						
2	What is your role in school?									
	Teacher	Teaching Assistant/ Learning support assistant	Headteacher	Senior Leadership	SENCo/ ALNCo	Other__________				
3	Where in the UK do you work?									
	Wales	Scotland	Northern Ireland	North West	North East	Midlands	South East	South West		
4	Have you ever worked with a pupil aged 10-16 years old with a diagnosis of Tourette Syndrome in school?									
	Yes, If yes, How Many? _______	No	Not Sure							
5	How knowledgeable do you feel about Tourette Syndrome? (1= not at all knowledgeable, 10= Very knowledgeable)									
	1	2	3	4	5	6	7	8	9	10
6	How confident do you feel in supporting children and young people with Tourette Syndrome in school? (1= not at all confident, 10= Very confident)									
	1	2	3	4	5	6	7	8	9	10
7	Have you received any training on Tourette Syndrome?									
	Yes	No	Not sure							
8	If yes, please describe who gave the training and areas covered:									
9	Which difficulties have you found that CYP with Tourette Syndrome experience in school? (tick as many as apply)									
	Physical difficulties									
	Social difficulties									
	Emotional difficulties									
	Learning									
	Other									
10	What type of support does your school provide for pupil(s) with Tourette Syndrome? Include support in relation to their learning, management of tics, social skills, emotions, physical difficulties and any other difficulties.									

<table>
<tr><td></td><td colspan="6"></td></tr>
<tr><td rowspan="2">11</td><td colspan="6">What, if anything, has been done to improve the knowledge of staff and pupils in relation to Tourette Syndrome?</td></tr>
<tr><td colspan="6"></td></tr>
<tr><td rowspan="2">12</td><td colspan="6">Which of the strategies put in place have been the most effective in supporting the pupil(s) with Tourette Syndrome? (please select top 3 strategies)</td></tr>
<tr><td colspan="6">1 ________________
2________________
3________________</td></tr>
<tr><td rowspan="2">13</td><td colspan="6">Have you ever requested the involvement of an Educational Psychologist for a pupil with Tourette Syndrome?</td></tr>
<tr><td colspan="2">Yes</td><td colspan="2">No</td><td colspan="2">Not Sure</td></tr>
<tr><td rowspan="2">14</td><td colspan="6">Have you contacted any of the following professionals to seek support for working with a CYP with Tourette Syndrome?</td></tr>
<tr><td>School Nurse</td><td>Occupational Therapist</td><td>Speech and Language Therapist</td><td>ELSA</td><td>Other</td><td>None</td></tr>
</table>

Appendix 4: Parents of CYP with TS questionnaire

1	Do you have a child with a diagnosis of Tourette Syndrome?	
	Yes	No

2	What is the current age of your child?

3	At what age was your child diagnosed with Tourette Syndrome?

4	Does your child have any of the following conditions as well as Tourette Syndrome?						
	Attention Deficit Hyperactivity Disorder (ADHD)	Autism Spectrum Disorder (ASD)	Obsessive-Compulsive Disorder (OCD)	Anxiety	Depression	Phobias	Other ____

5	What type of education provision does your child attend?			
	Mainstream primary school	Mainstream secondary school	Special Class within a mainstream school	Other______

6	Where in the UK do you live?							
	Wales	Scotland	Northern Ireland	North West	North East	Midlands	South East	South West

7	Overall, how happy do you think your child in school? (1=extremely unhappy, 10= extremely happy)									
	1	2	3	4	5	6	7	8	9	10

8	Overall, how satisfied have you been with the support for Tourette Syndrome your child has received in school? (1= not at all satisfied, 10= extremely satisfied)									
	1	2	3	4	5	6	7	8	9	10

9	How knowledgeable do you feel school staff are about Tourette Syndrome? (1= not at all knowledgeable, 10= Very knowledgeable)									
	1	2	3	4	5	6	7	8	9	10

10	Does your child experience any physical, social, emotional, learning or other difficulties in relation to their Tourette Syndrome? (please state specific difficulties)	
	Physical difficulties	
	Social Difficulties	
	Emotional difficulties	
	Learning	
	Other	

11	What type of support does your child's school provide for pupil(s) with Tourette Syndrome? Include support in relation to their learning, management of tics, social skills, emotions, physical difficulties and any other difficulties.

12	What, if anything, has been done in your child’s school to improve the knowledge of staff and pupils in relation to Tourette Syndrome?						
13	Which of the strategies put in place in school have been the most effective in supporting your child with Tourette Syndrome? (please select top 3 strategies)						
	1 ________________ 2________________ 3________________						
14	Has your child with Tourette Syndrome ever had involvement from an Educational Psychologist?						
	Yes	No	Not Sure				
15	Has your child with Tourette Syndrome ever been referred to any of the following professionals to seek support for Tourette Syndrome?						
	School Nurse	Occupational Therapist	Speech and Language Therapist	Emotional Literacy Support Assistants (ELSA)	Other	None	Not sure

Appendix 5: Information sheet for school staff questionnaire

You are being invited to participate in this research study. Before you decide if you would like to take part it is important for you to understand the purpose of the research and what it will involve. Please read the participant information below and feel free to get in touch with any questions you may have before participating in the research.

Who is carrying out this research?

My name is Hannah Warnock, I am a Trainee Educational Psychologist, conducting this piece of research for my doctoral thesis at Cardiff University. I am being supervised by Hayley Jeans, professional tutor, Doctorate in Educational Psychology. This research has been granted ethical approval by Cardiff University.

What is the purpose of the project?

The purpose of this research is to explore the views of school staff and parents of children with Tourette Syndrome with regards to the support schools provide to children with Tourette Syndrome. The findings from this questionnaire will be considered alongside information gathered from parents of children with Tourette Syndrome to gain an insight into the parents views of this support.

Do you have to take part?

Participation in this research is completely voluntary. Should you decide to take part you will be asked to complete a consent form declaring that you have read and understood the information in this document and that you consent to participating. Should you change your mind about participating, you can withdraw from the study before submitting the questionnaire. After such a point where you have submitted the questionnaire you will not be able to withdraw from the research as your responses will not be able to be traced but please be assured that all your responses will be anonymous. No identifying information will be gathered in the questionnaire and responses will not be traceable to you.

What will happen if you take part?

If you wish to take part in this study you will be asked to complete an online questionnaire about your experiences of supporting children and young people with Tourette Syndrome in a mainstream school setting. The questionnaire should take no longer than 15 minutes to complete. When you submit the questionnaire the answers will be sent to me anonymously and stored on the Qualtrics secure server. You may choose to leave any questions blank if you do not wish to answer them.

How can I find out more Information?

If you have any questions or would like more information please contact:

Contact Details	
Researcher: Hannah Warnock	**Supervisor:** Hayley Jeans, Professional Tutor, DEdPsy

School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS	School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS
Email: WarnockHC@cardiff.ac.uk	**Email:** JeansH@cardiff.ac.uk

Thank you for taking the time to read this information

If you would like to participate in this research please click the ‘Next’ Button below.

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). This information is being collected by Hannah Warnock. This information will be held securely and separately from the research information you provide. Only the researcher will have access to this form and it will be destroyed after 7 years. The lawful basis for processing this information is public interest.

Appendix 6: Information sheet for parents questionnaire

You are being invited to participate in this research study. Before you decide if you would like to take part it is important for you to understand the purpose of the research and what it will involve. Please read the participant information below and feel free to get in touch with any questions you may have before participating in the research.

Who is carrying out this research?

My name is Hannah Warnock, I am a Trainee Educational Psychologist, conducting this research for my doctoral thesis at Cardiff University. I am being supervised by Hayley Jeans, professional tutor, Doctorate in Educational Psychology throughout. This research has been granted ethical approval by Cardiff University.

What is the purpose of the project?

The purpose of this research is to explore the views of school staff and parents of children with Tourette Syndrome with regards to the support schools provide to children with Tourette Syndrome. The findings from this questionnaire will be considered alongside information gathered from staff working with young people with Tourette Syndrome to better understand the support available in schools for children with Tourette Syndrome and parents views of this support.

Do you have to take part?

Participation in this research is completely voluntary. Should you decide to take part you will be asked to complete a consent form declaring that you have read and understood the information in this document and that you consent to participating. Should you change your mind about participating, you can withdraw from the study before submitting the questionnaire. After such a point where you have submitted the questionnaire you will no longer be able to withdraw from the research as your responses will not be able to be traced but please be assured that all your responses will be anonymous. No identifying information will be gathered in the questionnaire and any responses will not be traceable to you.

What will happen if you take part?

If you wish to take part in this study you will be asked to complete an online questionnaire about your views of support your child received/receives in school in relation to Tourette Syndrome. The questionnaire should take no longer than 15 minutes to complete. When you submit the questionnaire the answers will be sent to me anonymously and stored on the Qualtrics secure server, meaning I will be the only one with access to this information. You may choose to leave any questions blank if you do not wish to answer them. At the end of the questionnaire there will be an opportunity for you to enter and email address to be contacted about the next phase of the research, which involves a short interview. Providing your email address is completely voluntary and the email address you provide will be stored securely and separately from your questionnaire responses to ensure your responses are anonymous.

How can I find out more Information?

If you have any questions or would like more information please contact:

Contact Details	
Researcher: Hannah Warnock	**Supervisor:** Hayley Jeans, Professional Tutor, DEdPsy
School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS	School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS
Email: WarnockHC@cardiff.ac.uk	**Email:** JeansH@cardiff.ac.uk

Thank you for taking the time to read this information

If you would like to participate in this research please click the '<u>Next</u>' Button below.

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Appendix 7: Consent form for school staff questionnaire

I confirm that I have read an understood the participant information sheet provided.	☐
I understand that my responses will be used as part of the research project described in the information sheet.	☐
I understand that my participation in this research is voluntary and that I can withdraw before submitting my responses.	☐
I understand that it is not possible to withdraw my answers once they have been submitted.	☐
I understand that I am free to ask any questions at any time (contact details below)	☐
I understand that my responses will be anonymous.	☐
I agree to participate in the described research project.	☐

Contact Details

Researcher: Hannah Warnock	**Supervisor:** Hayley Jeans, Professional Tutor, DEdPsy
School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS	School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS
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Appendix 8: Consent form for parent questionnaire

I confirm that I have read an understood the participant information sheet provided.	☐
I understand that my responses will be used as part of the research project described in the information sheet.	☐
I understand that my participation in this research is voluntary and that I can withdraw before submitting my responses.	☐
I understand that it is not possible to withdraw my answers once they have been submitted.	☐
I understand that I am free to ask any questions at any time (contact details below)	☐
I understand that my responses will be anonymous.	☐
I understand that should I choose to provide my email address to be contacted for the next stage of the research my email address will be stored securely and not be associated with my questionnaire responses	☐
I agree to participate in the described research project.	

Contact Details

Researcher: Hannah Warnock	**Supervisor:** Hayley Jeans, Professional Tutor, DEdPsy
School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS	School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS
Email: WarnockHC@cardiff.ac.uk	**Email:** JeansH@cardiff.ac.uk

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Appendix 9: Debrief information for school staff questionnaire

Thank you for taking part in this research.

The aim of this research is to gain the views of school staff and parents of children and young people with Tourette Syndrome with regards to the support available in mainstream schools for children and young people with Tourette Syndrome.

The questionnaire answers you have submitted will be stored securely and anonymously.

If you have any questions or would like any further information please do not hesitate to contact myself or my research supervisor (contact details below).

Regards,
Hannah Warnock

Contact Details		
Researcher: Hannah Warnock	**Supervisor:** Hayley Jeans, Professional Tutor, DEdPsy	**Cardiff University Ethics Committee**
School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS **Email:** WarnockHC@cardiff.ac.uk	School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS **Email:** JeansH@cardiff.ac.uk	Secretary of the Ethics Committee School of Psychology Cardiff University Tower Building Park Place Cardiff CF10 3AT **Tel:** 029 2087 0360 **Email:** psychethics@cardiff.ac.uk

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Appendix 10: Debrief information for parent questionnaire

Thank you for taking part in this research.

The aim of this research is to gain the views of school staff and parents of Children and young people with Tourette Syndrome with regards to the support available in mainstream schools for children and young people with Tourette Syndrome. The questionnaire answers you have submitted will be stored securely and anonymously.

If you are interested in finding out more or would be willing to take part in a short interview about your experiences, please follow the link below to enter an email address for the researcher to contact you. Please note that by providing an email address you are in no way obliged to take part in the interview and you will be given the opportunity to withdraw should you change your mind. The email address you provide will be stored securely and will not be linked to the questionnaire responses you have provided. The email address will be used only for the purpose of contacting you about the research and will be deleted if you choose to withdraw or, if you choose to participate, after the interview has been completed and transcribed.
[INSERT LINK]
If you have any questions or would like any further information please do not hesitate to contact myself or my research supervisor (contact details below).

Regards,
Hannah Warnock

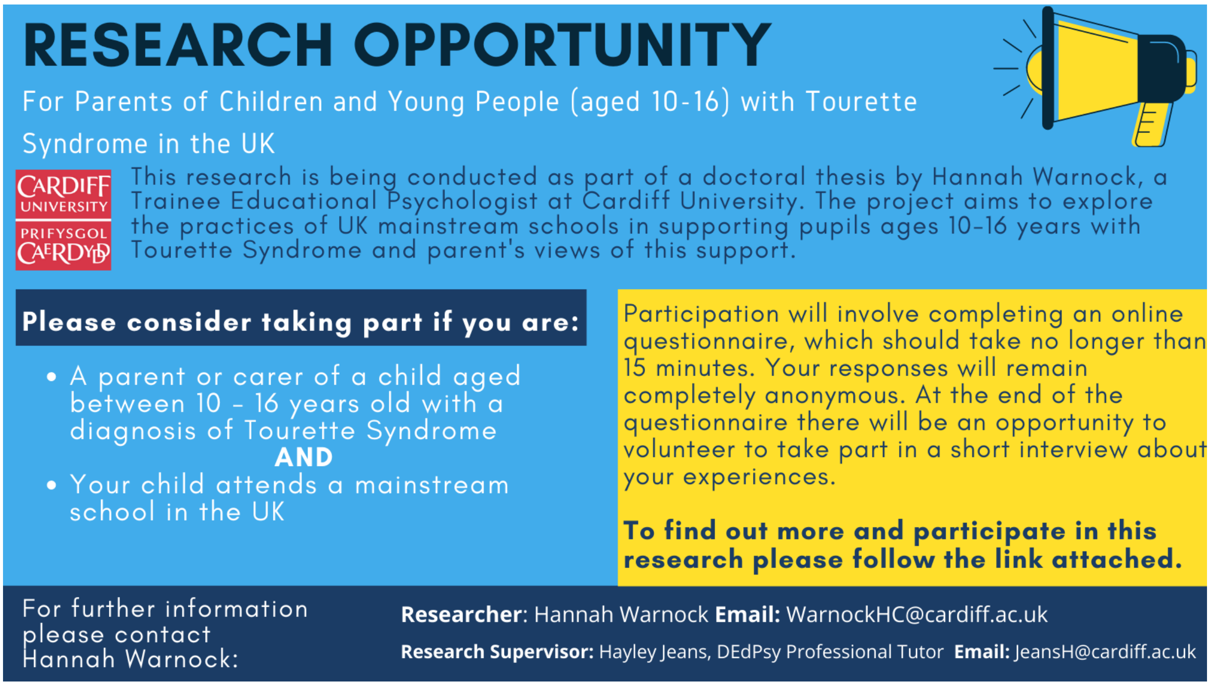
Contact Details		
Researcher: Hannah Warnock	**Supervisor:** Hayley Jeans, Professional Tutor, DEdPsy	**Cardiff University Ethics Committee**
School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS **Email:** WarnockHC@cardiff.ac.uk	School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS **Email:** JeansH@cardiff.ac.uk	Secretary of the Ethics Committee School of Psychology Cardiff University Tower Building Park Place Cardiff CF10 3AT **Tel:** 029 2087 0360 **Email:** psychethics@cardiff.ac.uk

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). This information is being collected by Hannah Warnock. This information will be held securely and separately from the research information you provide. Only the researcher will have access to this form and it will be destroyed after 7 years. The lawful basis for processing this information is public interest.

