The journey to a functional tics diagnosis and experiences of post diagnostic support: Perspectives from adolescents and their parents

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DClinPsy Thesis (Volume 1)

2024

University College London

UCL Doctorate in Clinical Psychology

Thesis Declaration Form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Tic disorders (TDs) are associated with increased relationship difficulties, stigmatisation, and co-occurring psychiatric diagnoses. It is important to understand factors contributing to reduced wellbeing in this population to support quality of life and effective service provision. Much of the literature however concerns TDs in the United States of America (USA), Europe, and Australia, with a focus on persistent TDs such as Tourette's syndrome (TS). This limits generalisability to other TDs and cultures.

Part 1 of the thesis is a scoping review which explores cross-cultural components of stigma (knowledge, beliefs, attitudes, and responses) in TDs outside of the USA, Europe and Australia. 20 relevant studies of mixed methods were identified and synthesised using a scoping review framework. Part 2 comprises a qualitative empirical study of experiences of obtaining a functional tics diagnosis and post-diagnostic support in a sample of adolescents and their parents. A reflexive Thematic Analysis (Braun & Clarke, 2019) was employed to analyse semi-structured interviews. Part 3 reflects upon issues central to the process of conducting the empirical study. This includes issues related to researcher bias, reflections on the study limitations and how challenges encountered during the research process were managed.

Impact Statement

This thesis has both academic and clinical value in the field of tic disorders, which remains a relatively under-researched area. The scoping review provides a synthesis of literature concerning experiences of stigma outside of countries which tend to conduct tic disorder research. The review supports an awareness of how the presentation and experiences of tic disorders can vary depending on social-environmental factors such as culture. This is particularly important to support appropriate adaptation of information and interventions for tic disorders, to in turn support effective clinical care. The review is broad in scope and therefore identifies gaps and limitations in the literature, which can support the design of future research studies to advance knowledge in the area.

The empirical study is the first known study to examine both adolescent and parental experiences of obtaining a paediatric functional tics diagnosis and their experiences of post-diagnostic support. This is a relatively new and emerging field of research given a sudden increased prevalence in functional tics during the COVID-19 pandemic. The findings highlight significant barriers and challenges faced by families in pursuing support for functional tics as well as navigating daily life in a society with poor understanding of the condition. It is hoped that these findings can increase the public's awareness and empathy for what it is like to have functional tics which perhaps could reduce stigma. The study also aims to support development of services which can provide timely, effective interventions that promote positive healthcare experiences. It is important for this qualitative research to be complemented by future quantitative methods such as studies inspecting the aetiology of functional tics. Randomised controlled trials examining intervention effectiveness in this population is vital to improving clinical provision. The findings of both studies in this thesis will be disseminated at an international conference for Tourette syndrome with subsequent aims to disseminate findings more widely through publication in research journals.

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Acknowledgements

First and foremost, I would like to express my gratitude to the young people and parents who took part in this project. I am honoured to have witnessed your stories. Thank you for trusting me with your words and memories, I hope I have done them justice. I am grateful to the families at Great Ormond Street Hospital who provided invaluable feedback on the design of this study. I would also like to extend my thanks to the team at Tourette's Action who supported study recruitment.

I am incredibly fortunate to have been supported throughout the research process by such a knowledgeable research team and group of supervisors. I am particularly grateful for Dr Morvwen Duncan and Dr Eve McAllister for offering this topic as a DClinPsy project. It has been deeply rewarding to see the initial idea for this project develop and come to life. Thank you also to Dr Tara Murphy and Dr Alana Loewenberger for your guidance, patience, and time. And to Corin Whitfield; for the moral support, particularly in the early, anxious stages! I hope maternity leave has treated you well and I wish you the best for your final year.

I would like to thank my friends and family for their unwavering support during this challenging and rewarding process. I'm incredibly thankful for my friends on the DClinPsy; for your compassion, community and constancy through this process. To Harry, for being my rock and for your relentless patience and support, even when I was glued to a screen. None of this would have been possible without my mum and my grandma who inspired this journey and continue to motivate me every day. I hold them close to my heart and know they would be proud.

Part 1: Literature Review

Cross-cultural knowledge, beliefs, attitudes, and responses to tics: A scoping review of evidence outside of Australia, Europe, and the USA

Abstract

Background. Tic disorders (TDs) are common neurodevelopmental disorders, and stigmatisation of TDs has been found to be associated with exacerbation of tic symptoms and distress. However, stigma research in TDs is overrepresented by Europe, the United States of America (USA) and Australia, which poses a barrier to understanding experiences of TD-associated stigma in other cultures. **Method.** The current scoping review seeks to identify and summarise evidence pertaining to the components of stigma (knowledge, beliefs, attitudes, and responses) in TDs in countries outside of the USA, Europe, and Australia. 20 relevant studies were identified using a systematic search across five electronic databases. **Results.** Countries varied in knowledge and exposure to TDs, causal attributions of TDs, beliefs about treatment, severity and impact of TDs, TD-related attitudes, and responses to TDs. Emerging evidence highlights the importance of considering intersectionality and individual differences in understanding cross-cultural experiences of stigma in TDs. Acceptance of TDs was reported to be supported through social support and acceptance by wider networks. **Conclusions.** Comparisons across studies and countries are constrained by heterogeneity and lack of reliability in study design and sample. Further research is required to examine cross-cultural differences in TD-associated stigma using statistical measures, as well as to investigate relationships between components of stigma to develop effective interventions to target stigma.

Introduction

Tic disorders (TDs)

Tics are sudden, repetitive, non-rhythmic and stereotyped movements or vocalisations. They can be deemed simple or complex in presentation and may or may not be preceded by premonitory urges. Examples of simple tics include blinking, nose twitching and coughing. Complex tics can include echopraxia (repetition of others' movements), echolalia (repetition of a word or phrase heard), palilalia (repeating own words or phrases) or coprolalia (saying words or obscenities). Though these actions can be considered appropriate, their repetitive nature and lack of social context is why they are considered atypical (Dale, 2017). The Diagnostic and Statistical Manual classifies TDs into subtypes differentiated by the number of motor or vocal tics and the duration of tics; namely, persistent motor or vocal TD, provisional TD or Tourette's syndrome (TS) (American Psychiatric Association, 2013). Table one summarises the diagnostic criteria for TDs.

Table 1

TD classifications and diagnostic criteria

TD classification	Diagnostic criteria
Provisional TD	One or more motor and/or vocal tics present for less than one year, with tic onset before the age of 18.
Persistent (chronic) motor or vocal TD	One or more motor *or* vocal tics present for at least one year, with tic onset before the age of 18.
TS	Two or more motor tics and at least one vocal tic for at least one year, with tic onset before the age of 18.
Other specified TD	Tics cause distress and impairment, but the individual does not meet diagnostic criteria for a stated reason. For example, tic onset is after 18 years of age.
Unspecified TD	Tics cause distress and impairment, but the individual does not meet diagnostic criteria.

Note. Information from American Psychiatric Association (2013). *Abbreviations.* Tic disorders *TD*, Tourette syndrome *TS*.

TDs are deemed neuropsychiatric in nature with genetic and environmental etiological risk factors (see Ramteke & Lamture, 2022 and Set & Warner, 2021). TS is more common in

males than females, affecting 1.06% of boys and 0.25% of girls (Knight et al., 2012). Evidence suggests that the clinical presentations of TDs are broadly consistent cross-culturally though prevalence rates differ across the globe, with low prevalence rates in African countries (Eapen & Robertson, 2008; Robertson et al., 2009). Meta-analyses indicate a global TS prevalence rate of 0.5% and a greater prevalence of transient TD which affects 2.99% of children (Jadari et al., 2022; Scharf et al., 2015; Knight et al., 2012).

TDs often manifest in childhood with an average age of onset of six years, often reaching peak severity between the ages of 10 and 12 (Leckman et al., 1998; Peterson et al., 2022; Erengerg et al., 1987). The clinical presentation of TDs wax and wane over time, with symptoms significantly reducing or resolving during adolescence in one half to two thirds of TS cases, and 82% of TS adults report reduction in tic severity over time (Bloch et al., 2006; Lowe et al., 2018). Female sex and greater tic severity in childhood have been found predictive of increased tic severity in adulthood (Ricketts et al., 2022). Co-occurring conditions are common in this population, affecting 85% of young people with a TD (Robertson et al., 2017; Hischtritt et al., 2015). Attention deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD) are the most common comorbidities, with comorbid ADHD prevalence estimates ranging from 38% to 60% and comorbid OCD prevalence estimates ranging from 11% to 66% in TS (Cavanna & Rickards, 2013; Gadow et al., 2002; Khalifa & Von Knorring, 2006). However, the presence of comorbidities and behaviours associated with TDs are thought to differ cross-culturally, highlighting how social-environmental and sociocultural factors contribute to the presentation and impact of TDs (Robertson et al., 2009).