Appendix 11: Validity and Reliability of Questionnaires

Stages of questionnaire development	**Considerations**
Initial Considerations	- Questions were based on previous literature identified in a literature review of relevant research (part A). - Questionnaires used previous literature were explored to consider good practice for questionnaire creation. - Considering how the school staff and parent questionnaires may require differences while gathering similar information to be able to triangulate data.
Question content, phrasing and response format	- The language used in the questionnaire aimed be easy to understand and avoided jargon and abbreviations. - Likert scales were used alongside a visual scale to improve ease of answering scaling questions. - ‘Other’ options, which provided opportunities to specify or add additional qualitative information were provided where appropriate. - Participants were not restricted by a word limit in open-ended questions to ensure opportunities to provide in-depth responses. - A range of response formats were used in the questionnaire, including sliding scales, multiple choice and open-ended questions. The suitability of response format for different devices (phones, tablets, laptops etc.) was considered.
Question sequence and layout	- Initial questions confirmed the participants met inclusion criteria, those that didn’t were not presented with any further questions and directed to the debriefing information. - Questions were presented in a logical order starting with basic demographic questions and moving to more specific questions related to experiences of school support for CYP with TS. - The ‘skip logic’ function of Qualtrics was used to ensure participants were not presented with questions that were not applicable based on previous responses.
Pre-test (pilot) and revision	- Questionnaires were tested with close contacts of the researcher to ensure the sequence was logical, questions were easy to understand and the format was compatible with a range of devices. Questionnaires were revised based on these tests.
Final questionnaire	- During data collection responses gathered were occasionally checked by the researcher to ensure the questionnaire was functioning as expected and responses were being saved correctly by the Qualtrics software.

Appendix 12 Parents of CYP with TS recruitment poster



RESEARCH OPPORTUNITY

For Parents of Children and Young People (aged 10-16) with Tourette Syndrome in the UK

This research is being conducted as part of a doctoral thesis by Hannah Warnock, a Trainee Educational Psychologist at Cardiff University. The project aims to explore the practices of UK mainstream schools in supporting pupils ages 10-16 years with Tourette Syndrome and parent's views of this support.

Please consider taking part if you are:

- A parent or carer of a child aged between 10 - 16 years old with a diagnosis of Tourette Syndrome

AND

- Your child attends a mainstream school in the UK

Participation will involve completing an online questionnaire, which should take no longer than 15 minutes. Your responses will remain completely anonymous. At the end of the questionnaire there will be an opportunity to volunteer to take part in a short interview about your experiences.

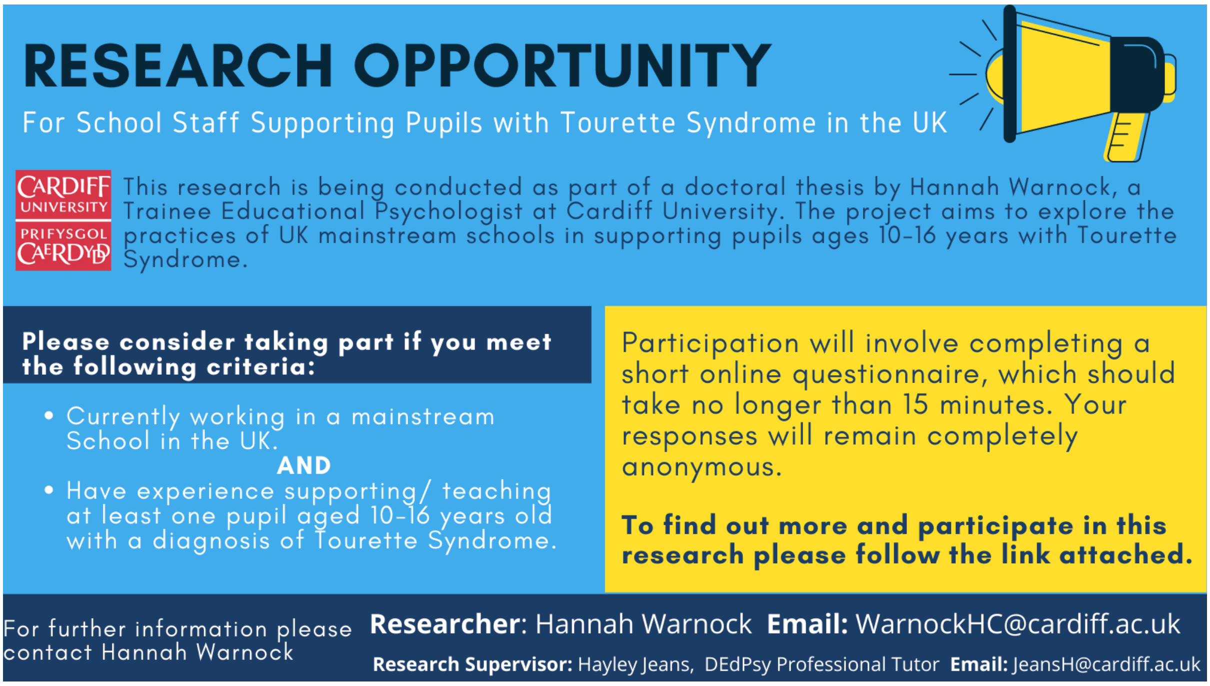
To find out more and participate in this research please follow the link attached.

For further information please contact Hannah Warnock:

Researcher: Hannah Warnock **Email:** WarnockHC@cardiff.ac.uk

Research Supervisor: Hayley Jeans, DEdPsy Professional Tutor **Email:** JeansH@cardiff.ac.uk

Appendix 13: School staff recruitment poster



RESEARCH OPPORTUNITY

For School Staff Supporting Pupils with Tourette Syndrome in the UK

CARDIFF UNIVERSITY PRIFYSGOL CAERDYDD

This research is being conducted as part of a doctoral thesis by Hannah Warnock, a Trainee Educational Psychologist at Cardiff University. The project aims to explore the practices of UK mainstream schools in supporting pupils ages 10-16 years with Tourette Syndrome.

Please consider taking part if you meet the following criteria:

- Currently working in a mainstream School in the UK.

AND

- Have experience supporting/ teaching at least one pupil aged 10-16 years old with a diagnosis of Tourette Syndrome.

Participation will involve completing a short online questionnaire, which should take no longer than 15 minutes. Your responses will remain completely anonymous.

To find out more and participate in this research please follow the link attached.

For further information please contact Hannah Warnock

Researcher: Hannah Warnock **Email:** WarnockHC@cardiff.ac.uk

Research Supervisor: Hayley Jeans, DEdPsy Professional Tutor **Email:** JeansH@cardiff.ac.uk

Appendix 14: Content Analysis Procedure

The procedure used for content analysis in this research was based on the procedures for content analysis described by Mayring (2014) and Hsieh and Shannon (2005).

Steps of content analysis followed:

- Familiarisation with the data – reading and re-reading data.
- Highlighting key concepts related to the research question using inductive category development
- Creating preliminary codes
- Organisation of codes into categories
- Recording frequency of categories

Appendix 15: Content Analysis Example of Coding procedure

Example of Qualitative Data Collected (key: related to support / Additional information)	Initial Codes/ Notes
We as parents have made each form teacher and teaching assistant aware for each year. There is good understanding by his form teachers usually. However, the senco refuses to believe the diagnosis and would not create a MyPlan. Communication to other areas of staff, such as lunchtime staff and outside staff coming in to take clubs etc. Consequently I would say there is no formal support in place. None. She has a pass out card to go into a quiet room. Hard to say at moment as not been well enough to return although been trying now for a few weeks and plan is not being executed very quickly. She is allowed to walk round the class as movement seems to reduce them. She is allowed chewellry (which she has) or sweets (which she doesn't, to protect her teeth as dad is a dentist), to reduce her vocal tics but was not allowed chewing gum as an alternative. She has a time out pass if she wants to leave the room although she never has. She has card with a brief explanation on the show new staff as she has sometimes had issues with cover staff who are not aware of the situation. Separate area for her to be in when in school Informed members of staff. SEND intervention. None known Not a lot! I've had to battle to get extra support for exams Use of quiet room, she can go and sit with someone who understands the situation. They offer exam support and senco support. Pupil support plan- she is able to leave without any fuss and have time in her own to tic. Extracts support, scribe if needed. Being able to use her laptop rather than write Not much - even within base for asn tourettes is poorly understood. Often approach as they would autism but this can actually make things more difficult Anxiety support Designated area to tic Toilet pass Room alone for exams	- Parents informing staff - Understanding staff - School staff not believing diagnosis - Communication between staff - No support - No support - Time out card - Quiet/ safe space - Slow support - Movement - Fidget/ sensory toys - Time out card - CYP doesn't use time out card - Pupil profile / information card - New/ cover staff not aware - Quiet/safe space - Specific interventions - No support - No support - Support for exams - Quiet/ safe space - Understanding staff - Exam support - SEN/ ALN department support - Time out card - Quiet/ safe space - Exam support - Support with writing (scribe) - Support with writing (laptop) - No support - TS poorly understood - Some unhelpful support - Support for anxiety - Quiet/safe space - Toilet pass - Exam support

Appendix 16: Themes and prompts for Semi-structured interviews

Background and contextual information:

- Age + gender of child
    - *To start with it would be great if you could give me a little bit of background about your child with TS*

Experience of TS

- Experience of diagnostic process.
    - *Can you tell me about the process of diagnosis of TS?*
- Co-occurring conditions?
    - *Does ____ have any other conditions or difficulties other than TS? – can you tell me a little bit about that?*
- Symptoms experienced
    - *Can you tell me a bit about the types of symptoms ____ experiences as a result of TS?*
- How do the family experience TS?
    - *How does this impact family life?*

School experiences

- Context of school
    - Can you tell me a little bit about the school ___ attends?
- Difficulties in school?
    - What kinds of difficulties does ___ experience in school?
- What do you think ____ thinks about school?

Support in school

- Kinds of support
    - What has been put in place to support ____ with symptoms of TS?
- What works well
    - What works well in supporting ____ in school?
- What could be improved
    - Are there things that you think the school could do that might better support ____?

Perceptions of school staff/ other professionals support.

- Are you happy with the support, process of securing support etc.?

Anything else relevant or that you want to share in regards to your child with TS and their experiences in school?

Appendix 17: Validity and Reliability of Interviews

Interviews used in part 2 of the research were assessed for validity and reliability using principles outlined by Yardley (2000)

Characteristics of good qualitative research, suggested by Yardley (2000).	**Considerations in current study**
Sensitivity to Context - *Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues*	- To ensure the current study was grounded within existing research and theoretical perspectives an extensive literature review was conducted and existing research considered in both part A and part B. - Relevant ethical issues were considered in depth (see section 3.5) and the research gained ethical approval from Cardiff University School of Psychology Ethics Committee. - The researcher's position was considered, acknowledging that the researchers experience may have been advantageous in being sensitive to participant's experiences while also introducing a risk of bias. - In an attempt to address any possible perceived power imbalances during interviews the researcher ensured there were opportunities for informal rapport building prior to commencing each interview. - Findings are discussed in relation to the context of mainstream schools in the UK.
Commitment and Rigour - *In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.*	- In depth engagement with the topic was sought through six semi-structured interviews with parents of CYP with TS. - Triangulation of data sources and data collection methods were used to explore the topic from multiple perspectives. - Regular supervision was sought throughout the research. - IPA procedures were used to analyse interview data, an audit with an independent research was conducted to increase validity of the analysis.
Transparency and Coherence - *Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method: reflexivity.*	- The researcher considered their own position and recognised potential sources of bias at various stages in the research. - The ontological and epistemological positions are explained (see section 3.1) and guided the development of the research. - A research journal was used by the researcher to encourage reflexivity. - Examples and materials relating to data collection and analysis procedures are presented in the appendices for transparency.

Impact and Importance - *Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).*	- This research aimed to address a gap in existing literature identified in the literature search (part A). - Findings are considered alongside psychological theory. - Practical implications for schools and EPs are considered in the discussion. - Directions for potential future research are discussed.

Appendix 18: Information sheet for semi-structured interviews

Before you decide if you would like to take part it is important for you to understand the purpose of the research and what it will involve. Please read the information below and feel free to get in touch with any questions you may have before participating in the research.

Who is carrying out this research?

My name is Hannah Warnock, I am a Trainee Educational Psychologist, conducting this research for my doctoral thesis at Cardiff University. I am being supervised by Hayley Jeans, professional tutor, Doctorate in Educational Psychology. This research has been granted ethical approval by Cardiff University.

What is the purpose of the project?

The purpose of this research is to explore the views of school staff and parents of children with Tourette Syndrome with regards to the support schools provide to children with Tourette Syndrome. The first part of this research involved questionnaires for both school staff and parents about their views of school support for young people with Tourette Syndrome. This second part of the research aims to gain a deeper understanding of the view of parents of children and young people with Tourette Syndrome regarding the support that their children receive in mainstream school.

Do you have to take part?

Participation in this research is completely voluntary. Should you decide to take part you will be asked to confirm your consent declaring that you have read and understood the information in this document. Should you change your mind about participating, you can withdraw from the study before or up to 2 weeks after the interview has taken place by contacting me.

What will happen if you take part?

If you wish to participate in this part of this study I will contact you on the email you provide at the end of the questionnaire in order to arrange a short interview at a time which is convenient for you. Due to the COVID-19 pandemic the interview will take place using a virtual platform such as Microsoft teams or zoom, whichever is most convenient for you. The interview is anticipated to last around 45 minutes and will involve a series of questions about your views of school support for your child with Tourette syndrome. The interview will be informal and you can ask to skip questions that you do not wish to answer. The interview will be recorded using the chosen virtual platform, this is to ensure that I can accurately type up the responses to the interview questions. I will be the only person with access to the interview recording and the recording will be deleted as soon as it has been transcribed, within 2 weeks of the interview taking place. Your name and any identifying information will be removed from the transcript and replaced by a participant number to ensure your anonymity.

How can I find out more Information?

If you have any questions or would like more information please contact:

Contact Details	
Researcher: Hannah Warnock	**Supervisor:** Hayley Jeans, Professional Tutor, DEdPsy

Appendix 18

School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS	School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS
Email: WarnockHC@cardiff.ac.uk	**Email:** JeansH@cardiff.ac.uk

Thank you for taking the time to read this information

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by Hannah Warnock.

The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only Hannah Warnock will have access to this information. After 2 weeks the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

Appendix 19: Consent form for semi-structured interviews

Thank you for showing interest in the second part of this research, please tick the box below to consent to the following:

- I confirm that I have read an understood the participant information sheet provided.
- I understand that my participation in this research is voluntary and that I will have the opportunity to withdraw my responses without giving a reason in the 2 weeks immediately following the interview by contacting the researcher.
- I understand that I am free to ask any questions at any time (contact details below)
- I consent to the researcher (Hannah Warnock) contacting me on the email address provided to arrange a suitable time and date for the interview.
- I understand that my responses will be anonymised and used as part of the research project described in the information sheet.

I consent to the above ☐

Email Address ______________

Contact Details	
Researcher: Hannah Warnock	**Supervisor:** Hayley Jeans, Professional Tutor, DEdPsy
School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS	School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS
Email: WarnockHC@cardiff.ac.uk	**Email:** JeansH@cardiff.ac.uk

Privacy Notice:
The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by Hannah Warnock.

The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only Hannah Warnock will have access to this information. After 2 weeks the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

Appendix 20: Debrief information for semi-structured interviews

Thank you for taking part in this research.

The purpose of this research is to explore the views of school staff and parents of children with Tourette Syndrome with regards to the support schools provide to children with Tourette Syndrome.

The information you shared with me will be held confidentially in a secure location, to which only myself as the researcher will have access to. The interview recordings will be transcribed (typed up) within two weeks, after which time they will be anonymised. If you wish to withdraw your interview responses from the research this can be done up to two weeks after the interview. If you decide to withdraw your data please contact me by email before **INSERT DATE**. Following this date your responses will be anonymised and will not be able to be traced to you.

If you have any questions or would like any further information about this research please do not hesitate to contact myself or my research supervisor (contact details below). If you have any questions related to Tourette Syndrome or would like further information about Tourette Syndrome, this can be found at https://www.tourettes-action.org.uk/

Regards,
Hannah Warnock

Contact Details		
Researcher: Hannah Warnock	**Supervisor:** Hayley Jeans, Professional Tutor, DEdPsy	**Cardiff University Ethics Committee**
School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS **Email:** WarnockHC@cardiff.ac.uk	School of Psychology, CUCHDS, Cardiff University, 70 Park Place, Cardiff, CF10 3AS **Email:** JeansH@cardiff.ac.uk	Secretary of the Ethics Committe School of Psychology Cardiff University Tower Building Park Place Cardiff CF10 3AT **Tel:** 029 2087 0360 **Email:** psychethics@cardiff.ac.u

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and Matt Cooper is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by Hannah Warnock.
The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years.
The research information you provide will be used for the purposes of research only and will be stored securely. Only Hannah Warnock will have access to this information. After 2 weeks the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

Appendix 21: IPA- description of steps and procedure

IPA procedures followed steps described by Smith et al. (2009), these steps with descriptions of specific procedures for this research are outlined below.

Step	Smith et al. (2009)	Description of procedures for current research
1	Reading and re-reading	The researcher initially familiarised themselves with the data through transcription of data, this involved watching the video recordings of interview and making note of body language and gestures alongside transcribing their words verbatim. Each transcript was read through thoroughly following transcription prior to analysis.
2	Initial Noting	Each transcript was examined and key words/ phrases highlighted in different colours based on descriptive, linguistic and conceptual comments. Notes related to the highlighted sections were recorded in the margin. Additional notes which were not considered to fit in descriptive, linguistic or conceptual comments were also noted.
3	Developing emergent themes	The researcher attempted to map initial notes and ideas into themes, which were them recorded in a separate colour on the transcript.
4	Searching for connections across themes	Themes identified were examined, looking for connections or patterns between them to be able to grouped together to form superordinate themes. During this process the research used methods described by Smith et al. (2009), including abstraction, subsumption and contextualism.
5	Moving to the next case	Steps 1-4 were completed for each of the transcripts separately.
6	Looking for patterns across cases	When all transcripts had been analysed separately, the themes conceptualised from all data were brought together to begin to look for patterns across cases. Themes were grouped and mapped in a range of ways before the final superordinate and subordinate themes were finalised. As suggested by Smith et al. (2009) themes were examined for recurrence across cases. The researcher considered the number of participants for which a theme was conceptualised to enhance validity of findings. All of

		the finalised themes were present in over half of the sample.
Independent audit		As an additional step to the process the researcher conducted what Smith et al. (2009) term a mini independent audit, this involved having a researcher who was not involved in the research but familiar with the IPA process to conduct initial noting and theme conceptualisation on an extract of all transcripts. These initial themes were then checked against those originally proposed by the researcher to ensure themes have validity to the text and the IPA process was followed. It was hoped this step would increase the reflexivity of the researcher.

Appendix 22: IPA – Examples of initial noting and emergent themes with transcript extracts (steps 2 and 3 of procedure)

Key:

Descriptive: content of what is said

Linguistic: use of language

Conceptual: interrogative and conceptual level

Red text: interviewer

Interview 1: Ann		
Exploratory Comments	**Transcript Extract**	**Emergent Themes**
CYP's view – wants to fit in CYP is 'different'- in what way? Parents reassuring CYP Forward planning Practical support - exams Parents involved/ checking on school work Scribe support CYP has friends 'loves' – many positive elements of school Practical lessons CYP is happy Attendance challenges	Yeah it was, first of all he didn't want to because he didn't want to be different to the other kids this is a big thing as well. He doesn't want to be different. He's already different. He doesn't want to be made more different. But we sort of said to him that, you know, if you go off, then you're going to get a better score and then you won't be different to your friends do you know what i mean you're going to be on par with them. And when he went there was a couple of other people that he knew so that sort of helped him, he was like, ohh yeah it was okay so and so was there so yeah, it wasn't so bad for him in the end. But Yeah, going forward, he will have extra time, I think, and help, and they've also spoke about scribes as well. Ohh okay so they're already kind of looking at that, I guess with the education, health care plan that'll keep being reviewed and kind of checked out and see what will be useful. Yeah and when we look at his books, sometimes you can see that it's someone who else has wrote the information in his books for him, or there will be certain things and it will say, Oh, this is, this is what Adam said but it was written by the helper. So there's, there are people there that help them at the moment and hopefully that will continue. Yeah. Then, can you give me a little sense about what Adam thinks about school I know you've said a little bit about his friendships and his kind of reluctance to feel different, but generally when he thinks about school, what does he tell you about school? Umm, He, he likes the friendships, and he likes that Going to secondary school, he, he loves. He loves all the different classes, you know, things that they've never had before, like IT and design and music and so different classes, you know, he really enjoys and he	CYP doesn't want to be different – social identity Role of parents – reassuring CYP Exams – thinking to the future Role of parents – checking work Support to show his own thinking Friendships- positive Enjoyment of school

Secondary as a positive change Learning life skills Parents supporting homework Parent contact with schools ‘bottom of the pile’ – see CYP as low. Parents keeping on top of school work Unhelpful comments from staff Staff not reading relevant information ‘can’t do’ – incapable of some things? Parents continued contact with school Resolution of conflict/ challenges Same for every child – need to view each CYP as an individual Commitment from key teachers Knowledge of CYP is important	gets on well with most, most kids as well so, and he's a bundle of joy. So, he finds everything, you know, really exciting. Yeah he does, you know generally he likes school and, you know, we've had trouble in the past with him, going to school, where he's not wanting to go at all, when he's been there, it's been completely fine, but he'll have this. No I don’t wanna go to school, and he’ll try and just keep talking and talking and talking that he does not want to go to school, and I’ll drop, in the end, I just never had any conversations with school with him because he would just keep it going, then, I don't want to go to school don't want to go to school. Yeah, secondary school, I think it's been really good for him. Actually, he's had more responsibility for himself, to go to the lessons, he's got to do the homework. He does struggle with homework quite a bit. Again he likes to talk his way out of doing it so that sometimes takes longer than him actually doing the homework. But as long as he does something and sometimes I will sort of scribe for him, as well I’ll do the typing, I’m like you tell me and I will put it down and then I will just email the teachers and say look this is what's happened. And they like normally they're completely fine with that, do you know what I mean. Sometimes it just goes on for too long, some, some, some of the homeworks, I think, this, this is way too much for Adam. You know I don't even know where they're coming from with some of it. I think that the kids are setted aren’t there in some of the classes, and then in some of them they're not like religious studies or. And so there's a mixed bag of kids and sometimes the homework is, is, is too much for some of the ones that are at the bottom of that pile basically. Are they quite supportive school, if you kind of point out that something isn't working. Will they you know find a way around? Yeah, yeah, Because with secondary school, you get an app. And so all the homework goes on to that app. So, parents have it as well so although we can't comment, or, we can see what the homework is, what he needs to do and we can see what he puts on. And sometimes, the teachers will write comments like, oh, you need to focus more or you need to, you know, like certain things especially when he first went there, which are all the things that are named in his educational health plan that he can't do. And so I did send a couple of emails to the SEN lady and just say, you know, maybe their comments could be more constructive rather than pointing out the things that Adam can't do you know what I mean. And so that sort of got resolved. I think sometimes teachers have certain things they say, And that, you know for every child basically. Yeah, and then you get one teacher that's all in, knows everything about your child, and they’re so good and you think God that teachers got it.	CYP learning life skills Role of parents – Supporting work Role of parents – communicating with school Views on coping – work at correct level Parents sharing views of school support Staff not aware of how to support Each CYP as unique CYP has limitations Bespoke feedback. Key teachers are important – some better than others Knowledge about CYP is important.

Appendix 22

Interview 2: Becky		
Exploratory Comments	**Transcript Extract**	**Emergent Themes/ comments**
Impact of COVID CYP has strategies to manage TS in school Waxing and waning of tics Tics worsen in some circumstances Seating considerations in school CYP doesn’t want to tic in front of peers Challenge of following instructions Peer difficulties Struggle for CYP TS in complex Tics wax and wane Tics disrupting peers TS is a disability Risk of Discrimination Tics worse when emotions are high	Yep. So, again, it's a little bit difficult because prior to COVID. Apart from like the four or five months leading up to COVID. Obviously, they, although she had little tics that like sniffing and eye tics they weren’t really that noticeable, and she'd obviously developed a routine to help her, hide her tics, with the whatever routine she had in place and obviously COVID came along, wiped that routine out of the way like you're seeing, we're seeing with many people. And, obviously, the tics have come fast and furious because of that. So, the experience during COVID. It was virtual learning so the issues we were having on virtual learning was the computers make her tics, a lot worse. So even though we have blue light filters on them, umm she, she, she doesn't do well on the computers her tics are a lot worse when she's on any type of video game or TV, etc. And she didn't want to be on camera because she didn't want people to be able to see her, in the classroom she could quite easily sit at the back of the classroom and but on the camera when everyone can see she was really uncomfortable with that. Umm so that didn't help. Following instructions, obviously, on a virtual classroom it's really hard to follow instructions when the teacher is telling you and it's not written down, and you have to remember those instructions and then do something, and she she really struggled with that so. In the classroom then umm so, she, she got bullied quite a bit. When she went back to school by quite a few of the pupils in the class. Some of the comments that they were saying they obviously, they basically thought that, [talking off camera: out of here please, shut the door] They thought that she was, the children anyway thought that she was doing it for attention, and they, they would obviously go home and say things to their parents and their parents not knowing the full story would be like oh she's just doing it for attention. Leave her alone and then children would come in and say that to her. She was going through a stage where she had, I would call it a squeaking tick however J said it was a barking tick so she had a tic of a kind, that was very loud. And I suppose there was a fine balance in the class as to how much you would, you could allow it to interrupt the other children and allow it to continue but similarly you can't discriminate against a child or you shouldn't discriminate against a child for what's classed in the equalities act as a disability which it is. And so on a few occasions she was sent out the classroom to, because obviously it was a distraction to other people, that only made her tics worse because obviously she got upset, and the more emotion or more your emotions play up whether it's positive or negative as an impact on your tics. And then she would come home and she would feel really sorry for herself and then she wouldn't sleep so the impact obviously had a knock on effect, and school didn't really know how to deal with	Routine is important Challenges associated with COVID Classroom environment Challenges of COVID Difficulties with peers Peers/ parents not understanding TS Recognise challenges for peers and school staff

Impact on CYP's emotional/ mental health Impact on range of aspects of life School don't know how to deal with TS – take easy option Diagnosis led to changes/ support Practical support – exams, safe place, toilet pass Tics are varied -some can't be seen School see CYP as incapable – she is capable Impact on CYP's self esteem Impact on parents – sad Parents asking for the support School not proactive in providing support Diagnosis as a challenge Impact on parents Lack of information shared with parents Parents seeking their own information about TS and support. 'Fight for justice' – strong language 'gone wrong' – hasn't gone to plan	it, because whilst it's becoming more common now, whether or not that's because it is more common or because more people are being diagnosed, I don't know but school didn't really know how to manage it, and therefore sending a child out the classroom is the easy option, and that might be a bit harsh, but that's our experience. And then they had an educational psychologist come in and do a review on her, who, since we've got the diagnosis said that she had to have extra time for exams, she needed to have our own special place where she could go and tic if she needed to, her she has internal tics which affect her waterworks and her bowels so they gave her a toilet pass so she could go to the toilet whenever she wanted. The only issue with that is, they, they treat her has a child who isn't able to do an exam so they would send Beth with other children who couldn't read and write, and therefore needed lots of extra support whereas Beth didn't need the support she just wasn't able to be in a classroom with everybody else. And that made her feel really bad about herself and therefore, she's just gone down and down and down in terms of her education which has had a real impact on her on her ability on her educational ability which has been quite sad, so. Yeah, sounds like it's been quite difficult, especially the last couple of years, sounds like it's been quite difficult in school there. Yeah Yeah, Is there anything that school have kind of put in place has been really helpful in terms of support in school? Umm. To be fair, everything that we've asked them to do. They've done, but they've done because we've asked them to do. They haven't done anything off their own accord, but I think that's because when we got the diagnosis, me and my husband, well, bearing in mind the first diagnosis we got wasn't great. We felt really bad. And because there was nobody given us any information obviously we did a lot of the research ourselves and therefore we're very, because we both struggled with the diagnosis, mentally ourselves, because there was no where to get any information, and I, I put all my attention into finding out about Tourette's and what I could do to support her and how I could fight for justice because of what's gone wrong in her case.	Lack of knowledge/ experience of TS in schools Diagnosis as a turning point TS is varied Practical support – based on CYPs needs School not understanding how to support CYP Impact on CYP – self esteem/ mental health Role of parents – asking for support Impact on parents- mental health Diagnosis as a challenge Limited information about TS available Impact on parents – time and attention commitment