Extant research highlights that TDs are associated with increased levels of educational and relationship difficulties such as peer victimisation, social withdrawal, social exclusion, and family stress (Rivera-Navarro et al., 2014; Stokes et al., 1991; Pappert et al., 2003; Eddy et al., 2011; Zinner et al., 2012). When TDs persist into adulthood they are associated with reduced

quality of life and increased familial dependence (Elstner et al., 2008; Altman et al., 2009). The impact of comorbidities has been examined in TS populations. Comorbidities compound difficulties experienced by people with TS and have been argued to have a larger impact than TS itself, though the conditions likely interplay and exacerbate one another (Robertson, 2012; Rizzo et al., 2014; Isaacs et al., 2021). For instance, evidence suggests that young people with TS experience anxiety related to their tics which in turn exacerbates tics, whilst they also find anxiety-related emotions associated with tics distressing (Cuenca et al., 2015). It is therefore critical to understand the factors contributing to reduced wellbeing and quality of life in people living with TDs to develop targeted and effective interventions.

Stigma in TDs

Studies have begun to examine the potential role of stigma underpinning difficulties associated with TDs. Stigma was originally defined as "an attribute that is deeply discrediting" which "reduces the bearer from a whole and usual person to a tainted, discounted one" (p.3) resulting in social rejection (Goffman, 1963). Stigma can be overt, such as verbal abuse or bullying, or covert, such as microaggressions. Table two defines the components of stigma and different forms of stigma.

Table 2

Stigma definitions

Components of stigma	Description
Cognitive	Negative stereotyped knowledge and beliefs
Affective	Attitudes, prejudice, and negative feelings held about a stigmatised attribute.
Behavioural	Behavioural responses and discrimination
Types of stigma	**Description**
Public/Social stigma	Stereotypes, prejudice, or discrimination enacted towards a stigmatised individual.
Self-stigma/Internalised stigma	Stigmatised individuals internalise negative beliefs and stereotypes.
Associative/Courtesy stigma	Stereotypes, prejudice, or discrimination towards individuals associated with a stigmatised person, such as relatives

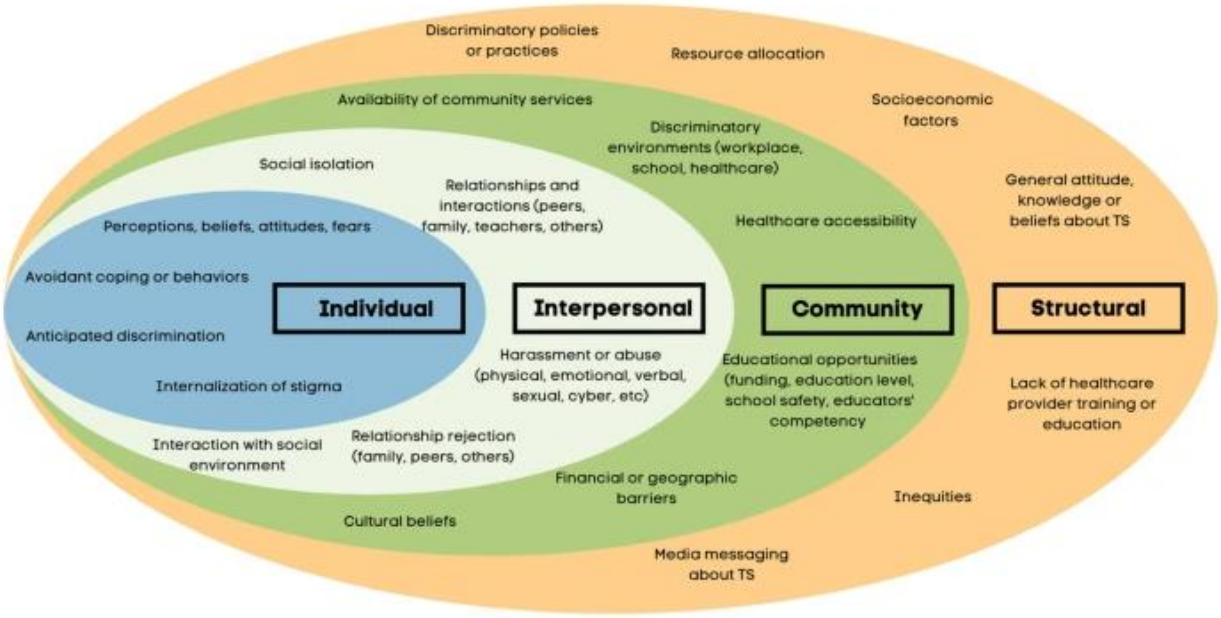
Note. Information from Fiske (1998) and Sheehan et al. (2022)

Updated definitions of stigma acknowledge the role of environmental and social factors in shaping experiences of stigma, such as the inherent power differential between the stigmatised and stigmatiser which facilitates status loss and discrimination (Link & Phelan, 2001). The social ecological model has been used to demonstrate how stigma is perpetuated and reinforced at multiple levels in the social environment; namely at the individual, interpersonal, community and structural levels (Bronfenbrenner, 2000; Ismail et al., 2022; Fry et al., 2023). Figure one, taken from Pring et al (2023) summarises different forms of stigma that can be experienced at multiple levels within the social environment. Goffman (1963) distinguishes between visible and invisible stigmatised attributes whereby invisible attributes can be concealed to support identification with the dominant group, or they can be disclosed. Individuals with TDs present with visible differences which are difficult to conceal and therefore may be particularly susceptible to misconception, negative attitudes and discrimination which exacerbate the risk of psychological difficulties. Indeed, evidence indicates that coping with TS is focused on the visibility of tics and associated stigma, and

misconceptions and lack of knowledge about TDs are prevalent issues (Maxwell-Scott et al., 2024; Ludlow et al., 2022). Educational exposure can foster increased knowledge of and positive attitudes towards TDs, perhaps then being a useful intervention to reduce stigma (Holtz & Tessman, 2007; Nussey et al., 2014).

Figure 1.

The social ecological model of stigmatisation in TS.



Note. Figure sourced from Pring et al (2023) which is an open access article. This permits unrestricted reproduction provided the work is properly cited.

Systematic and scoping reviews have examined how stigma is experienced in TDs highlighting social stigma, internalised stigma, and associative stigma in TDs at multiple social ecological levels (Malli et al., 2016; Pring et al., 2023). At the individual level, peers of people with TDs express negative attitudes about TDs and young people with TDs present with reduced self-esteem, self-stigmatisation and engage in avoidance behaviours to cope with stigmatisation. In addition, parents experience associative stigma whereby they express guilt about their child's condition. At the interpersonal level, individuals with TDs experience higher rates of bullying, loneliness and abuse, whilst at the community level, individuals with TDs are

subject to discriminatory environments at school and work. The literature indicates that at the structural level, there is a limited knowledge of TDs and negative attitudes, thought to be underpinned by inaccurate portrayals of TDs in the media (Pring et al., 2023; Ludlow et al., 2018; Malli & Forrester-Jones, 2022).

The impact of stigma on TDs has been researched in the United States of America (USA) and demonstrates the role of interpersonal stigmas in exacerbating and perpetuating tic symptoms. Negative responses to tics are associated with increased tic severity and frequency (Capriotti et al., 2015; Himle et al., 2014). In addition, lifetime interpersonal stigma is associated with discrimination and tics in adulthood, thereby indicating that stigma can have a lasting impact on individuals with TDs (Shiu et al., 2023). Lifetime traumatic events such as being teased or being asked to stop a group activity, as well as subtle mistreatments such as not being invited to social events or being stared at, were both associated with tic severity in adulthood. It is therefore vital to understand experiences of stigma in TDs to develop targeted interventions at multiple social-environmental levels.

Culture, stigma, and TDs

Although initial evidence suggests that stigma is a profound issue within the TD community, research is vastly overrepresented by Europe, the USA and Australia, posing a barrier to understanding experiences of TDs and stigma in other cultures. The health stigma and discrimination framework acknowledge that the experience of stigma will vary by culture, health condition and intersecting identities such as gender (Stangl et al., 2019) and therefore it is argued that findings from countries which dominate the evidence base should not be generalised across countries. Indeed, cross-cultural differences in reactions to tics have been demonstrated within such countries, whereby parents of children with TDs in the United

Kingdom (UK) report significantly more reactions to their child's tics compared to parental report in the USA and the Netherlands (Stiede et al., 2021). Reactions were from parents, other adults and other children and included providing attention such as offering comfort, aversive responses such as being teased, and escape responses such as the child not going to school for the day.

Reasons for underrepresentation of other cultures in TD literature and reduced prevalence rates of TDs has been under debate. Though cultural disparities were initially proposed as a result of genetic differences, other cultural factors have since been considered such as differences in awareness and conceptualisation of TDs, which may impact attitudes and responses to TDs such as discrimination and help seeking (Malik, 2021, Robertson, 2008). For example, tics in South Africa's Tshivenda culture are understood and labelled as "*Davhi/Ḽa thavha*" (English meaning unknown; Luhalima et al., 2023) and differences in terminology likely limit a collective understanding and comparison of TD experiences cross-culturally. Pring and colleagues' (2023) scoping review highlights that in recent years there has been an increase in TD stigma evidence outside of Europe, the USA and Australia. The authors identified 13 papers which originated from outside of the USA, Europe, and Australia. Three studies were noted to examine cultural differences in beliefs towards individuals with TDs, such as local causal attributions of TDs involving evil spirits and displeased ancestors (Lemelson & Tucker, 2017; Rodin et al., 2021). In addition, a review of lived experience in TS children and their parents identified three of eight qualitative studies that were from outside of the USA, Europe, and Australia (Suh et al., 2022). The synthesised review findings demonstrated that a challenge experienced for children with TS and their parents included prejudice and stigma posing barriers, as well as being isolated from others due to public ignorance and misunderstanding of TS. Due to the nature and focus of these reviews, findings

were synthesised rather than compared for cross-cultural differences. Therefore, the nature and extent of cross-cultural differences in stigma remains unknown.

Aims and Objectives

In context of minimal literature exploring stigma outside of the USA, Europe and Australia, this scoping review aims to interrogate the components of stigma in greater detail. The cognitive, affective, and behavioural components of stigma set out by Fiske et al (1998) will be used to guide the review whereby knowledge, beliefs, attitudes, and responses to TDs will be inspected in countries outside of the USA, Europe and Australia. The scoping review aims to answer the following questions:

- What evidence for components of stigma (knowledge, beliefs, attitudes, and responses) exist outside of the USA, Europe and Australia?
- Do differences exist in knowledge, beliefs, attitudes, and responses to TDs between countries and continents?
- Where possible, what factors influence the components of stigma?

Methods

Study design

A scoping review method was selected for the current review. This methodology is deemed appropriate in identifying and providing an overview of literature available on a topic with emerging evidence that has not yet been comprehensively reviewed (Peters et al., 2015). In comparison to systematic reviews which seek to answer a specific question and appraise the quality of existing literature, scoping reviews do not aim to assess the methodological rigor of

existing evidence (Munn et al., 2018). Therefore, a quality appraisal tool was not employed. The current scoping review was guided by a scoping review framework established by Arksey and O'Malley (2005) and further developments by Levac et al. (2010) and Peters et al. (2015, 2017, 2020).

Search strategy

All searches were conducted on 13th November 2023. To identify studies relevant to this scoping review five electronic databases were searched: PsycINFO, EMBASE, MEDLINE, Global Health and Web of Science. Search terms focused on three areas listed below (see Table 3 for a list of all search terms):

a) Cross-cultural: countries outside of USA, Australia, and Europe
b) Tics or Tourette's
c) Knowledge, beliefs, attitudes, or responses

A publication date restriction of after 1990 was applied to all searches. As population-level knowledge and beliefs have a propensity to change over time, a date restriction was used to identify literature that may more closely mirror contemporary knowledge, beliefs, and responses to tics. No restrictions were placed on language. During the screening process, articles identified which were not written in English were translated using Google Translate to assess eligibility.

Table 3.

Search terms

Cross-cultural	Tics	Attitudes, beliefs, and knowledge
"cross?cultural" or "ethnography" or "cultural difference*" or "cultur*" or "Afghanistan" or "Algeria" or "Angola" or "Antigua" or "Argentina" or "Azerbaijan" or "Bahamas" or "Bahrain" or "Bangladesh" or "Barbados" or "Belize" or "Benin" or "Bhutan" or "Bolivia" or "Botswana" or "Brazil" or "Brunei" or "Burkina Faso" or "Burundi" or "Ivory Coast" or "Cote d'Ivoire" or "Cabo Verde" or "Cambodia" or "Cameroon" or "Central African Republic" or "Chad" or "Chile" or "China" or "Colombia" or "Comoros" or "Congo" or "Costa Rica" or "Cuba" or "Democratic Republic of the Congo" or "Djibouti" or "Dominica" or "Ecuador" or "Egypt" or "El Salvador" or "Equatorial Guinea" or "Eritrea" or "Eswatini" or "Fiji" or "Gabon" or "Gambia" or "Ghana" or "Grenada" or "Guatemala" or "Guinea" or "Guyana" or "Haiti" or "Holy See" or "Honduras" or "India" or "Indonesia" or "Iran" or "Iraq" or "Israel" or "Jamaica" or "Japan" or "Jordan" or "Kenya" or "Kiribati" or "Kuwait" or "Kyrgyzstan" or "Laos" or "Lebanon" or "Lesotho" or "Liberia" or "Libya" or "Madagascar" or "Malawi" or "Malaysia" or "Maldives" or "Mali" or "Mashall Islands" or "Mauritania" or "Mauritius" or "Mexico" or "Micronesia" or "Mongolia" or "Morocco" or "Mozambique" or "Myanmar" or "Burma" or "Namibia" or "Nauru" or "Nepal" or "New Zealand" or "Nicaragua" or "Niger*" or "North Korea" or "Oman" or "Pakistan" or "Palau" or "Palestine" or "Panama" or "Papua New Guinea" or "Paraguay" or "Peru" or "Philippines" or "Qatar" or "Rwanda" or "Saint Kitts and Nevis" or "Saint Lucia" or "Saint Vincent and the Grenadines" or "Samoa" or "Sao Tome and Principe" or "Saudi Arabia" or "Senegal" or "Seychelles" or "Sierra Leone" or "Singapore" or "Solomon Islands" or "Somalia" or "South Africa" or "South Korea" or "South Sudan" or "Sri Lanka" or "Sudan" or "Suriname" or "Syria" or "Tajikistan" or "Tanzania" or "Thailand" or "Timor-Leste" or "Togo" or "Tonga" or "Trinidad" or "Tunisia" or "Turkmenistan" or "Tuvalu" or "Uganda" or "United Arab Emirates" or "Uruguay" or "Uzbekistan" or "Vanuatu" or "Venezuela" or "Vietnam" or "Yemen" or "Zambia" or "Zimbabwe" or "Asia" or "Middle East" or "North Africa" or "Greater Arabia" or "Central America" or "Caribbean" or "South America" or "Africa" or "Sub?Saharan Africa" or "Oceania" or "developing countr*"	"tic disorder" or "tics" or "tourette*"	"attitude" or "belie*" or "stigma" or "knowledge" or "understand*" or "health belief*" or "awareness" or "education" or "training" or "perception" or "perceive" or "perspective" or "self?concept" or "self?image" or "self?perception" or "self?worth" or "feelings" or "attitude to health" or "reaction" or "feelings" or "response" or "opinion" or "judge*" or "assume*" or "assumption" or "tolerance" or "idea*" or "view*" or "esteem"

A literature search of Google Scholar was also conducted to examine any existing grey literature not otherwise found through electronic databases. The reference lists of articles identified in searches and the reference lists of similar reviews (Smith et al., 2015; Malli et al., 2016; Pring et al., 2023; Su et al., 2022) were examined to identify any additional relevant articles.