Appendix 22

Interview 3: Carol		
Exploratory Comments	**Transcript Extract**	**Emergent Themes/ comments**
Supply teachers are a challenge for CYP Staff have limited experience with TS Recognising challenges for school staff CYP doesn't want to get in trouble COVID leads to staff challenges Difficult for all children Dealing with many changes Consistent staffing important Coprolalia challenging for the CYP CYP feeling guilt about tics Pupil passport with info about TS Drawing attention to TS as a challenge for CYP	Obviously with, with everything that's been going on with the pandemic and I know this from my school. We've had days where the number of staff office being absolutely, you know, just so many people not in. So it means there's a lot of supply teachers working and the supply teachers don't get that information unless it's put on the sheet, specifically by the class teacher they won't know. And they probably won't be in a situation where they, they've had much dealings with it if they're just doing supply here and there. So I understand it's very difficult for them, but it was getting to the point where she would walk in see a supply teacher and walk back out again, because she didn't want to be told off. Yeah. So yes it's been, the staffing in schools has been so hard throughout the pandemic and even, even when the kids were back at school that didn't mean that the staff are alright. It's been really hard, and it's been really hard for the kids, because they sort of adapted and then adapted again and then come back in and half their teachers still aren't there. So I'm hoping it'll settle down a bit more for her because she she's starting her GCSEs this year so she should have the same teachers for two years. Yeah, which will hopefully sort of negate that as it will only be in the corridors where there might be people who don't know. Yeah, so she's going into year 10?. Yeah, yeah, in September, yeah, yeah so that consistency hopefully then teachers will kind of better understanding then, yeah. And can you talk a little bit about some of the difficulties or some of the challenges that she faces in school kind of because of her tourettes, I know you mentioned a few kind of tics there and especially the eyes of causing her pain, are there things she finds particularly difficult because of ticks or because of tourettes in general. I think the most again the most difficult for her is the coprolalia, it's the swearing, she feels so bad when it happens, and obviously teachers, especially sort of SLT when they're walking break times, lunchtimes in between lessons, they will be listening out for bad language. And because she has her card and she knows that most people know. She will. She sort of blanks it when she when they're calling, and she's like oh well it can't be me because they know. And then she's called back over and she's having to explain herself and then you're stood in the middle of the corridor in front of a lot of people have me to sort of say everything that's wrong with you, which is just not a very nice thing to do. And she, luckily most of her teachers have moved her to seats within the class where she's at the front and near the door. So that means she can leave if things are getting too much and if she throws things she's not throwing things that other kids, which was, was one of her real worries, 'but if I'm sat in the back and I lob	Lack of knowledge/ experience of TS Recognising challenges for school staff Impact of COVID – staffing in schools Looking ahead to future/ qualifications Impact on CYP – guilt about tics Conflict between rules and needs

Practical support – seating in class CYP worries about impact on peers Friends understand her TS Friends as a support in class	something, and I hit someone, then I'm going to have to cope with that.' And so most of the time she is sat at the front, and she's usually sat next to one of her friends so they understand what's going on. And they can support her and calm down and tell her to leave if she needs to, which has been really useful for her, how have kind of obviously her friends and their real support for her. How do the rest of her peers, kind of respond to her. Does she have any issues there or?	Challenge for CYP – explaining TS Challenge for CYP – guilt/ worry about peers
Bullied previously Peers attempting to trigger tics COVID – changes in classes Hope for future	Yeah, I mean she was, she was suffering bullying before. Before it happened, before it came on. And I think it was a real struggle at the start. And also another, it's another one of those when they realised that she, she was swearing that would be, they would try and set that off every lesson, it's what do we have to do to make her swear. So that's really difficult in terms of sort of managing it, but also the classes last year were mixed up because of COVID So, they weren't in sets they weren't in any of their normal groups. And so I'm hopeful that going into sets for GCSE will mean that she's in a class with people who are a bit more, sort of like minded, and really want to be there because it's been a bit of a trouble the class that she had last year a lot of them I don't think wanted to be there at all. And we're just looking for any excuse.	Practical support in classroom Peers as a support Peer difficulties Challenges associated with COVID- changes in classes Future considerations/ hopeful

Interview 4: Diane		
Exploratory Comments	**Transcript Extract**	**Emergent Themes/ comments**
Contact with school Challenges for CYP CYP struggling due to lack of support	I went in with her one morning, I'd emailed the school, to kind of say look She is absolutely hysterical, you know she's, you know, really, really struggling. Her tic attacks have been horrendous, she's actually been sleeping in with me, umm, you know she's she's really really going to through a tough time, because the supports not been there. And so we went in and spoke to the teacher. Now, especially with girls. When she's in	Role of parent in working with school Difficulty securing support in school

TS not always visible TS is different at home and school Parents not feeling believed Limiting support when TS not visible Peers supportive, seeking to understand Contact with school Support is important Argument – conflict between home and school Drastic actions due to lack of support CYP missing learning opportunities due to incorrect support Complaint to school Inconsistency from school Range of teachers created challenges for awareness of TS Card highlighting support needed as a useful strategy for CYP Praise for school Flexibility with school rules	school, although she is ticcing, shes, you know, girls are masters at masking it. Yeah, they are masters at, you know, trying to reduce their anxiety, and then when they come home. It's like a boiled pot just spilling over. Umm So, Basically, I was told, well, she's not showing any tics in school. So I can, I felt as if they were saying well we don't believe you, So prove it. Prove it. And we're not, or we're not giving her the support, Now I know for a fact that she was ticcing, because some of her friends have gone to their parents and asking about the tics. Okay so they were seeing them? Yes, they were seeing them, they were asking, you know, what can I do to help? Like should I just ignore them? You know, I, I don't want to make things worse, so children but asking their parents so I know for a fact she was ticcing, she just wasn't doing it, obviously to level that she can do it. Umm But, as I said to the school, the whole point is we don't want her to be ticcing. The whole point is the support needs to be put in place so that her tics are down to a minimum. Yeah. And, you know, I don't want her to be showing that anxiety, we don't want her to be freaking out. That's the whole point. That's why these things have to get put in place. Yeah. So, We then got the personal profile from [charity name], that coincided, that actually came on the day that I was having an argument with the school. So I had to pull her out of school, because they were refusing to put the support in place. I pulled her out of school and said she'll be back when you put the support in. So put a complaint, I had to put a complaint in to the head teacher, so a meeting was called, and we went to we went with our social worker. And by that point as I said, I emailed them the personal profile, from [charity name] and at that point they backtracked on everything. No, the support will be put in place, this is what we're going to be doing. And they've actually put together a card, and they've laminated it. And they've basically listed what support Daisy needs. And because obviously it is in high school. There's so many different teachers, you know, the chances of [talking off camera] Obviously you can get supply teachers in, teachers can be covering, there's a much higher chance of having a different teacher. So, put this card together. And it means that she can just show the teacher why she's doing it, She doesn't need to explain herself, as she doesn't need to get into a conversation with anybody. She just shows her card. And that's it. So, you know they have been umm, They have been really good in certain ways so she's got a lanyard so she doesn't need to wear a mask, because masks are still compulsory up here, so if she puts a mask on her tics just sky rocket. They just sky rocket, so she's got a lanyard to confirm she doesn't need to be in a mask. She's got an allowance for her school uniform. And so rather than wearing an actual shirt, where she couldn't cope with the collar, she wears a polo shirt. And as I say everything's on this card, so she can take this card about. She's got access to a kind of quiet room during lunch and break, so if the playground is particularly rowdy or she's having a bad day, she can just go into this room and just kind	TS not always visible TS different at home and school Parents not feeling believed Supportive peers Parents role in contact with school Support is important Conflict between home and school Lack of support leads to drastic actions CYP missing learning opportunities Inconsistency from school Variation in teachers Card highlighting support is useful. Flexibility in school rules

Quiet room access to support Fire drill walk through Bad day leads to tic attacks at home Understanding and flexibility CYP enjoys learning and homework Been there done that – experience is useful Put your foot down Firm with school Fighting language Previous experiences with other child led to ‘fighting’ Parent taking control of what is happening	of chill a bit. Umm, they went through fire drills. Umm so we actually walked through the fire, the fire drill just us, so that she knew what to do and where she was to go, I’m trying to think what else. Homework is well, and obviously she gets homework every day, every day, in which I think is just homework is so important. It really really is but if she's had a bad day, she's come home. She could literally have tic attack after tic attack after tic attack and she's exhausted. So, they’ve said, you know, not to worry about. If she's having a bad day. Obviously, under general circumstances if they don't do the homework, they get what's called a D-merit. So, I suppose its kind of like, if you don't do it three times you get like a D-merit, it's what's like a warning type thing. [noise off camera] And so it's like a kind of a black mark, really, but they’re not allowed to do that with her. So obviously, when she's having a good day, the thing is, she loves her homework, you know she loves her school work, she’s ridiculously intelligent, and she's I've never ever, ever had to um prompt her or chase her with any of her homework, she just does it. And then she ends up doing more because she just loves, you know, She just loves looking into lots of different things and, you know, finding out information. And so, you know, it's not something that she's ever shied away from. And so, yes, all these things as I said it took a bit of a fight. But, as I said, I think because I've been there and done that knew that you have to put your foot down. Yeah, so do you think it's come a lot from you then having to kind of say this is what we need to do, and you've been very involved there? Yeah, you know, it's like a kind of, I just fought, I did I had to fight so much for my son. [talking off camera] My son, basically lost an entire year of school in umm in mainstream down south, just, they were just horrible, they would lock him in rooms umm they would phone me ‘you need to come and get him’ ‘why?’ ‘he’s in the playground’ ‘yeah, why do I need to come and get him’ ‘well he won’t come in’ . ‘Well, obviously, you know there's a reason why he won't come in, rather than phone me, you know, you know. Anyway, that was a huge big thing so I knew, when you have to take drastic measures. And yeah put your foot down and say no, this is what's happening. and have the school been quite good at sticking to that now that you've got kind of those things in place? Yeah, well they’ve actually kind of, They have been really good umm, she had a bit of a, she had quite a big argument was one of her friends, in which she was really really really struggling with and the school kind of took on that and kind of said I think even being in a full day is potentially going to make things really, really bad. So she was allowed to, to go into the classes that she really enjoyed. She was allowed to use what they call the base. So, it's somewhere for during class time, that she can go. They’ve offered her different	Quiet room for support Unpredictability in TS CYP enjoys learning Experience with TS is useful Parents role to advocate Parent fight for support Taking drastic actions

Recognition that school have been good Challenges due to peer problems Access to school facilities when she needs it Offers of various support Seeing challenges led to better support Acknowledgment of challenges for CYP is important Always room for improvement for support Importance of sharing information across the school TS is more than tics May not see challenges CYP is experiencing Information useful for teachers School reluctant to take up training	kind of therapies so they do like lego therapy or beauty therapy, and, you know, various different things like that. So they've actually kind of put more things in place after they've seen that she's really struggled, umm which has, which has been really good. Ahh okay, so the awareness, kind of, they've got that information from the card, it sounds like that’s helped them to be more aware of what they should be doing or what they could be doing. Definitely, definitely. And you know they are kind of I suppose actually acknowledging what she's kind of going through. And, and, you know they’ve kind of seen it first hand. So, yeah, I think I feel as if we’ve definitely turned a corner now. So, obviously in a big high school, it will be varied with a different staff, but how do you think the knowledge of tourettes, kind of was at the beginning, compared to now, do you think it's improved since these things have, you know, you've shared these things, and is it quite good now or does it still need to improve do you think? I would say that there is, there's always the potential for improvement. And, you know the profile that Daisys got was emailed to all the teachers. And that actually does give you know a kind of Overview of tourette's and explains that, you know, tourettes isn't just about the motor, and vocal tics, you can have internal Tics when it looks, you know, visually, as if their coping, they could actually be going through a major internal struggle, and you know they need to take that into place, and, and a lot of the teachers have fed back that that information was actually really useful. However, they’re not at the moment taking up the offer of training.	Recognition of school doing well Peer problems Access to school facilities Access to additional support Important for school to acknowledge CYP’s challenges Support could be improved Sharing of information is important TS is more that tics Internal and invisible symptoms of TS School reluctant to take up training offer.

Appendix 22

Interview 5: Emma		
Exploratory Comments	**Transcript Extract**	**Emergent Themes/ comments**
Parents not recognising TS initially Range of tics Thought he would grow out of tics Family life event impacting tics/ TS Difficulty – attention in school Didn't think much of TS symptoms initially More extreme symptoms led to concerns Recognition of difference Mental health difficulties – anxiety, depression Confusion between roles of professionals Importance of non-judgemental professionals School uninterested, no support in place	Okay, great. so, could you tell me a little bit about that process of realizing that Ethan had tics or that kind of initial where that came from having started in terms of getting a diagnosis for Tourette's and that kind of story, if that's okay. Okay so, initially, Ethan started doing like funny little movements and things like that when he was about six or seven. And we just kind of put it down to sort of habits of kids, you know, kids get habits and then they'll sort of stop and things like that, initially it's I think it started off with umm. I think it was like the Wriggling his nose [mimics nose wriggling] and then there was other things like his blinking really liked scrunchy blinking blinking [mimic exaggerated blinking] and there were loads of different little things one thing moved on to the to the other, but to be honest, we just didn't didn't put it down to, I thought he'd grow out of that kind of thing and every time it was like 'you better stop doing that, you'll start it'll become a habit' and then, you know, and that was through primary school, and he had a bit of a tricky time at primary school because, especially in that year sort of three four time when he's about sort of six or seven, because my, my, my dad was very ill. And Ethan was quite close to him, and I was sort of going, going out and trying to looking after him So, there was a little bit of instability I suppose because he didn't necessarily know if I was going to be coming back home of a night or, or whatever. And also, there was a lot of uncertainty around his granddad as well, he knew something's going on but you know it was all a bit weird. Umm He struggled, struggled with school with attention and things like that, and again, didn't really sort of think too much of it. But then he started doing really quite strange things like sort of putting a skipping rope around his neck, being really volatile at school, saying really quite strange things that weren't really sort of, hate to use this word, but 'normal'. And, you know he was getting very anxious and very, in some ways depressed. So we got in contact with P-cams, it was at the time and eventually we got a six sessions with a, I'm not sure, I think she was more like a counselor, but she was very she was lovely and Ethan really liked talking to her and because he could just talk, and he just didn't feel that she was judging him or anything like that. But this was actually towards the middle of year six, so he was pretty much nearly finished there, and the primary school just really weren't interested in sort of putting anything in place or to be quite frank looking but they weren't particularly supportive of any of his, sort of, traits or things. I mean, which we now realise is, you know, Autism and Tourettes, and they just put it down to him being naughty and he got into trouble and you know be sent out for rolling his eyes when it was actually really a tic and he couldn't help it, He'd tell people, I can't help it, I can't help it. And then they wouldn't believe him, tell him to stop. He couldn't and then then he'd get frustrated,	Parents not necessarily knowledgeable or aware of TS prior to diagnosis TS changes due to life events Difficulties with attention in school TS recognised as symptoms more extreme CYP mental health impact Difference in support from different schools Some school staff unsupportive CYP seen as naughty Not being believed.