Inclusion and exclusion criteria

Included studies were required to be 1) empirical in nature, 2) published after 1990, 3) conducted in countries outside of the USA, Australia, or Europe and 4) include a measure or data concerning attitudes, beliefs, knowledge, or responses to TDs. Qualitative, quantitative and mixed-methods studies were all considered for inclusion. No exclusion criteria were used for study participants. Case reports, case studies and other papers in an anecdotal format not preceded by empirical research were excluded. Conference abstracts were included in the review if empirical data were included in the abstract. Studies were also excluded if data concerning TDs could not be separated from other clinical groups (for example, OCD) or if data concerning countries of interest could not be distinguished from data from the USA, Australia, or Europe.

Search outcomes

All articles identified were imported to a reference manager software. The search strategy yielded 1831 articles. Duplicates of articles were removed, and titles and abstracts of remaining articles were screened. The full text of 49 articles were read to assess eligibility, of which 18 met inclusion criteria. Two additional papers were sourced from the references of

included articles and related reviews, resulting in 20 papers for inclusion in the review. A flow diagram of the search process is shown in Figure 2 and Table 4 summarises the included studies.

Data synthesis

A narrative synthesis was employed to combine evidence from mixed-methods, quantitative and qualitative studies identified (Popay et al., 2006). This was deemed most appropriate given the broad study question and the resulting diversity of papers identified. Qualitative data were not extracted and reanalysed collectively to generate new themes, due to the paucity of qualitative studies identified. Studies were grouped and synthesised based on the components of stigma (cognitive: knowledge and beliefs, affective: attitudes, behavioural: responses).

Results

Study characteristics

The 20 included studies were diverse in study design, study population, and measures used (Table 2). All articles were written in English except Kim and Tak (2020). Most studies were conducted in Asia; Table 5 summarises the number of studies from each country. Study participants ranged from healthcare professionals (5/20 studies), TD patients (7/20 studies), parents or guardians of TD patients (3/20 studies), a combination of professionals, TD patients and/or relatives (2/20 studies) and samples from the general population (3/20 studies).

Figure 2.

PRISMA flow diagram

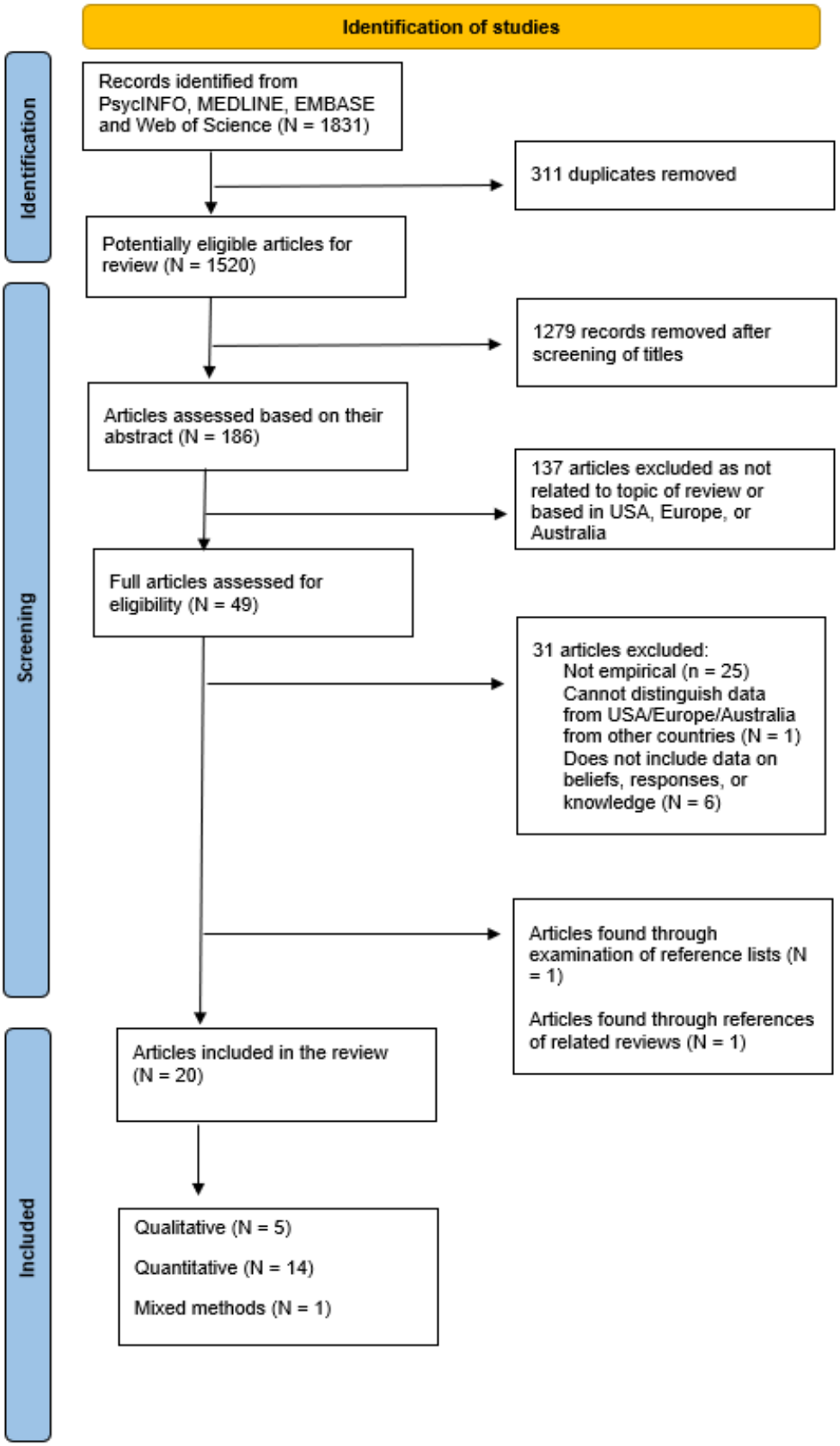


Table 4.

Papers included in the scoping review

Number	Authors	Country	Topic addressed	TS or TDs	Design and methodology	Total n	Participant characteristics
1	Alawan et al. (2022)	Saudi Arabia	Knowledge Beliefs	TS	Cross-sectional quantitative survey developed and validated by Marcks et al. (2004)	375	59 primary care physicians, 316 medical students; 253 males, 333 were Saudi Arabian
2	Brook & Boaz (2006)	Israel	Knowledge Beliefs Attitudes	TS	Cross-sectional quantitative survey with topics on knowledge and attitudes of TS	99	Pupils from a high school, 48% male. Mean age 16.7± 0.8 years. 58% had previous knowledge and recognition of a person with ADHD or TS.
3	Chao et al. (2010)	Taiwan	Attitudes	TS	Cross-sectional, quantitative questionnaire to develop the SICATS.	116	100 males, 16 females with TS with a mean age of 12.7 years (range 10-18 years). 53% had co-occurring ADHD, 36% had co-occurring OCD.
4	Eapen & Robertson (2008)	United Arab Emirates and United Kingdom	Beliefs	TS	Quantitative, cross-sectional study using the National Hospital Interview Schedule (Robertson & Eapen, 1996), YGTSS (Leckman et al., 1989) and DCI (Robertson et al.., 1999)	70	35 TS patients from UAE (25 males, 10 females) and 35 TS patients from the UK (26 males, 9 females). Age range of 5-17 years. Mean age of TS onset 6.0 years for UK cohort and 6.4 years for UAE cohort. 21/35 of UK cohort and 24/35 of UAE cohort had co-occurring ADHD. 15/35 of UK cohort and 13/35 of UAE cohort had co-occurring OCD. Oppositional defiant disorder was diagnosed in 19/35 of UK cohort and 4/35 of UAE cohort.