Primary school not supportive School put down to being naughty Sent out for tics Staff not believing CYP that he couldn't help tics TS makes school unpleasant for CYP Tics change over time Professional involvement not always helpful CYP getting in trouble at school Peer difficulties- picked on Becoming socially isolated Tics different at home and school Supresses tics at school Suppression of tics leads to poorer concentration. Gets in trouble for tics. Time out of lesson Access to support facilities in school No formal paperwork to outline support Support for ASD. Diagnosis opened doors	then he'd get really angry and it kind of, you know, it wasn't a pleasant experience for him. So anyway move on to secondary school, tics are still continuing, but sort of different ones now, you know, he's kind of, it's like he's convulsing sometimes and things like that - so we go to the doctor. Oh no sorry and actually when he was umm, when he was little. So when he was little as well we went to the doctor and he got referred to her to the tic lady in umm in the [hospital name] at the Children's Hospital. But that didn't really seem to do much good anyway so they didn't, didn't do anything further with that but then in, sorry, now we're back to when he went to secondary school. And, yeah, his behaviour, He was getting in trouble as well at school, sort of, year seven. Umm, Lots of kids were picking on him, he found it difficult to integrate. And it's kind of really just, it's just got sort of, he's become more and more isolated. But then at same time he's become more or less - less and less tolerant of people. But in terms of the tics. They've been getting quite, I mean when he comes home, they're really quite prevalent and he's trying to suppress them all day at school. And so he's concentrating, that he's more concentrated on suppressing the, suppressing the tics and then not concentrating at school. So he'll kind of get in trouble for that but then at school now they, they've always been sort of fairly good in the fact they've, they have this little center called 'the Bridge', which is where kids can sort of like go and take time out you know if they need to take time out of a lesson to sort of calm down or whatever. And, yeah, so, I mean that was more sort of, I think they were kind of, they got they got we got, they got the SEN coordinator involved and although he wasn't, he's not got an EHCP or anything, they kind of they did give him an extra sort of assistance on sort of like the special needs kind of aspect of things, and but I think they were kind of going more down the, or looking at him as though had autism but we didn't actually get a diagnosis from CAMHS until this year actually, actually January this year, January this year. And was that the diagnosis for the ASD and the Tourettes? At the same time? ASD and Tourettes, yeah, yeah. And once that happened, that seemed to kind of open a few more doors and the fact that the school is like, they actually believed him then. And so, stuff on his student profile got then amended so he wasn't getting into trouble so much with the teachers and, umm, And yeah, so things like preparing for exams and stuff they've now told me now that he can, that they'll be able to sort of do the like, the extra support things so, where he can sort of possibly sit in another room or have extra time, because, sort of some of the things he's, you know, the attention and some of his motor skills, his writing skills aren't the greatest. So yeah, it's been. Since He's got a diagnosis it feels like it's been a little bit more constructive, shall we say.	School not pleasant for CYP TS changes/ is varied Peers picked on CYP Social isolation Difference in tics at home and school Supresses tics in school Access to support facilities in school Time out of lessons No formal support plan in place School supporting ASD – more confident with this that TS Diagnosis as turning point for more support Exam support

Diagnosis lead to being believed by schools Exam support in place Difficulties – attention, motor skills, writing. Diagnosis lead to more constructive progress Differences in schools in support offered. Secondary better than primary. School staff rude, arrogant, uninterested. School staff not recognising TS Parents expectation of school staff to recognise TS Seen as a naughty boy Pupil profile -secondary EP involvement Additional support from various professionals – put in place through school.	So it sounds like the tics and some of these kind of characteristics have been there for quite a long time, but the diagnosis is only relatively recent? Mmm, Yeah, yeah. I mean I would say that throughout it all the secondary school has been more supportive than the primary school. the primary school, I found the SEN coordinator extremely rude, arrogant, and just really quite uninterested. Okay. And I think she was a little bit old school, to be honest, it was just a case of like not recognizing that there could have been something. I mean, I would have thought sort of with her, with her depth of experience that she would have seen sort of children that have that were exhibiting these kinds of signs or anything like that, and could have kind of given us a viewpoint or maybe signposted us somewhere or whatever but it was no, it was very much like 'well he's naughty boy, and we're not basically not going to do anything to help him', Whereas at secondary school, they've been, you know they they've set up pupil profiles. They got the educational psychologist involved, and they are, they have contacted the communications interactions team as well for the for the local council as well so that they're hopefully going to be doing some work with him in this this term as well, so, yeah.	Diagnosis made support more constructive Secondary better than primary for support School staff not recognising TS CYP seen as naughty School not putting support in place Additional professional involvement through school.

Interview 6: Fiona		
Exploratory Comments	**Transcript Extract**	**Emergent Themes/ comments**
TS is more than tics Range of tics	Yeah, it's, I think the the tics themselves are just what people see but there is so much more going on both in his head and inside him. And I think, so, so the manifestation of the Tourette's is shoulder rolling, head movements, He's had a head shaking tic	TS is complex Tics are varied

Wants to hide TS Suppression of tics in school Confusion in disentangling symptoms from co-morbid conditions People don't see the struggles Hard work for CYP with TS to function day to day Difficulties – focus, writing, distractions Missed learning Desperately sad Intelligent but difficult to show his knowledge Importance of education Parents worry for future Challenges associated with moving schools Key member or staff Supportive staff	[mimicks head shaking tic] for right from before the end of term, which he's absolutely hated because he can't hide it, and he's in conversation and he's shaking his head, whereas lots of them he can suppress quite a lot. And he, if he gets, he struggles with cold sores, and then he gets a licking tic and a jaw stretching tic. So it's often in response to something. And he's, and he's also said about, and again, this is where I don't know where the different things crossover but compulsions so we've had to put the child locks back on the [car] door because he's got a compulsion to open the door when we're moving at the moment, when we're driving, and it's, it's the things that his, his brain is working on that no one has any idea of on a day to day basis, he is working harder than probably anybody I know. Just to get through the day. There's and just try to bring that focus on to what he's meant to be doing so, if he's trying to suppress a tic, that's taking concentration, if he was wanting to click his fingers and is meant to write. That's really hard, focus. And then somebody distracts him, you know, across the other side of the room. And it's hard to explain. To give an example he once said that he, his eye got caught by a toilet sign outside the classroom door, and he got fixated with how many times it was being slid across from vacant to open during the day and he missed the whole lesson because he was just staring at the sign, and he just said he had a blank book in front of him, and you know it sounds funny in a way but it's also desperately sad because you think, what can. He's so intelligent and he's so capable, but it's unlocking that that jumble. And also when he receives information, It goes in like spaghetti. He doesn't have that filing system in his brain to just just store stuff, so the conversations that he has with people and myself are amazing. He's, he's full of stuff. But in terms of opening the door to next level education, I worry for his, for his GCSEs and that's that's a real concern. So he's 13 now. Yeah, so he'll be in year? Year 9 - he's just started. Okay, yeah. So that obviously, the Tourette's and ADHD that would have affected his whole schooling pretty much then if it started quite young. Yep, yep, So maybe, to start with if we talk about the primary school, and kind of how he experienced primary school and how they supported him, and then we'll move on to the secondary school afterwards just to make it easier. So, how was, how was Primary School was it kind of a large primary school, a small primary school, what was the school like and how did they support Freddy? well the we've had through circumstance, we've moved schools quite a lot, which again, I know is the worst possible thing. But year three, he had an amazing teacher. When he got his diagnosis, and, you know, was, was very supportive, but not, umm more pastorally than academically, and was more of the opinion that if we support him holistically, the the academic stuff stuff will come. So, he was always there for him to	CYP wants to hide TS/ tics Suppression of tics Confusion with multiple diagnoses Difficulties not always seen Impact on CYP – hard work Impact on CYP - Missed learning Helplessness Education is important Impact on parent – worry for future

Pastoral support is important Holistic support Minimal support in place Differences in teacher support each year Chunking information/ tasks Errands, movement breaks Self esteem Falling through the gaps Difficulty sitting still Difficulty reading Learned his own coping strategies Teachers have helped CYP No formal support plan Difficult to access funding or support SEN differences across schools Lack of experienced or passionate SEN staff Time and attention in meetings No support put in place ‘Got through’ Avoiding unnecessary pressure and stress CYP is capable but academic environment doesn’t suit him. ‘Disaster’	chat to, but didn't really put anything in place for him as an individual. The following year, he had a teacher who, she was just amazing in terms of she put everything in place. This was so this this year, year, four or year five, I can't remember but, basically, she would give him a task, He did that task he went back to her she gave him the next one, you know small things, where work was broken down it was chunk size, she didn't want quantity, she wanted quality, and she kept telling him that, she gave him movement breaks, she, but without bringing it to attention of the class, she would just give him errands to do. At that time, he had a, he was unable to leave the room, he had this real fear of going anywhere by himself which he still does, to a degree. So she, she got him to a point of, from not being able to leave the room, to being able to go with another people to collect the register, so she was just constantly chipping away at what he could do. and also building building his self esteem through that. Umm Year six was pretty rubbish, In terms of him just falling through the gaps. I was, I was lucky or unlucky enough to be the cover supervisor at the school at the time, so I had to teach him one afternoon a week, and I just saw firsthand how he was working in a class it even just saying, at the end of lunch, you know, five minutes quiet reading. He had the book open, but he was couldn't sit in his seat. He was all over the place he was looking around the room and he wasn't reading a word, I mean he doesn't read. He just can't, he isn't. He can’t read very well because His eyes are just skipping skipping the lines, so he hasn't got that comprehension. So I think in primary school. He learned some amazing coping strategies himself, he was helped by teachers as well. But there was never any uptake on the, you know, getting something either high needs block funding or proper SEN provision in place there was never a SEN support plan. In year, in year 6 we actually moved from [place name removed] where we were to [place name removed], or was that year five or year six, and the SEN was very different in that, I actually became the SEN governor at the school. And, again, saw, the SENCo then left and I saw what, I think she'd been put into the role without any real understanding of it or any real love for it. And so everything went a bit pear shaped and unfortunately he crossed over with, with that time. So despite numerous meetings, nothing was ever, ever put in place. So that was primary, he got through. Yeah, he did it pass his SATs, with the pass mark which was amazing. it was like it was [relieved expression] he didn't sit the 11 plus, which they do, because I just didn't think it worth putting him through it, he's, he's more than capable of doing really well, but he doesn’t he wouldn’t suit the academic environment. Right okay. Year seven was just a disaster. He wasn't, everything kind of gets worse because more and more is expected of you, I think as you get older, you're expected to be independent, so he was missing really important building blocks in his learning, his ADHD symptoms were coming out more- So he was then getting in trouble at school, he	Key members of staff in schools Lack of support in schools Key support strategies – chunking, movement breaks, Different support every academic year Difficulties – reading, sitting still, concentration CYP Developed own support strategies No formal support plan Differences in support between schools Lack of experienced staff Capable learner- school not suited to needs

Expectations in secondary school were challenging for CYP Missed learning Getting in trouble in school Poor attendance Attendance as a trigger for support 'finally twigged' took a long time to get message across to school Impact of covid School try their best. 1:1 support is useful Lack of consistency in staffing School under resources Role of parent – to advocate - 'fight' Emailed school Support changes every academic year – back to square one Promised support not implemented.	is, he's a child who is desperate to please and desperate to do well. So then he was refusing school so he by the end of year 7, his attendance, it was less than 70%. And at the end of that last term, Attendance is always a trigger for getting something done, I've worked out, I've realized. It sounds awful but it's, that's where schools are measured. So if you want to if you want to lean on them you have to point to attendance. So they finally twigged that there was actually something happening and I had one meeting with the SENCo that year. And that was when we then, Lockdown happened, and we moved to [place name removed]. The school he was in last year, they are. Again, I'm sure this happens up and down the country it's not just us that's unlucky, They've tried to do stuff, they gave him a keyworker, which was great. And she's been supporting him in lessons which has been fantastic. The SEN for Key Stage Three went on maternity leave, and she wasn't replaced. The director of learning was then on long term sick, I think possibly she was new in the role I think she was probably freaked out by the sheer volume of SEN needs, I think I would be, but I get that and I get they're under resourced that I get they are a massive state school in the town, the only one, and they're they're coping with all sorts of needs, but my role as a parent is to fight for my son and I've literally just emailed them this morning because we are Week Three in term, and there is no SEN provision plan in place, all his supported learning has been withdrawn, just from summer holidays to now, his timeout card has disappeared, we were promised the use of a laptop, he hasn't got that, you know it's just back to square one. So, yeah, that's a very long answer to your question [laughs].	Missed learning Poor attendance Challenges in securing support Inconsistent staffing in school Role of parent – communication with school Lack of resources as barrier to support Role of parent- advocating The fight for support Promised support not implemented

Appendix 23: IPA: Themes conceptualised for each transcript (step 4)

1: Ann		**2: Becky**	
Superordinate themes	**Subordinate Themes**	**Superordinate themes**	**Subordinate Themes**
TS is varied	- Not just tics - Tics/ behaviour change - Traits associated with co-morbidities - Range of tics - Each CYP with TS is different - Acceptance easier at younger age - TS is unpredictable	TS is misunderstood (more than tics)	- Tendencies of other disorders - Iceberg model - Stigma of TS - Media stereotypes - Peers and others don't understand - Parent didn't know about TS, learning as we go - Impact on mental health
CYP school experience	- Tics don't impact CYP - Denial of diagnosis - Doesn't want attention - Enjoys school	School difficulties	- Impact on academic function - Side effects of meds - Sleep - Future concerns - Peers - Missing learning - Impact of covid - Doesn't' want to draw attention - reading
Barriers to support	- Difficult to diagnose - Not being believed/ listened to - School policies - Promised support not delivered - Support dropped after diagnosis	Support for TS	- Key staff members - Impact on other pupils - Toilet pass - Seating - Quiet room - Fidget toys - Exams - Lack of resources in school - Routines / notice of changes - School didn't know how to manage TS - Parent school communication - Parents asking for support - Playing up to TS
Impact on parents	- Worry and stress - Emotional ride - Guilt - Cost – financial - Tiring	TS is unpredictable	- No rule book - Emotions/ tiredness impacting tics - Changes daily
Role of parents	- Explaining and providing info - Breaking misconceptions - Advocacy - Responsibility to secure support - Struggle for support - Planning for future	Diagnosis	- Journey - Kick in the teeth - Relief - TS not initially picked up - Impact on CYP - Impact on family

Positive factors	- Happy to get diagnosis - Acceptance in small community - Being listened to	Knowledge of TS in school	- Better for other disorders - Parents sharing info - Personal interests / experiences of staff - Lack of knowledge/ experience in school - Importance of increasing knowledge in school
Relationships	- CYP-teacher - Parent-teacher -	Support services	- Lack of funding - Lack of pathway for TS - Impacted by covid - Lack of professionals - Medical neglect case - Lost in the system - Long waiting times - Incorrect information - Key professionals
Lack of awareness	- Lack of experience - Peers lack understanding - Teachers not understanding - Parents don't have all the answers - TS not as well understood as other conditions - Need more info about TS - Variation in teacher knowledge - Importance of knowledge and information	Impact on parents	- Impact on family - Financial Cost - Parental mental health - Time and attention - Sharing info - Seeking info
Specific difficulties in school	- Writing - Memory - Focus - Attendance - Homework - friendships		

3: Carol		**4: Diane**	
Superordinate themes	**Subordinate Themes**	**Superordinate themes**	**Subordinate Themes**
Support service	- Lack of TS pathway - Postcode lottery - Should be easier to access - Rejections are difficult - Long waiting times - Lack of support following diagnosis	CYP's views	- CYP enjoys learning - Challenges - Strong academically - Transition between primary and secondary
School support	- Card to leave lessons - Lanyard - Passport - Seating - Exam arrangements - Fidget toys - Support comes from parents requests	Diagnosis struggle / Lack of professional knowledge	- No- one taking responsibility for diagnosis - GP not knowledgeable

	- Paperwork required for support - Strategies that work at home can't be used at school - Support for anxiety - Challenges of getting school to make referrals		
CYP experiences of school	- TS changed the way CYP was seen in school - Doesn't want to be a burden/ ask for help - Learning is important to CYP - Worries about impact on peers - CYP learning about TS - Explaining TS - Told off in school - Hides truth in school - Coprolalia is a challenge - Friends are important - Challenges of COVID (supply teachers) - Difficulties with peers	Teacher knowledge of TS	- Range of teachers - Not taking training - Learning about each CYP - Need for training (in all ALN) - Lack of knowledge
Impact on family	- Sibling doesn't understand - Parents feel guilt - Parents learning as they go - Parents building new relationships with school each year - Parents communicating with school	TS as more than tics	- Possible other diagnoses - Invisible tics - TS in girls - Quick onset - Each CYP with TS is different
Knowledge of TS	- Knowledge better for other conditions - No-one has the answers - Knowledge/ awareness varied across staff - Lack of awareness means inappropriate reactions - Staff given info but don't read it - TS not understood - School try their best	Difference at home and school	- Supress at school so come out at home - School not seeing tics - Parents not feeling believed - Parent/ school conflict
TS as a diagnosis	- Range of tics, cycling of tics - TS constantly changing - Confusion around diagnosis of TS vs TDD - TS better understood than other Tic disorders - Additional tendencies and comorbidities - Painful tics / suppression - Tics signal something is wrong	Charity support	- Best support available - Range of support - Postcode lottery - Knowledgeable about TS - Opportunity to vent

	-	Impact on parents	- Financial cost - Difficult process
	-	Proactivity of parents	- Fight for support - Removing from school - Put foot down - Parents doing it themselves - Parents voice is important - Can be difficult for some
	-	Support in school	- Friends/ peers are a good support - Suportive staff - Support for anxiety - Out of class early - Access to lift - Support not consistent - Sharing of info in school about CYP - lanyard - Flexibility in school rules - Quiet room - Fire drill - homework - Support when seeing her struggle - Additional professionals - Exam support

5: Emma		**6: Fiona**	
Superordinate themes	**Subordinate Themes**	**Superordinate themes**	**Subordinate Themes**
Importance of diagnosis	- Diagnosis led to being believed - Turning point - Change in attitudes from school staff	More than TS	- Not just TS - Complication of multiple diagnoses - Difficulty in disentagling TS vs other conditions - More than tics
Lack of awareness of TS	- Parents not aware of TS prior to diagnosis - Lack of teacher awareness (primary) - Lack of teacher awareness secondary - Disentangling TS and ASD - Parents don’t have answers - General understanding needs improving - Better awareness for other conditions	Lack of knowledge about TS	- Teacher knowledge of TS - Range of staff - Staff want to understand - CYP sharing info about TS to class - Understanding better for other conditions

Appendix 23

TS is varied/ changes	- Tics change - Internal tics - TS is more than Tics - Sudden onset/ worsening with life event - Different in home/ school (supresses in school)	Role of parents	- Fighting/ advocating for CYP - Sharing information - Continuous communication
TS is misunderstood	- Peers lack of understanding - Media view of TS - misconceptions	Impact on parents	- Didn't know about TS before (didn't recognise initially) - Making difficult decisions - Acceptance of diagnosis - Worries about the future - Guilt for contacting school - Financial Cost - Parents need post-diagnosis support - Recognising the challenges for other families with TS
Impact on CYP	- Mental health - Not being believed - Social isolation - Viewed as 'naughty' - Peer difficulties - Doesn't like to shared diagnosis - Worries about others view of him - Pain - Negative view of school	Barriers to support in school	- Struggle to get support - Reluctance for EHCP/ formal support - Under resourced - Staff changes/ lack of consistency - Different every year - Expectations - Promises not delivered - Difficulties with communication
Difficulties	- Emotions - Concentration - Sleep	Useful support in school	- Key members of staff - Chunking - 1:1 support - Errands/ jobs in school - Movement breaks - Time out card - Routines and consistency - Break and lunch are important - Praise
Support	- Safe space - SEN support - Exams - Access to facilities in school - School doing their best - Pupil profile - Seating considerations - Limited support	Challenges for CYP	- TS coincided with life events - Trying to supress tics - Exhaustion - Distractions - Unable to show his knowledge in written form/ capable but not academic - Reading - Mental Health - Peer problems - Social - Attendance - Doesn't want to share diagnosis

Support services	- Secondary school better than primary - COVID impact on support available - Range of services/ professionals involved - Confusion between services/ professionals	YP’s Strengths	- Likes communicating verbally - Career opportunities - Resilience
Barriers to support in school	- Primary school didn’t put support in place - Schools don’t know how to support - Staff changes - Range of staff - Parents recognise challenges for school - Lack of experience	Support services	- Differences across the counties - External counsellor - Unusual pathway to diagnosis
Impact on parents / role	- Sharing info with school - Feeling helpless - Role in ensuring support is in place - Use of ‘we’ (school and parents in securing school support)	Importance of the education system	- CYP falling through the gaps - Education opens doors - Education doesn’t fit society

Appendix 24: Consideration of Ethical Issues

Ethical Consideration	Part 1 Procedure	Part 2 Procedure
Informed Consent	The online questionnaires for school staff and parents included information about the research and consent was given with an explicit tick box before being presented with the questionnaire (appendices 7&8). Participants were reminded of the opportunity to contact the researcher to ask any questions prior to completing the questionnaire. Participant who did not tick the consent box were automatically directed to the end of the questionnaire.	Each interviewee confirmed consent to participate in an interview through an explicit tick box after reading the information sheet (appendix 19). Verbal consent was also gained at the beginning of each interview.
Anonymity and Confidentiality	Participants followed an anonymous link to the online questionnaire. The questionnaire did not request any personal or identifying information and consequently it was not possible to make a link between the participants and the responses provided. The questionnaire responses were stored on a secure online server and IP addresses were removed. At the end of the survey parents who wished to volunteer for part 2 of the survey were asked to follow a link to another Qualtrics survey which asked for their email address. Information from this second survey was stored separately and was not able to be traced to responses from the initial questionnaire.	Participant's information and identity was kept securely by the researcher, their identities were not shared and any information provided was stored on a password protected computer. Two weeks after the interviews took place, the transcripts of interviews were anonymised, with the participants name being replaced by a pseudonym and any identifying information being omitted from the transcript. Following transcription, the recordings of the interviews were permanently deleted 2 weeks after the interviews took place.
Right to Withdraw	Prior to completing the online questionnaire, participants were informed that they had the right to withdraw prior to submitting their responses. The information sheets (appendices 5&6) explained that once the questionnaires were submitted, they would no longer be able to withdraw their response as there was no identifying information to be able to trace the responses of a participant. Participants were	Prior to completing the interview, participants were informed both in the information sheet (appendix 18) and verbally that they have the right to withdraw from the interview without giving a reason. Participants were also informed of their right to skip any questions during the interview without giving a reason. Participants were informed that they had 2 weeks from the date of the interview to

	also informed that they were free to leave any questions blank should they wish to do so.	remove their response should they decide they did not want their responses to be included. After this 2-week period the interview transcripts were anonymised and interview recordings deleted so participants were unable to be identified from the interview transcripts and were therefore no longer able to withdraw their responses.
Debrief	All participants were provided with debriefing information (appendices 9&10) at the end of the questionnaire. For further information, queries or concerns participants were provided with contact details for the researcher, research supervisor and Cardiff University ethics department.	All participants were provided with debrief information at the end of the interview, both verbally and via email (appendix 20). Participants were given an opportunity to ask any questions at the end of the interview and provided with contact details for the researcher, research supervisor and Cardiff University ethics department.

Appendix 25: Content analysis categories with quotes

Parent Data			
Category	**N**	**Initial codes included**	**Illustrative Quotes**
Exam Arrangements	10	Exam support Separate space for exams	'She has custom exam conditions - own room, extra time, rest breaks.' 'Special/access arrangements for exams' 'Separate room for exams'
Time out opportunities	20	Time out card Step out of classroom Avoiding busy spaces – leaving lessons early etc	'able to take himself out of class if he needed some space. ' 'She can leave the classroom anytime she needs if her tics are becoming too much for her.' 'Allowing her to take time out when she needs it.'
Fidget/ Sensory toys	6	Fidget toys Chewing gum Sensory toys	'Allowed chewing gum and fidget toys in class' 'She is allowed chewellry (which she has' 'fiddle toys'
Quiet/ safe space	15	Safe place to go Sensory room Access to quiet area	'provision of a quiet space to chill' 'Use of quiet room, she can go and sit with someone who understands the situation.' 'ard to go into a quiet room.'
Seating considerations	2	Seated with friend Seated at back of class	'she was allowed to sit at the back of the class next to an understanding friend.'
Support with writing	7	Use of laptop/ device Use of a scribe	'allowed to use a chrome book and iPad as writing is impossible at times.'
Access to facilities at school	3	Lift SEN facilities	'access to a building with support teachers, sensory room and a calm room.' 'ability to use the lift in school'
LSA/ TA support	3	LSA in class TA prompting	'named LSA so he has someone to check in with him.' 'has LSA's in class to prompt him to re focus and carry on with his work,'
No support	22	None Nothing No formal support in place	'I would say there is no formal support in place.' 'None. The school are completely useless.' 'Nothing specific'
Supportive staff	8	Staff provide emotional support Teachers are supportive	'staff were very supportive. ' 'The teachers are very good and do provide additional emotional support'
Support plan in place	4	EHCP IEP Formal outline of support	'has an EHCP which covers support he should get in school' 'Pupil support plan'

Information Sharing	6	Pupil profile Parents sharing info Info shared within school	'All of her teachers know of her TS' 'We as parents have made each form teacher and teaching assistant aware for each year' 'Communication to other areas of staff, such as lunchtime staff and outside staff coming in to take clubs etc.'
Movement breaks	3		'Could walk around class to stretch his legs' 'movement breaks'
Specific interventions (social, anxiety)	9	ELSA Social groups Anxiety interventions	'anxiety group' 'Small group work to support with engagement and social interaction' 'interventions for self regulation, knowing his anger triggers, friendship skill, worry explorer.'
External professionals	3	EP OT Communication team	'engagement of Ed Psych,' 'Occupational therapy input for emotional regulation, gross and fine motor skills'
Extra time	2		'extra time' 'More time for tasks'
Support from peers	2		'Support group of friends and peers.'
Reduced workload	2	Reduced timetable Reduced homework	'Option to reduce hours, homework'

Additional codes from parent data			
Category	**Constructed definition of category**	**N**	**Quotes**
Staff lack of awareness or understanding of TS	Reports that school staff do not understand, recognise or know how to support CYP with TS	9	'People don't understand this condition' 'negative experience with supply staff not believing he has TS'. 'school don't understand TS they think it's just swearing and haven't made an effort to take us seriously'
School responding inappropriately to TS	Reports that the support is not right or that support is inappropriate or unhelpful for CYP with TS	3	'there was never the right support' 'Investigations due to inappropriate staff behaviour and management of tics and has been given detentions we had to contest' 'Often approach as they would autism but this can actually make things more difficult'

Lack of consistency with Support	Reports that support was not consistent across years in school, not following through with plans.	3	‘Been very variable each year depending on teacher’ ‘SEN plan but it’s not always followed.’
School unwilling to provide support	Reports that school are unwilling or not supportive in providing appropriate support	4	‘school were less supportive.’ ‘they have an unwillingness to support her as it is costly and an inconvenience.’

School Staff Content Analysis			
Category	**Definition/ Initial noting**	**Frequency**	**Illustrative quotes**
Individualised pupil plan	Reference to existence of a specific support plan for individual student.	4	‘Voice of young person shared with teachers’ ‘support for pupil and teacher on how to manage each individual’
Safe/ quiet space	Provision of a safe or quiet space the pupil could access	5	‘Safe places’ ‘use of quiet space during tic attacks or high/increasing anxiety’
Time out card	Opportunities to leave classroom/ lesson when required	4	‘Time out’ ‘Time out passes’
Exam arrangements	Arrangements for additional support in exams, including extra time, scribe or separate room	2	‘Access arrangements for exams’
TA/ LSA support	Access to additional adult support in the classroom	4	‘TA support when needed’ ‘currently providing 1:1 support’
Social skills	Support with development of social skills in school	2	‘Social skills’ ‘Social skills support.’
Additional service involvement	School referring to additional services, this includes school counsellors and services to support the family.	5	‘Referred families for Early Help to provide wider support’ ‘Access to school counsellor.’
Use of technology	Laptop for writing or phone for music	3	‘use phones to listen to their calming playlist’
Fidget toys	Sensory tools or fidget toys	2	‘Fidget tools’
Pastoral support	Access to some form of pastoral support in school	4	‘Pastoral support in school. ‘ ‘pastoral support’
Reduced workload	Reduced workload through reducing timetable or class work or homework.	4	‘reduced timetable’

Lunchtime arrangements	Specific arrangements to support CYP at lunchtime.	3	‘Skip lunch queue’ ‘access to our 'hub' facility when needed (during lessons and social times’
Peer support	Providing training for peers or ensuring CYP has access to a supportive peer	2	‘Always have a friend with them training for peers to ensure they understand the condition’
Staff awareness	Increasing staff awareness through training or sharing of information	3	‘training for all teaching staff about the individual students’
No reading aloud	-	1	‘Don’t ask to read aloud’
Memory support	Chunking or recaps	1	‘Small chunks of information’ ‘Powerpoints and email recaps’
Emotional support	-	2	‘emotional support’
Flexibility in rules	Allowances to behaviour policy	1	‘Bespoke behaviour management’
Academic support	-	1	‘Academic support when needed’