Table 4 continued

Number	Authors	Country	Topic addressed	TS or TDs	Design and methodology	Total n	Participant characteristics
5	Jatchavala & Pitanupong (2021)	Thailand	Knowledge	TDs	Quantitative, longitudinal. Questionnaire ratings of self-perceived competence completed at graduation and 1 year later	118	42 male and 76 female general practitioners. Mean age of 24.5±0.6). n = 31 completed one-year follow up (13 males, 18 females, mean age of 25.7±0.7).
6	Kano et al. (2008)	Japan	Attitudes	TS	Cross-sectional, quantitative using parental measure of CBCL (Achenbach & Edelbrock, 1978), self-report measures of CRA (Kano et al., unpublished, 2002) and RSQ (Budman et al., 2003)	29	23 male TS patients, 6 female TS patients. Mean age of 13.5±3.7 years. 11 (37%) had comorbidities
7	Kim & Tak (2020)	South Korea	Knowledge Beliefs Attitudes Responses	TS	Qualitative, unstructured interview using grounded theory	10	Parents of children with TS. Average age of TS onset was 6.9 years, average age of diagnosis of 9.2 years. Children with TS were in high school or were adults.
8	Lawal et al. (2012)	Nigeria	Knowledge	TDs	Cross-sectional, quantitative questionnaire focused on awareness of movement disorders, sources of knowledge and recognition of specific movement disorders.	314	228 undergraduate medical students and 86 resident doctors of various specialties

Table 4 continued

Number	Authors	Country	Topic addressed	TS or TDs	Design and methodology	Total n	Participant characteristics
9	Lee & Park (2019)	South Korea	Beliefs	TS	Cross-sectional, quantitative online survey of subjective mental health knowledge, TIPI to assess personality traits and adapted statements from a TS survey to evaluate beliefs about TS.	673	General population, 50% male. Mean age of 41.77 ± 12.03 years. N = 87 of participants had a relative of friend with a TD and N = 4 had a TD themselves
10	Lee et al. (2019)	Taiwan	Attitudes Responses	TS	Qualitative, semi-structured interviews. Descriptive phenomenology used as a theoretical framework.	16	14 males and 2 females with TS. Mean age of 17.5 ± 2.16 years (range 14-20). Average age of onset of 7-8 years. Severity classified as mild (N = 8), moderate (N = 5) and severe (N = 3). N = 7 had no comorbidities, N = 3 had ADHD, N = 1 had OCD, N = 2 had ADHD and OCD and N = 2 had ADHD, OCD and depression.
11	Lee et al. (2016)	Taiwan	Attitudes Beliefs Responses	TS	Qualitative open-ended interviews. Phenomenological framework applied with Giorgi's phenomenological methods	12	8 males and 4 females with TS. Average age 16.6 years. Average age of TS diagnosis was 8.8 years. N = 9 had co-occurring ADHD.
12	Lemelson (2009)	Bali	Beliefs Responses	TS	Qualitative longitudinal ethnography. Qualitative ethnographic data provided in excerpts	60	40 cases of TS or OCD and their families, proportion of TS cases unknown. Interviews with 20 faith healers. Families and traditional faith healers were interviewed. Demographics unknown.

Table 4 continued

Number	Authors	Country	Topic addressed	TS or TDs	Design and methodology	Total n	Participant characteristics
13	Lemelson & Tucker (2017)	Bali	Beliefs Responses	TS	Qualitative longitudinal ethnography	2	Two adults with TS and their families
14	Liu et al. (2023)	China	Beliefs Responses	TDs	Quantitative, cross-sectional questionnaire examining tic severity (YGTSS), parent anxiety (SAS; Zung, 1971) and parent depression (SDS; Zung, 1965)	318	Parents of children with TDs. Average age of children with TD was 8.38 ± 2.54 years.
15	Mathews et al. (2001)	Costa Rica	Beliefs	TS	Quantitative, cross-sectional study using the YSRF (Tourette Syndrome Association International Consortium for Genetics, 1999), YGTSS.	85	82% male participants with TS, mean age 11.4 years (range 5-28 years). Mean age of onset was 6.1 years, mean age of diagnosis was 10.8 years. No participants had a diagnosis of TS prior to the study.
16	Nwazor & Okeafor (2019)	Nigeria	Knowledge	TDs	Quantitative cross-sectional questionnaire with questions on knowledge and attitudes towards movement disorders	78	Final year medical students (mean age 27±2.78 years, male to female ratio 1.3:1).
17	Park et al. (2018)	South Korea	Beliefs Responses	TS	Cross-sectional online quantitative survey. Demographics, vignette used and told that the child had ADHD, TS, or ASD. Causal attribution for ADHD, TS and ASD using a 15-item questionnaire. Modified version of BSDS (Bogardus, 1925).	674	General population of 337 men and 336 women. Mean age of 42.77 ± 12.03 years.

Table 4 continued

Number	Authors	Country	Topic addressed	TS or TDs	Design and methodology	Total n	Participant characteristics
18	Rodin et al. (2020)	Uganda	Knowledge Beliefs	TS	Mixed methods. Cross-sectional survey developed by researchers, focusing on knowledge of tics, experiences, attitudes towards tics. Semi-structured interview focused on experiences of tics, cultural barriers, and areas for future training/research.	152	152 healthcare professionals of varying disciplines Semi-structured interviews with 6 participants (50% female, age range of 23-44 years)
19	Steinberg et al. (2013)	Israel	Beliefs Attitudes	TS	Quantitative, cross-sectional. BATS developed for the study. PUTS (Woods et al., 2005), YGTSS, SCARED (Birmaher et al., 1997) and the CDI (Beck et al., 1961)	56	48 males and 8 females with TDs, age of 10-18 years. Comorbidities: OCD (10%), depressive disorder (10%), anxiety disorder (24%) and ADHD (35%)
20	Yang et al (2022)	China	Knowledge Beliefs	TDs	Quantitative, cross-sectional survey of demographic information, guardian cognition of TD, guardian's medical behaviour and medication choices.	610	Guardians of patients with TDs. 77% of patients were male, mean age of 7.86 ± 2.38 years. 26.1% of patients had comorbidities. 52% had transient TD, 27% had chronic TD, 11% were classified as other and 8% had TS.

Abbreviations. Attention deficit hyperactivity disorder *ADHD*, autism spectrum disorder *ASD*, Beliefs about Tics Scale *BATS,* Bogardus Social Distance Scale *BSDS*, Child Behaviour Checklist *CBCL*, Children's Depression Inventory *CDI,* Clinical Rating of Aggression *CRA*, Diagnostic Confidence Index *DCI,* obsessive compulsive disorder *OCD*, Premonitory Urge for Tics Scale *PUTS,* Rage Screen and Questionnaire *RSQ*, Self-Rating Anxiety Scale *SAS*, Screen for Child Anxiety Related Emotional Disorders *SCARED,* Self-Rating Depression Scale *SDS*, Stress Index for Children or Adolescents with Tourette's Syndrome *SICATS*, tic disorders *TDs*, Ten-Item Personality Inventory *TIPI*, Tourette syndrome *TS*, Yale Global Tic Severity Scale *YGTSS*, Yale Self Report Form *YSRF*.

Table 5.

Frequency of included studies by country, region, and continent

Continent	Region	Country	Number of studies
Africa			3
	East Africa		1
		Uganda	*1*
	West Africa		*2*
		Nigeria	*2*
Asia			16
	East Asia		9
		China	*2*
		Japan	*1*
		South Korea	*3*
		Taiwan	*3*
	Southeast Asia		3
		Indonesia (Bali)	*2*
		Thailand	*1*
	West Asia/Middle East		4
		Israel	*2*
		Saudi Arabia	*1*
		United Arab Emirates	*1*
North America			1
	Central America		
		Costa Rica	*1*

The ages of participants with TD were either under 18 years (n = 5), adults (n = 1) or both children and adults (n = 2). It was not possible to ascertain the age of the sample in one article (Lemelson, 2009). Studies often concerned more than one theme of interest (knowledge, beliefs, attitudes, responses) though most frequently concerned tic-related beliefs (14/20 studies) followed by knowledge (8/20 studies), attitudes (7/20 studies) and responses (7/20 studies). Four studies concerned TDs and 16 studies specifically concerned TS.

Cognitive: Knowledge of TDs

Professional knowledge of TDs

Of the identified studies examining TD knowledge in healthcare professionals, self-reported levels of TD knowledge varied. In Nigeria, 46% of undergraduate medical students and resident doctors self-reported recognition of TDs, with TD knowledge greater in resident doctors compared to undergraduate medical students (Lawal et al., 2012). However, a higher proportion of final year Nigerian medical students demonstrated knowledge of TDs (81%), with rates of TD knowledge third highest following Parkinsonism (91%) and chorea (88%) (Nwazor & Okeafor, 2019). In a Ugandan sample of healthcare professionals (Rodin et al., 2020) motor tics were more commonly recognised than vocal tics, with the most identified motor tic being eye blinking (78% reported) and most common vocal tic being shouting (43% reported). Frequently co-occurring conditions identified included ADHD (67.8% reported), anxiety disorder (62% reported), OCD (58% reported) and autism (52% reported). In Saudi Arabia, 66% of primary care physicians and medical students evidenced knowledge of TS diagnostic criteria and half of the sample were aware of the high incidence of comorbidity in TS. (Alawan et al., 2022). However, knowledge of TS, as assessed by general knowledge questions about TS, was found to vary depending on medical discipline, whereby family physicians had a greater knowledge of TDs compared to general practitioners, paediatricians, and 'other' specialties.