Appendix 26: IPA example quotations for finalised themes

Superordinate theme	Subordinate theme	Example Quotes
Understanding of TS	Complexity of TS	‘it is different, and he is completely different from one month to the next,’ (Ann) ‘he's not predictable if you know I mean, it's strange, but I find that the whole time is that he's really unpredictable, in his behaviours’ (Ann) ‘So it depends on how she is on any given day’ (Becky) ‘the vocal tics, they sort of, they seem to cycle, so she'll have one for a while and she won't even know she's doing it, and then it will get replaced with something else, and then a couple of months later it'll come back.’ (Carol) ‘but yeah, I mean, sort of, they do get worse and get better.’ (Carol) ‘So there will be times where she's really okay and she's not ticcing too much, and then suddenly a few days later, they'll just spiral back in again. Even if there doesn't seem to be any reason on the surface why it's happening. ‘ (Carol) ‘Yeah yeah, it really increases when she's worried about something, or, you know, so like going back to school or going on holiday both of these are things that have really sort of heightened it,’ (Carol) ‘You know, people, you say a child oh this child's got Tourette's, and they just think oh, they're just gonna make some noises or or movements, and that’s it they don't realize about all the other things that would stop them from learning, you know, try not to tic, you know, or it taken away their focus and stuff like that so’ (Ann) ‘you can have internal Tics when it looks, you know, visually, as if their coping, they could actually be going through a major internal struggle,’ (Diane) ‘because I know that with Tourettes you can have internal tics which are, which result in sort of like bad thoughts which then can come out and you can't help, you know, you can't help saying them. So yeah, I think it's a bit of a combination of both, to be honest.’ (Emma) ‘think more understanding of the actual condition itself. And this isn't just with school but in general, I think, the appreciation of how much it takes out how much it takes out of an individual, and the fact that it actually hurts, you know how much it takes out of you mentally and physically.’ (Emma) ‘the the tics themselves are just what people see but there is so much more going on both in his head and inside him.’ (Fiona) ‘she can sort of control it to that point that she found that she was holding them in so much that when we got back at the end of the night she was just really going.’ (Carol) ‘Now, especially with girls. When she's in school, although she is ticcing, shes, you know, girls are masters at masking it’ (Diane) ‘then when they come home. It's like a boiled pot just spilling over’ (Diane) ‘I was told, well, she’s not showing any tics in school.’ (Diane)

		‘To be honest, I don't really know what the best way of doing it is because I think the way he is at school is different to what he's like at home’ (Emma) ‘I mean when he comes home, they're really quite prevalent and he’s trying to suppress them all day at school. And so he's concentrating, that he's more concentrated on suppressing the, suppressing the tics and then not concentrating at school’ (Emma) ‘yeah, I'm not sure what he does at school, I presume, they'd be sort of similar but like he says he tries to suppress them so that people don't think he's, in his words, ‘don't think He's weird’ (Emma) ‘So, it's not kind of apportioning blame on staff, but I think there's a real lack of understanding out there, people think that because they don't see tics if you're suppressing them in school, then he's okay’ (Fiona) ‘we've met children before that have tourette’s or they'll have, you know, OCD, a bit of OCD a bit of ADHD thrown in. It's like a mix of all these different brain things all mixed together in a different way’ (Ann) ‘so she has really bad anxiety. And she has really bad, I say OCD tendencies but they are more. They're more things that she lives of all the time so things that have to be done in a certain way.’ (Becky) ‘It doesn't mean that she's got ADHD but it means that those tendencies are there and dependent on how she is on that day depends on what tendencies she has’ (Becky) ‘My child has Tourette's, however she has OCD tendencies. She has anxiety tendencies and she has ADHD tendencies, but her diagnosis is just Tourette's.’ (Becky) ‘it's like a pyramid and on the top of the iceberg, you've got motor tics and vocal tics, I don't know if you've seen it, and then that's the top of the iceberg and then you've got a line where the iceberg hits the water, and then under the iceberg, you've got the rest of the iceberg. And that iceberg got like 10 or 15, lots of different symptoms like OCD ADHD, anxiety, rage, etc.’ (Becky) ‘And she kind of wants to hide and then her anxiety gets worse than the tics get worse.’ (Carol) ‘I wonder whether she's, possibly sort of on a OCD spectrum. Some of the things she does will sort of suggest that, but really the only comorbid is, is the anxiety, which is a massive issue.’ (Carol) ‘the anxiety started to be more of a problem for about a year before the tics started. And it was sort of building. And I do wonder whether that's what's triggered it but, again, not quite sure.’ (Carol) ‘well what they're thinking is that, potentially there is another diagnosis, and they might need to go back to CAMHS again.’ (Diane) ‘I'm not sure where that's the Tourette's or whether that’s autism,’ (Emma) ‘we first started seeing consultant when he was four, he got the diagnosis when he was six. And he's also diagnosed with ADHD and has some sort of OCD traits as well, but that's not diagnosed,’ (Fiona) ‘The other thing I should probably say is he struggles with really high anxiety’ (Fiona) ‘they again thought there was probably something underlying with the Tourette's masking ADHD and vice versa.’ (Fiona) ‘I mean where where all the different things crossover, I get a bit lost,’ ‘he's also said about, and again, this is where I don't know where the different things crossover but compulsions’ (Fiona)

Appendix 26

	Misconceptions	You know, people, you say a child oh this child's got Tourette's, and they just think oh, they're just gonna make some noises or or movements' (Ann) 'he [doctor] said he could he could call it one of two things we could either call it Tourettes or he could call it Chronic tic disorder motor and vocal, which has a less of a stigma, in his words attached to it, and he recommended we went for that' (Becky) 'I think people like we did when we first found out know what they know from the, from the TV and the press and you think Tourette's and you think of swearing, because that's what you think and it's very naive and very stereotypical, but we all do it'(Becky) 'all you know is what you see on the telly, which is obviously, they always show you the worst of the worst they never show you the normal case'(Becky) 'Tourette's is something that just seems quite everybody assumes it's swearing And there's an awful lot of misconceptions about it,' (Emma) 'you know the stereotypical kind of thing you see on YouTube or like in documentaries where it's people that are just uncontrollably swearing and stuff but that's obviously only a little bit of it.' (Emma) 'he said well the people that I have sort of shared it with they say 'ohh, you ain't got Tourettes, you don't swear.' (Emma) 'it's that, that stereotype and he does, but the fact now they don't actually believe he's got it because of the fact that he doesn't do the things that they think he should be doing' (Emma) 'I mean some of them simply think it's swearing still, they're still have that such a basic level, and some say, 'oh, yeah I understand it' (Fiona)
	Understanding = support	' It was like, "ohh, he's a boy that's why he's behind. That's why he's hyper is because, you know, boys are like that"' (Ann) 'just that struggle of, you know, kids with Tourette's, I don't know if it's really outlined that much on how it effects their schooling.' (Ann) 'And so you clearly know that they do not know at all.' (Ann) 'you get teachers that will say, oh, oh Adams really tired in class and Adam does this in class, we're like yeah that's because he's got Tourette's' (Ann) 'school didn't really know how to manage it, and therefore sending a child out the classroom is the easy option, and that might be a bit harsh, but that's our experience.' (Becky) 'I don't think they've had a child at that school before that has had Tourettes so, so for them this has been a massive learning curve' (Becky) 'I think it will become more knowledgeable for schools to know what to do. But I don't think there's enough' (Becky) 'school didn't really know how to deal with it' (Becky) 'if we were aware of that and schools were aware of that [iceberg model], I think they'd be able to manage children with Tourettes, I think it would be an easier situation to manage. So I from an educational perspective, I think, that type of material needs to be shared more widely.' (Becky)

		‘I don't think there's enough of an understanding from school, as to actually what those hidden disabilities mean for a child with Tourette's’ (Becky) ‘the coprolalia is extremely difficult for her, she's not really somebody who swears. And it's that thing of I think people see it as, oh, a teenager, so she's just trying to push it and she's saying these things and then she feels awful’ (Carol) ‘So it [COVID] means there's a lot of supply teachers working and the supply teachers don't get that information unless it's put on the sheet, specifically by the class teacher they won't know’ (Carol) ‘I know a lot of the senior team don't seem to read emails because she gets pulled up in the corridor’ (Carol) ‘I still don't think it's fully understood’ (Carol) ‘I think it would just be a case of them understanding more’ (Carol) ‘They Don't know, You know, how to deal with them. They just haven't got a clue’ (Diane) ‘I think she was a little bit old school, to be honest, it was just a case of like not recognizing that there could have been something. I mean, I would have thought sort of with her, with her depth of experience that she would have seen sort of children that have that were exhibiting these kinds of signs or anything like that, and could have kind of given us a viewpoint or maybe signposted us somewhere or whatever but it was no, it was very much like ‘well he's naughty boy, and we're not basically not going to do anything to help him’,’ (Emma) ‘they just thought he was putting it on.’ (Emma) ‘once he got the diagnosis of Tourette's, the SEN, the lady who was in charge of the SEN bit, in the site that he was on actually said to me, Look, we're not really, we don't really know a lot about it.’ (Emma) ‘ the primary school just really weren't interested in sort of putting anything in place or to be quite frank looking but they weren't particularly supportive of any of his, sort of, traits or things’ (Emma) ‘I still think they, they’re not really sure how to handle it’ (Emma) ‘Urrghh, just frustratingly low. I've sent every teacher he’s had I send the stuff from [charity name] and say this is, this is more, there's more to this than you think. I mean some of them simply think it's swearing still, they're still have that such a basic level, and some say, ‘oh, yeah I understand it’, but I don't think,’ (Fiona) ‘I don't think, I didn't understand it and as a teacher I wouldn't have understood it either, because it's so complex and it's so specialized.’ (Fiona) ‘So, it's not kind of apportioning blame on staff, but I think there's a real lack of understanding out there, people think that because they don't see tics if you're suppressing them in school, then he's okay’(Fiona) ‘I don't think there's any, any, any training out there that they've accessed.’ (Fiona)
Role of parents	Fight for support	‘But when you sort of got a child that struggles and then you then have to struggle to get them some help, is, yeah, it's quite tiring actually,’ (Ann) ‘don't sit back and wait for things to happen because they won't.’ (Ann) ‘we've had to push for everything that we've got basically, you have to be on the ball and, making sure that they are doing that all the time.’ (Ann) ‘There didn't seem to be support, unless we've, we've had to really push for the educational side, because he's not, you know where he should be basically.’ (Ann)

		‘To be fair, everything that we've asked them to do. They've done, but they've done because we've asked them to do. They haven't done anything off their own accord’ (Becky) ‘all of the information that we've done, we had gathered and sent it to the school and everything we've asked for, they've put in place, because it's obviously trial and error because there is no rulebook for this’ (Becky) ‘It's not been any unreasonable requests, it's been things like she's got an issue with her bowels can she please be allowed to go to the toilet or the tablets that she's on. It affects her heart rate so she's constantly got to be hydrated can she have water on her desk.’ (Becky) ‘I don't think she's got the best support that she could have at the moment, I think’ (Becky) ‘I put all my attention into finding out about Tourette's and what I could do to support her and how I could fight for justice because of what's gone wrong in her case’ (Becky) ‘I felt as if they were saying well we don’t believe you, So prove it. Prove it. And we're not, or we're not giving her the support,’ (Diane) ‘I was having an argument with the school.’ (Diane) ‘So put a complaint, I had to put a complaint in to the head teacher’ (Diane) ‘. The whole point is the support needs to be put in place so that her tics are down to a minimum’ (Diane) ‘all these things as I said it took a bit of a fight. But, as I said, I think because I've been there and done that knew that you have to put your foot down.’ (Diane) ‘you have to take drastic measures. And yeah put your foot down and say no, this is what's happening.’ (Diane) ‘I do tend to rub people up the wrong way, because I am brutally honest. And I won’t hold anything back’ (Diane) ‘I basically took it upon myself,’ (Diane) ‘we can find out what worked well for him, what didn't work so well for him and then, you know, trying to sort of put something in place ready for the actual real thing.’ (Emma) ‘but my role as a parent is to fight for my son’ (Fiona) ‘I have flagged it [exam arrangements] up, and they've said it doesn't kick in, till year 10 But I know you have to have the evidence and apply in advance so I'm going to get back on their case again’ (Fiona) ‘So my job this year is to keep knocking on the door with that one.’ (Fiona) ‘it's completely me completely!’ (Fiona) ‘So I'm just going to use everything in my power to keep going back to school. Even though I just know they hate it every time they see my name on an email, I’ve got to do it.’ (Fiona) ‘but then the onus is on schools to, to really do everything. And that is, that's been a real struggle.’ (Fiona) ‘you go back to school and you say, Okay, here's the letter, we've had the diagnosis, this is what they've recommended, and they go, ‘oh, you know, that's how you feeling it must be really difficult to have that’ ‘yes yeah so what are school going put in place’. ‘Nothing.’ ‘Ohh Okay.’ ‘So what happens now?’ ‘well he just carries on, you know, he's doing okay.’’ (Fiona) ‘I said, you know, he said he's had no support and lessons what what's going on.’ (Fiona) ‘So despite numerous meetings, nothing was ever, ever put in place.’ (Fiona)

	Advocacy	You have to advocate for your son, because no one else is going to' (Ann) 'He [doctor] said you have to, you know, if something is going on, you need to sort it out' (Ann) 'and I'm on the phone every day going, you can't, you can't punish her for this because it's not her fault.' (Carol) 'but my role as a parent is to fight for my son' (Fiona) ' [EP] she was really good, really sort of listened to us and what how Adam was and, and what sort of things he needed' (Ann) 'at least our GP took us seriously, some people don't even get that so it's such a lottery as to where you are and who will see you and who won't that's just quite difficult to deal with ' (Carol) 'I mean I'm constantly sending the articles from from the Tourette's awareness but I don't know that read them' (Carol) 'I felt as if they were saying well we don't believe you, So prove it. Prove it. And we're not, or we're not giving her the support,' (Diane) 'I think, they need to listen to the parents more, because the, the school seems to be very focused on what the professionals thought what support the professionals wanted to put in place. But the parents are the ones that deal with the children, Every single day, they're the ones that see the child, And what helps them, what doesn't help them and you know as much as the professional side is invaluable. I think sometimes parents can get kind of pushed to the side a bit.' (Diane) 'So I think you know our voice needs to be heard a bit more.' (Diane) 'So despite numerous meetings, nothing was ever, ever put in place.' (Fiona)
	Impact	'that's quite upsetting sometimes that, you know' (Ann) 'you know, it's quite an emotional ride, you know, going through something like this' (Ann) 'I know it sounds terrible but you know we've all got life and work and family, and it's quite stressful when you're chasing something all the time.' (Ann) 'But when you sort of got a child that struggles and then you then have to struggle to get them some help, is, yeah, it's quite tiring actually,' (Ann) 'there was nobody given us any information obviously we did a lot of the research ourselves and therefore we're very, because we both struggled with the diagnosis, mentally ourselves, because there was no where to get any information,' (Becky) 'actually the diagnosis isn't just for the person it's for the whole family. It's a family diagnosis' (Becky) 'when we got the diagnosis, me and my husband, well, bearing in mind the first diagnosis we got wasn't great. We felt really bad' (Becky) 'then there is one [support group] specifically that is just for, you know, kind of, parents and guardians, so that you can I suppose kind of vent how hard that is for you' (Diane) 'Yeah, It's not fun. Not fun. ' (Diane) ', I've seen other parents that are, you know, really struggling because they don't have Maybe the, the confidence, or just the kind of personality to actually say ' no do you know what, enough is enough.' (Diane)