Two studies reported rates of exposure to patients with TDs. Alawan and colleagues (2022) reported that 89% of Saudi Arabian primary care physicians had never treated a patient with TS, whereas 51% of Ugandan healthcare professionals reported having had clinical contact with a patient with tics (Rodin et al., 2020). Only 31% of the sample reported confidence in diagnosing TS. In Thailand, 27% of medical student graduates self-reported

incompetence in diagnosing TDs (Jatchavala & Pitanupong, 2021). Rates of self-reported incompetence in TD diagnosis increased to 44% at one-year post-graduation, though change over time did not reach statistical significance.

Three studies examined professional knowledge of treatment for TDs. In Jatchavala and Pitanupong's (2021) sample of Thai medical student graduates, rates of self-reported incompetence in TD treatment significantly increased from graduation (33%) to one-year follow up (65%). In Alawan and colleagues (2022) Saudi Arabia study, 72% of primary care physicians and medical students agreed that antipsychotics can help to control tics and 74% had not heard of habit reversal therapy, an evidence-based psychological treatment for TDs (Muller-Vahl et al., 2022). In contrast, in Rodin and colleague's (2020) Ugandan cohort of healthcare professionals, the most frequently identified treatment was cognitive behavioural therapy (74%) followed by family therapy (71%) and psychoeducation (67%), with 19% endorsing medication as a treatment for TDs.

Two studies examined professional barriers to an understanding of TDs and subsequent diagnosis and treatment. Nigerian final year medical students reported that a lack of patients with movement disorders was a barrier to learning and understanding during medical training, though this was not specific to TDs (Nwazor et al., 2019). Healthcare professionals in Uganda reported that challenges include a lack of knowledge about TDs (75%; Rodin et al., 2020). Other challenges identified via semi-structured interviews included a lack of professional training on TDs, with limited information on TDs available and professional training prioritising other conditions. Professionals felt that a lack of training and limited exposure to TD patients contributed to reduced confidence and knowledge in diagnosing and treating TDs. Improvements in professional training such as support to identify tics and differentiate TDs from other disorders was recommended to support detection and treatment of TDs.

Community sources of knowledge and recommendations for improvement

In a large Chinese survey, parents of children with TDs self-reported sources of knowledge on TDs (Yang et al., 2022). 53% of parents reported having learnt about TDs from medical staff, whereas 52% learnt about TDs through self-education.

Ugandan healthcare professionals suggested use of community education, such as use of psychoeducation videos, to support community understanding and awareness of TDs, with aims of reducing stigma and increasing detection of TDs (Rodin et al., 2020). Outcomes following educational interventions in youth were variable. In Taiwan, young people with TS reported an improvement in their own views of TS and hope for the future following a TS psychoeducation movie called 'Front of the Class' (Lee, 2016). However, the same video was reported to have adverse effects in a different cohort of adolescents with TS, resulting in greater misunderstandings and mockery by their peers (Lee et al., 2019). In Israel, levels of TS knowledge were assessed in adolescents after several months of exposure to TS information in education, demonstrating an average knowledge score of 68%, with a higher score indicating better knowledge (Brook & Boaz, 2006).

Cognitive: Beliefs

Causal attributions of TDs

Several studies examined the perceived aetiology of TDs in either professionals, relatives of people with TDs, school peers or the general public. Some variability in causal attributions of TDs was found in Saudi Arabian medical professionals, with 62% of primary care physicians and medical students agreeing that TS is mainly a biological disorder rather than a psychological disorder. Three studies considered cultural differences and how these may shape causal attributions regarding the aetiology of TDs (Rodin et al., 2020; Lemelson, 2009;

Lemelson & Tucker, 2017). In Uganda and Bali, spiritual explanations of the origin of TDs dominate local culture and traditional healers are often sought for guidance. Healthcare professionals in Uganda noted that TDs may be understood as possession by demons or ancestral spirits or because of witchcraft, with TDs viewed as punishment due to an individual's or ancestor's wrongdoings.

Similarly, Lemelson's (2009) ethnography explores the prominence of indigenous Balinese medicine in cultural understandings of TDs. Models used to explain TDs include sorcery, reincarnation, and improper enactment of rituals by an individual or their family. For instance, a parent of a child with TS reported that a traditional healer attributed his son's tics to the disturbance of the house yard spirit, whereby the family did not pay the spirit sufficient attention when they moved (Lemelson, 2009). Lemelson and Tucker (2017) report two divergent cases of TS in Bali. One of the cases describes a woman called Gusti who was taken to numerous traditional healers within her local village. Multiple explanations were provided for Gusti's tics such as poisoning, a witch attack and an impure household. In addition, it was suggested that tics were a result of Gusti's family displeasing an ancestor with improper ritual offerings. Lemelson (2009) also reports of the use of humoral theory by traditional help seekers in Bali to understand TDs. The body can be seen as in poor condition due to a disrupted balance between the body and the environment, for example through changes in weather.

In China, a large survey found that the majority (83%) of a sample of parents of children with TDs endorsed that TDs were caused by neurotransmitter imbalance, indicating consensus regarding biological causal attributions (Yang et al., 2022). 81% of the parent sample believed that TDs were a neuropsychiatric disease, with 8% reporting TDs to be a psychological disease and 5% reporting that TDs were not a disease. Beliefs regarding the factors that increase tics were also explored, whereby most of the sample reported stress (81%), followed by shock (72%), being reminded of tics (51%), fatigue (49%) and other less reported factors such as

focusing attention (20%) and infections (1%). Biological causal attributions were also indicated in approximately half of a sample of Israeli teenagers who had educational exposure to TDs (Brook & Boaz, 2006).

Causal attributions of TDs in samples of the South Korean general population have been examined in two identified studies (Park et al., 2018; Lee & Park, 2019). Park and colleagues' (2018) survey demonstrated that most of the general population (73%) sample indicated brain dysfunction as a cause of TS, followed by childhood trauma (63%), which suggests a combined endorsement of both biological and psychosocial causal attributions. Other causes identified were everyday stressors (59%), poor parenting (46%), environmental pollutants (33%) and genetic defects (29%). Differences in causal attributions between TS, autism and ADHD were also evaluated whereby dietary, physical, and biological causes were significantly more endorsed in autism compared to TS and ADHD. Social-environmental causes were endorsed significantly more for TS compared to autism, and significantly less endorsed for TS when compared to ADHD. In Lee and Park's (2019) survey, the highest reported causal attributions were parenting and psychological causes, followed by neurological and biological causes, with dietary and environmental causes being the least frequently endorsed. Analyses also included individual factors associated with causal attributions. Endorsement of parenting and psychological causes were associated with female respondents and greater subjective mental health knowledge, whereas endorsement of neurological and biological causes was associated with higher conscientiousness personality trait scores and greater subjective mental health knowledge. Endorsement of dietary and environmental causes of TDs were associated with older age of participants, reduced familiarity with TDs and higher extroversion personality trait scores.

Impact of causal attributions and beliefs about treatment

Healthcare professionals in Uganda suggested that misconceptions about tics may result in a TD diagnosis not being considered by fellow professionals (Rodin et al., 2020). Participants reported that Ugandan healthcare professionals might view tics as voluntary movements underpinned by a drive to access attention or a psychosomatic expression of stress. This was reported to result in difficulties distinguishing TDs and thus resulted in differential diagnoses.

In China, Liu and colleagues (2023) examined factors associated with mental health in parents of children with TDs. Causal attributions of TDs were found to predict parental depression, whereby misinterpreting TD as a harmful behaviour habit rather than as a disease was associated with fewer depressive symptoms. The authors suggest that this relationship may be related to genetic causal attributions of TDs resulting in guilt, self-blame as well as perceived stigma and reduced self-esteem.

Lemelson and Tucker (2017) present two TS case reports in Bali where a neurobiological explanation for TS was offered by a psychiatrist to two families with differential results. In the first case, a girl called Gusti is described. Gusti's family were reported to not be convinced by the neurobiological explanation for her TS symptoms and though some of her symptoms were alleviated through prescribed medication, the family discontinued use due to the financial expense. This was reported to reinforce the belief that Gusti's TS symptoms were of supernatural causes or due to her non-cooperation and so could not be treated through medication. The second case described is of a boy named Wayan who also experienced TS symptoms. He and his family were also offered a neurobiological explanation by the psychiatrist and support strategies were offered. This appeared to have a positive impact; the

family continued pharmacological treatment and educated teachers and peers about TS with aims to prevent Wayan from experiencing stigma.