		‘And you know he gets really down with it, he like, ‘Ohh Mum lets just chop my brain out, I just hate having these’. It is really, Yeah It’s heart-breaking really sort of when he’s getting when he has quite bad, sort of Episodes of them’ (Emma) ‘It's you have, it's that acceptance process. It, it, Basically saying your child has a disability. That's really tough.’ (Fiona) ‘but it is a brain altering drug, and that's, that's quite hard, as a parent to, to give that [medication] to your child.’ (Fiona) ‘but in terms of opening the door to next level education, I worry for his, for his GCSEs and that's that's a real concern.’ (Fiona) ‘it sounds funny in a way but it's also desperately sad because you think, what can… He's so intelligent and he's so capable, but it's unlocking that that jumble.’ (Fiona) ‘I know that he ultimately he'll be okay, well that's what I hang on to. But I just want him to somehow get through the stuff that's going to be measured that that gives him the next steps’ (Fiona) you feel like you're a pushy parent’ (Ann) ‘Yeah, yeah, I sent a lot of emails, I’m very annoying.’ (Carol) ‘you just want to do something to take away from it and you just can’t’ (Emma) ‘I just feel like just such a horrible person constantly haranguing the school. [laughs] But you, you just have to.’ (Fiona) ‘So I'm just going to use everything in my power to keep going back to school. Even though I just know they hate it every time they see my name on an email, I’ve got to do it.’ (Fiona) ‘we don't want to be ringing up or chasing this is something we haven't got time for’ (Ann) ‘her behaviour is getting to the state now where sometimes we struggle to manage that behavior, it's not fair on our other children’ (Becky) ‘we queried that three times and complained about that three times and gotten no further. And in the end we have to make an official complaint to the hospital,’ (Becky) ‘I put all my attention into finding out about Tourette's and what I could do to support her and how I could fight for justice because of what's gone wrong in her case’ (Becky) ‘I wrote a business case, or I wrote some information for J to send to the commissioners around.’ (Becky) ‘I often think about the families with kids who have additional needs who aren’t in as good a position as me, I don't mean good as in academically, I just mean in having the time to, and the background to fight his corner, and those who just have to rely on what the school says, I just think how on earth. We're just, we're just continuing the problem, we're not solving’ (Fiona) ‘I know it sounds terrible but you know we've all got life and work and family, and it's quite stressful when you're chasing something all the time.’ (Ann)
The journey	Influence of others	‘he had such a brilliant teacher at primary school that knew him. And, you know, had a good relationship with us as well’ (Ann)

		‘and it helps the teacher that Beth has now, or she will be having when she goes back actually has Tourette's herself and her daughter I believe has Tourette's as well. So that's helped massively,’ (Becky) ‘she's had somebody that actually understands how it feels on the other side which has been amazing.’ (Becky) ‘However, on the last few occasions when I've spoken to school, They've got a really proactive learning advisor who she herself has a son who's autistic and suffers with anxiety as Beth does I think she sees a few common traits between them. She's proactively herself gone on to some of those [charity name] courses and actually got some information.’ (Becky) ‘now we know that Beth's new teacher also has Tourette's, I think, the willingness for her to want to know how to support someone outside of her family unit, that obviously doesn't have the connection as you would do from a parent to a child, and will probably enhance that offer in the school as well.‘ (Becky) ‘I'd spoken to the head teacher. And I’d also spoken to the head of support for learning, and both of them couldn't have been more supportive’ (Diane) ‘when he had that really great teacher in primary I told you about, and he, he stood up in front of his class and I went into school, and he did a PowerPoint presentation to his whole class. And I was just so proud of him’ (Fiona) ‘But year three, he had an amazing teacher when he got his diagnosis, and, you know, was, was very supportive, but not, umm more pastorally than academically, and was more of the opinion that if we support him holistically, the the academic stuff stuff will come’ (Fiona) ‘she was just amazing in terms of she put everything in place.’ (Fiona) ‘any teacher that can, you know, give him a well done. He will do anything for them. So he loves it.’ (Fiona) ‘a really lovely guy called J, who works in Professor H’s team and he was an absolute superstar.’ (Becky) ‘and he just made us instantly feel better about the diagnosis talked us through what it was how we could support her, gave us all some family education which is what we needed.’ (Becky) ‘she's usually sat next to one of her friends so they understand what's going on. And they can support her and calm down and tell her to leave if she needs to, which has been really useful for her,’ (Carol) ‘they're [peers] really really good, umm they just, they just ignore them. And because you know that's that's kind of what they've been asked to do so’ (Diane) ‘So they’ve been absolutely fantastic, so they have and she’s, She's got some really good friends there.’ (Diane) ‘sometimes he makes some funny choices with friends, but he's got lots of friends.’ (Fiona) ‘but socially he's absolutely great, if he, if he's at home on a weekend, and he's not seeing people he's like a caged lion and he has to be out and playing football or at the park or going for a ride, you know, that just hanging out with others.’ (Fiona) ‘in terms of the social aspect, he could survive without support. But I don't want him just to survive and drift. I want him to learn. That's the frustration.’ (Fiona)

	Road blocks	‘CAMHS aren't commissioned in this area to support Tourette's. The primary comorbidity is Tourettes so every discussion that they have will ultimately come down to your child has tourettes and [county] was not commissioned to support children with tourettes.’ (Becky) ‘I think one of the worst things is to actually ours has been quite easy in comparison to some that I read, you know at least our GP took us seriously, some people don't even get that so it's such a lottery as to where you are and who will see you and who won't that's just quite difficult to deal with ‘ (Carol) ‘We then we then moved counties, which, for me to start a new job, which wasn't the best, because then I had the whole CAMHS switch which was a nightmare’ (Fiona) ‘Adam was the youngest person that they'd ever seen there and I don't think they really had umm, They might have seen people adult wise with Tourette syndrome but not kids’ (Ann) ‘I don't think they've had a child at that school before that has had Tourettes so, so for them this has been a massive learning curve’ (Becky) ‘Whilst professors are fantastic in the field of Tourette's and mental health, it would be really good to have advanced practitioners’ (Becky) ‘bearing in mind that there's a lot of kids that the statistics are that 1 in 100 people have Tourette's. I'm really surprised that they haven't, They haven't sort of got more children that were kind of displaying those sort of sort of traits that they perhaps could be the same’ (Emma) Yeah I think that's the hardest thing is, you expect your child to go to school, and if they need help, that they'd get it, not to be told, “oh we haven't got the budget for that”, Or, “oh they need to be two years behind to get any help”.’ (Ann) ‘Unfortunately she didn’t get any support due to the resources in the school’ (Becky) ‘they're [CAMHS] not, they're not funded to cover that [TS], even though her issue at the time was anxiety which they are funded for, they wouldn't touch her’ (Becky) ‘like many others around the country [county] doesn't have provision for children with Tourette's’ (Becky) ‘there's no pathway for Tourettes, they wouldn't see her CAMHS wouldn't see her for her mental health because the primary comorbidity was Tourettes’(Becky) ‘, it's the sheer lack of provision, that is, is, is the only thing that, and I know that there's lack of staff and it's lack of resources and or there's lack of funding.’ (Fiona) ‘so many of these kids are just falling through the gap because it's such a narrow frame that they want all these are these young people to go in’ (Fiona) ‘you've got to know them differently and see that actually the systems just broken [laughs],’ (Fiona) because COVID taken away our routine. Some of those people have gone into full blown Tourette’ (Becky) ‘So it [COVID] means there's a lot of supply teachers working and the supply teachers don't get that information unless it's put on the sheet, specifically by the class teacher they won't know’(Carol) ‘the classes last year were mixed up because of COVID So, they weren't in sets they weren't in any of their normal groups.’ (Carol)

		‘staffing in schools has been so hard throughout the pandemic and even, even when the kids were back at school that didn't mean that the staff are alright.’ (Carol) ‘and it's [the pandemic] been really hard for the kids, because they sort of adapted and then adapted again and then come back in and half their teachers still aren't there. So I'm hoping it'll settle down a bit more for her because she she's starting her GCSEs this year so she should have the same teachers for two years’ (Carol) ‘you're basically saying, Come on, like, something you’ve sort of said to us that you would do, not even asked for it, so it's almost like you're told things just to sort of appease you and you know sort of say yeah I've said I'd do that go away something’ (Ann) ‘she talked a really good game basically’ (Ann) ‘I think the support on paper is there, What he needs it’s just making sure that they implement it and in everything,’ (Ann) ‘I'm not sure head head pastoral head of year will be this year so I don't know if we've got to sort of build that up again.’ (Carol) ‘so it's just that consistency of care and just having some kind of roadmap for where you should go and what the school should be doing, because they haven't got any more clue and we do.’ (Carol) ‘, there was different kind of things put in place, and then we came into week two, and everything seemed to stop.’ (Diane) ‘I think there's been a bit of a lack of consistency over the staffing, and they do tend to kind of change, change a fair bit. But there's, you know, once he gets a relationship with, with them you know he does build quite, quite good relationships and trust and that with them.’ (Emma) ‘we've got different staff one is the same as last year but the rest of them seem to have changed. So feel a little bit, not necessarily back to square one. But back to say square three, or something’ (Emma) ‘They've had 17 new teachers in the school. So it's like okay, we've just got to start again, and it's so frustrating and I can see him get into year 11 And this cycle is still going on’ (Fiona) ‘So the director of learning takes over year nine upwards so takes over from 9,10 and 11, and I just don't think that handovers happened.’ (Fiona) ‘teachers, staying with classes throughout so Key Stage Three having the same teacher for Key Stage three would be amazing, and then key stage four, the same, but for example for science. He has four science teachers in the course of two weeks at the moment. And there's, there's that there's consistency is absolutely key.’ (Fiona) ‘Year six was pretty rubbish, In terms of him just falling through the gaps’ (Fiona) ‘we are Week Three in term, and there is no SEN provision plan in place, all his supported learning has been withdrawn, just from summer holidays to now,’ (Fiona) ‘And she's like, oh, you know it's been a really chaotic start to term and we're all really busy. And I thought, I know, I get that but had he, it's over two weeks since he's been back’ (Fiona) ‘Year seven was just a disaster. He wasn't, everything kind of gets worse because more and more is expected of you, I think as you get older, you're expected to be independent,’ (Fiona)

		‘I think really that they [school] should be taking the training’ (Diane) ‘a charity like [charity name], that are willing to give you one to one training that is maybe specifically geared towards a particular individual, then you take it. you take it because you can get your, your general tourettes training and it helps you understand it and deal with it, but to have that specific one to one for a specific child is invaluable.’ (Diane) ‘The schools, at primary they, they don't really want to go down the EHCP route, despite the medical advice advising that’ (Fiona) ‘I think in primary school. He learned some amazing coping strategies himself, he was helped by teachers as well. But there was never any uptake on the, you know, getting something either high needs block funding or proper SEN provision in place there was never a SEN support plan.’ (Fiona) ‘. I've had the SENCo say, well you can't get a, You can't get an EHCP with an ADHD diagnosis, and I’m like he's got a Tourette’s diagnosis as well. You can do it if look, I've got four letters here from different professionals saying please, this will benefit Freddy, what is holding you back.’ (Fiona) ‘since he was in year six, I've been actively pursuing it [EHCP]. I'm now at the point where I'm going to do it myself. I know it's not as easy to do, but I just I need to do it now, or he's gonna finish school and, you know, that will be it.’ (Fiona) ‘teachers still say to me, he'll receive all the help he needs without the EHCP in one breath, and then say, ‘Oh well, he doesn't need to SEN support plan because he hasn't gotten an EHCP and you're going - Well, which one is it?’ (Fiona) ‘his timeout card has disappeared, we were promised the use of a laptop, he hasn't got that, you know it's just back to square one’ (Fiona) ‘they’re [school] not at the moment taking up the offer of training.’ (Diane)
	Diagnosis as a turning point	‘but we found that [diagnosis] that was the best thing for us is to know what was wrong’ (Ann) ‘its sort of like Adam was diagnosed, and that was it basically’ (Ann) ‘because we don't want medication that was like okay then - bye, you know, get on with your life basically’ (Ann) ‘we were quite happy just getting the diagnosis, if you know I mean, we were like okay great’ (Ann) ‘since we've got the Diagnosis Diagnosis I think that was really important to get that’ (Ann) ‘It was a kick in the teeth to get that diagnosis’ (Becky) ‘If However, we would have got the diagnosis from J or another specialist in a hospital setting, who or any setting who sat us down and said, yes, it's a Tourette's diagnosis like he did, however, there are lots of medications we can try and there's all this research that's being …[WORDS REMOVED] If we would have had that, that I think it would have been relief, because when you know that and you know the information that comes with it, it's manageable’ (Becky) ‘even though we've got a diagnosis, we currently can't see anybody about that diagnosis because there is no pathway for it.’ (Becky) ‘you wait, they've, they've had a diagnosis. And that's it.’ (Carol)

		‘You know, there's very little, sort of ongoing ongoing plan, you know how to deal with it, it kind of left to work that out for yourself.’ (Carol) ‘And once that [diagnosis] happened, that seemed to kind of open a few more doors and the fact that the school is like, they actually believed him then.’ (Emma) ‘Since He's got a diagnosis it feels like it's been a little bit more constructive, shall we say.’ (Emma) ‘I think since since he's had his diagnosis, there's been a lot more, he did that he did say that there was a change in attitude and one of the, one of the teachers that he was having particular problems with, which was good and significant and that was when I had the conversation with my parents evening when they weren't overly negative about sort of how he'd been or anything so that was good.’ (Emma) ‘if there's some way of people like yourself, who do this amazing research, of getting to parents right at the start of their journey and saying, ‘This is what you need to do,’ rather than letting individuals sort of feel their way through the system.’ (Fiona) ‘you've just got that diagnosis This is what you now need to do, this is who you need to go to this is what you need to ask the school for and put in place. It's a little bit of a sink or swim.’ (Fiona) ‘ yeah, you just presume it's at the start of doors opening, and actually, it's the end, if that makes sense, right, CAMHS go. Okay, so here's the diagnosis, thank you very much and get in touch, you know, in the future if there's any anything else and you're going, Well what happens next? Go, just go, tell school. So yeah so that whole thing is a bit of a shock.’ (Fiona) ‘ I find that umm that's not quite forthcoming most of the time people don't like to say that's what we had with CAMHS is that they don't actually like to label kids with something,’ (Ann) ‘It's not been an easy journey’ (Becky) ‘everybody’s saying yeah, she's got tourettes. But nobody seems to know whose responsibility it is actually put the diagnosis formally’ (Diane)
	Acceptance of TS	He's always been a bit, umm, even now sort of in denial about it all.’ (Ann) ‘she wants to know why she's got it [TS] and nobody else has got it’ (Becky) ‘I'd already pointed her towards [charity name], and similar sort of websites so that she could read it and pick up her own, you know, in her own time.’ (Carol) ‘And so she'd sort of come to terms with it on her own.’ (Carol) ‘He doesn't want to advertise the fact.’ (Emma) ‘he said well the people that I have sort of shared it with they say ‘ohh, you ain't got Tourettes, you don't swear.’ (Emma) ‘he gets really down with it, he like, ‘Ohh Mum lets just chop my brain out, I just hate having these’. It is really, Yeah It’s heartbreaking really sort of when he’s getting when he has quite bad, sort of Episodes of them.’ (Emma) ‘It's you have, it's that acceptance process. It, it, Basically saying your child has a disability. That's really tough.’ (Fiona)