Knowledge of and engagement in treatment types appears to be impacted by causal attributions of TDs across cultures. In both Uganda and Bali, qualitative evidence suggests that the primary source of support for TDs is not that of medical professionals. Professionals in Uganda reported that due to beliefs that TDs are a result of supernatural forces, local people turn to their faith, such as engaging in prayer as well as seeking support from religious leaders and spiritual leaders (Rodin et al., 2020). Qualitative evidence from Bali highlights that individuals with TDs and their families often pursue advice from numerous faith healers who offer multiple treatments, which many families report lack in efficacy (Lemelson, 2009).

In Korea where parenting and psychological causes were most frequently attributed to TDs, the strongest belief reported by the general population sample was that therapy was effective (Lee & Park, 2019). In Yang and colleagues' (2022) study in China, most parents of children with TDs identified medication (89%) and psycho-behavioural therapy (78%) as common TD treatments. This coincides with most parents endorsing neuropsychiatric causes of TDs as well as acknowledging how psychological factors can impact tics. A study with Israeli adolescents examined beliefs about curing TS rather than treating TS (Brook & Boaz, 2006). Despite educational exposure to TS, adolescent beliefs were variable, whereby 46% agreed that TS can be cured by alternative medicine.

Beliefs regarding clinical presentation, severity, and impact

A limited number of studies examined cultural differences in perception of TDs with regards to their clinical presentation, severity, and associated distress. In Costa Rica, 60% of a TS sample denied any impairment caused by tics, rating motor tics as more severe than vocal

tics. Likewise in Uganda, 59% of healthcare professionals reported that families may not seek support for TDs as they do not perceive TDs as a clinical concern (Rodin et al., 2020). Reasons for reduced parental concern included viewing tics as a typical, temporary feature of development or perceiving their child as 'stubborn'. These beliefs were proposed to be underpinned by a lack of knowledge of TDs, denial, or difficulty acknowledging the potential negative impact of TDs.

The only study which directly compared clinical features of TS across two countries found that both individuals with TS from the United Arab Emirates (UAE) and the UK presented with similar clinical features, however subjective distress and impairment was lower in the UAE sample (69%) compared to the UK sample (94%; Eapen & Robertson, 2008). In addition, the UAE sample presented with lower rates of coprolalia, co-occurring conditions and behavioural difficulties when compared to the UK sample. Factors contributing to differences in perceived impairment and distress were not evaluated.

The only study to examine beliefs regarding the clinical presentation of TDs was Brook and Boaz's (2006) study of adolescents in Israel. In line with variability reported in causal attributions of TS, 31% of adolescents believed that adolescents with TS can control their tics or 'disruptive behaviour', whereas 62% reported a belief that adolescents with TS cannot control outbursts.

Affective: Attitudes

Tic-related attitudes in individuals with TDs

Several studies examined how individuals with TDs view themselves or their tics, highlighting the negative impact of tics on identity and wellbeing. In Israeli children with TDs, negative beliefs about tic suppression predicted levels of tic-associated impairment, and

negative beliefs about tic suppression were strongly associated with depression in older children (Steinberg et al., 2013). Children and adolescents with TS in Japan commonly (73%) reported experiencing guilt in response to rage attacks experienced in the six months prior to study participation (Kano et al., 2008). A qualitative Taiwanese study exploring social adjustment experiences highlighted that adolescents with TS often experience irritation and panic in response to a perceived uncontrollable body, which preoccupies them and interferes with aspects of their life such as learning (Lee et al., 2019). Participants viewed themselves as abnormal and perceived TS as an obstacle which caused physical and psychological pain, including worries about how TS may impact careers, romantic relationships, and genetics. Taiwanese adolescents with TS expressed a belief that peers perceive them as strange and unfamiliar and they feel apprehensive about whether their tics will be accepted (Lee et al., 2019). Additionally, Taiwanese adolescents with TS perceive others to lack knowledge and familiarity of TS and subsequently they feel misunderstood, different and experience loneliness (Lee et al., 2016). However, in a quantitative Taiwanese study of children and adolescents with TS, the highest mean stress score provided was for symptom control, followed by concerns about the future, psychological stress, and unfairly treated stress (Chao et al., 2010). This suggests that symptom control is the most common concern about TS above interpersonal difficulties. Variability in symptom control stress scores indicate that perceived stress varies greatly between participants, with girls reporting greater levels of stress compared to boys.

Tic-related attitudes in others

A South Korean qualitative study examined parental experiences of their child's TS (Kim & Tak, 2020). Parents expressed feeling a sense of loss at an inability to raise the 'ideal child' which in turn negatively impacted their view of themselves as a parent, including their

sense of pride and perceived social success. In addition, parents described experiencing significant levels of anxiety and worry about their child's future and whether they would be able to live their life as expected. Extent of worry was influenced by factors such as tic severity, presence of co-occurring conditions and changes in tics over time. Despite these challenges, parents also reflected on positive self-growth and discovery because of their child's TS. This included a shift in values away from social status and towards not judging other people. Similarly, Taiwanese adolescents with TS report parental embarrassment of their tics, with concerns that tics would result in parents losing respect and social prestige (Lee et al., 2019)

Israeli adolescent peers expressed a range of both positive and negative attitudes towards TS adolescents (Brook & Boaz, 2006). 80% of respondents believed that TS adolescents would drop out of school and 31% believed that they could live a normal life. 44% believed that people should empathise with TS adolescents and 56% believed that peers should sit near them in class and develop friendships with them. However, 27% believed that there would be a place to severely punish TS adolescents for their behaviour. 83% believed that all pupils should receive education on TS.

Behavioural: Responses

Responses to tics

Studies highlight discriminatory interpersonal and societal responses to tics across countries. Ugandan healthcare professionals discussed how children with TDs are often laughed or yelled at in society and so they proposed that parental guilt was a barrier to help seeking (Rodin et al., 2020). Taiwanese adolescents with TS reported that peers would laugh at them, mock them or ridicule them, for example describing them as being possessed by a ghost (Lee et al., 2019; Lee et al., 2016). Additional responses to tics by peers included being

frightened and responding with dislike, which is perceived as rejecting by adolescents with TS (Lee et al., 2016). In a case report of TS in Bali, a girl named Gusti was reported to be mocked for her motor tics by neighbours, who expressed that she had gone insane or was possessed by an evil spirit (Lemelson & Tucker, 2017). Neighbours also distanced themselves from her as she was thought to have a contagious illness. 70% of South Korean adults expressed preference for a high social distance to people with TS, though preference for low social distance was greatest for TS compared to ADHD and autism (Park et al., 2018). However, in Costa Rica negative responses to tics were reported as less prominent, as 13% reported infrequent interpersonal problems (Mathews et al., 2001). Two negative responses were reported which included receiving death threats due to difficulty stopping tics and physical assault by a priest who was offended by vocal tics.

Institutional discrimination was reported in Taiwan, Costa Rica, Bali, and Uganda whereby children were excluded from school due to tics (Lee, 2019; Mathews et al., 2001; Lemelson, 2009; Rodin et al., 2020). Taiwanese teachers were reported to perceive TDs as a disruptive disability and moved affected adolescents to special education classes, which resulted in adolescents feeling excluded and disrespected (Lee et al., 2019). Individual differences emerged in two Balian case studies of TS whereby a girl named Gusti was forbidden to attend school due to her tics, however a boy with tics named Wayan continued to attend school and was accepted by peers and teachers (Lemelson & Tucker, 2017).

Some studies explored familial reactions to tics. Taiwanese adolescents with TS described their parents as accepting however had trouble tolerating tics, often complaining about vocal tics which increased feelings of being misunderstood (Lee et al., 2016). In Bali, families expressed discomfort with their child's tics, particularly vocal tics which were termed as inappropriate shouting (Lemelson, 2009). Liu and colleagues (2023) study in China found that parental reactions to tics was significantly associated with parent anxiety, however parental

reactions did not remain a significant predictor of parental anxiety after adjusting for confounders. There was a trend of increased odds of parent anxiety if parents responded with an 'angry but put it aside' rather than a 'scold and curb it' response to tics, and a decreased odds of parent anxiety if parents ignored tics and distracted their attention. Societal responses to tics were shown to have a wider impact on the family in Bali, whereby Gusti's siblings were viewed as undesirable marriage partners as Gusti's symptoms were viewed as an unknown illness which did not respond to local treatments (Lemelson & Tucker, 2017). This associative stigma resulted in increased familial stress and discord, including abusive responses to Gusti.

Studies illustrate suppression and avoidance as common responses to stigmatisation. In Uganda, children were reported to be hidden from societal view, taken out of school, and excluded from school events due to parental embarrassment and fear of their child expressing inappropriate verbal tics (Rodin et al., 2020). Similarly, Taiwanese parents ask their children to suppress their tics in front of others to avoid social embarrassment (Lee et al., 2019). However South Korean parents responded to their child's tics by becoming increasingly protective and involved in their lives (Kim & Tak, 2020). For example, parents reported attempts to block their child from public view to minimise hurt from comments or stares from others. Other responses included supporting their child to develop practical skills and support with planning for the future, as well as trying to develop knowledge and understanding of TS in others.

Suppression and avoidance were also noted as common coping strategies for adolescents with TDs facing stigmatisation. Taiwanese adolescents reported a desire to fit in and meet societal expectations and so suppressed their tics to be accepted (Lee et al., 2019). To avoid attention, they would distance themselves from peers or attempt to maintain relationships through profusely apologising for the tics (Lee et al., 2016). Adolescents also remained hypervigilant to monitor their behaviour around peers, evaluating how others might perceive

them to decide how to interact (Lee et al., 2019). Monitoring of other peoples' attitudes and responses was reported as a tool to evaluate whether adolescents needed to conceal their tics (Lee et al., 2016).

Factors associated with positive attitudes and responses

Preliminary evidence demonstrates how positive self-identities and self-perceptions can emerge in the presence of TDs. Taiwanese TS adolescents discuss how positive beliefs about tics are supported by social support and acceptance by their peers, teachers, and relatives, which in turn improves self-esteem and supports them to feel courageous and accepting of their TS (Lee et al., 2019). Other supporting factors identified include faith and religion which supports adolescents to positively frame TS as 'uniqueness', as well as a commitment to demonstrating their strengths to prove that they are as capable as their peers. Educational support was also identified as a factor promoting self-acceptance in Taiwanese adolescents with TS (Lee et al., 2016). Similarly in Bali, Wayan's parents were reported to educate teachers at his school about the neurobiological model of TDs; he remained in school with his tics being normalised (Lemelson & Tucker, 2017).

For individuals with TDs, finding peers who accepted tics helped them to develop coping strategies (Bali; Lemelson & Tucker, 2017), provided psychological support, shifted their self-concept from 'freak' to 'normal' and supported them to live their life with tics (Taiwan; Lee et al., 2016). Benefits of social support for parents of individuals with TDs were also identified. South Korean parents discussed the use of groups to access social support, empathy, and knowledge (Kim & Tak, 2020) whilst in China, parent anxiety and depression was negatively predicted by family relationships and their child's social relationships (Liu et

al., 2023). Parents in South Korea also discussed how adjusting their expectations of their child helped them to positively support their child (Kim & Tak, 2020).

Some studies explored factors associated with attitudes and responses to TDs. In Israeli peers, positive attitudes about TS were significantly associated with increasing age (Brook & Boaz, 2006). Peer experience of familial mental health difficulties was associated with positive attitudes though did not reach significance. In South Korea, adults who preferred a high social distance to people with TS were more likely to be older in age, endorse biological causal attributions for TS and not have a family or friend with a diagnosis of TS (Park et al., 2018).

Discussion

This scoping review summarises existing literature examining cross-cultural differences in knowledge, beliefs, attitudes, and responses to TDs outside of the USA, Australia, and Europe. This aims to increase awareness of evidence examining the components of stigma cross-culturally and whether differences exist between countries. The review demonstrates high levels of variability across countries in how TDs are conceptualised, perceived, and responded to. Despite variation across studies in cross-cultural components of TDs, there appears to be consensus in the utility of social support and acceptance from an individual's network in fostering self-acceptance and reducing TD-associated stigma. This parallels findings from Europe, the USA and Australia which suggest social support promotes adaptive coping and positive self-identity in TS (Maxwell-Scott et al., 2024).

Across countries and studies, healthcare professionals' knowledge of TDs varied with broadly half of each sample demonstrating an understanding of TDs. Preliminary evidence suggests that knowledge may be impacted by training type and level, with barriers to knowledge in healthcare professionals including lack of exposure to TDs, lack of prioritisation

in professional training, and reduced help-seeking for suspected TDs. Professional awareness of treatments for TDs also varied across countries, with Ugandan professionals endorsing psychological intervention whereas Saudi Arabian professionals endorsed medication use. Knowledge of TDs may have important consequences for clinical management of TDs, such as misdiagnosis and reduced access to effective intervention.

Attribution theory suggests that the perceived cause of a stigmatised condition such as TDs, including its perceived controllability, locus of control and stability of the cause will govern responses to the condition (Weiner, 1995). Initial evidence tentatively suggests some variation across countries in causal attributions, although this has not been statistically examined. In China, neurotransmitter imbalance was commonly identified as a cause of TDs, alongside an understanding of psychological and environmental triggers for TDs. In Israel, biological explanations were endorsed by approximately half of the sample, whereas in South Korea, social-environmental causes for TDs were more commonly reported compared to other neurodevelopmental conditions. Spiritual explanations were reported in Bali and Uganda and qualitative evidence suggests this may shape help-seeking behaviour, such as seeking prayer or alternative medicine rather than visiting a medical professional.

Appraisal of biological explanations for TDs may vary across countries. For example, viewing TDs as a disease versus a behaviour was associated with maternal depression in China. Factors contributing to this association such as associative stigma were not examined, however cultural beliefs surrounding biological aetiologies may contribute to this relationship. Mental health literature suggests biological attributions can have variable impact whereby they may emphasise difference in individuals with a condition and reduce perceived capacity for change, though conversely may reduce stigma, as the condition is not viewed as under ones' control (Kvaale et al., 2013). In Ugandan and Balian studies identified, TDs were attributed as a collective punishment on the family for wrongdoings. In turn, collective attributions rather than

individual attributions may increase the likelihood of associative stigma and shame. Study findings indicate a shared experience of internalised stigma in individuals with TDs. Qualitative studies conducted in Asia highlight that adolescents with TDs feel different and left out from their peers, which parallels USA, European and Australian literature (Malli et al., 2016; Pring et al., 2023; Smith et al., 2015; Suh et al., 2022). Tic suppression and avoidance were frequently reported coping strategies in the face of TD stigma.

Perceived distress was also found to vary cross-culturally; for example, in Costa Rica motor tics were perceived as more severe than vocal tics, whereas individuals with TDs in the UK reported greater distress compared to UAE participants who presented with reduced behavioural difficulties and coprolalia. Further research is required to understand how cultural beliefs regarding social behaviour and causal attributions of TDs may contribute to perceived distress. It is possible that coprolalia is increasingly stigmatised in society, particularly in Asian cultures which places value on upholding social 'face', akin to social esteem (Hwang, 2006; Lee et al., 2019). One must also consider how knowledge and exposure to TDs may contribute to perceived distress, such as an increased awareness of tics lending to distress, thereby furthering comorbidities (Martino et al., 2017). Alternatively, in Uganda parents were suggested not to see TDs as a concern due to different understandings of TDs, for instance viewing tics as a manifestation of stubbornness. Not perceiving TDs as a concern could perhaps be protective against stigmatisation, however the relationship between perceived distress and components of stigma cross-culturally requires further research.

Cross-cultural relationships between components of stigma are tentative and descriptive and require exploration in greater detail. In Uganda, not viewing TDs as a concern was reported to shape help-seeking which may contribute to reduced professional exposure of TDs and subsequent professional knowledge. This may have important implications for treatment, such as reduced access to support, as well as potentially perpetuating wider cultural

attitudes regarding TDs. The relationship between knowledge and attitudes across cultures is currently unclear. Use of psychoeducation to increase knowledge of TDs in Taiwan and Israel demonstrated variable impact whereby an increase in knowledge did not always result in fewer negative attitudes. These findings may reflect the importance of tailoring TD psychoeducation material to the target population and culture, rather than taking a one size fits all approach.

Importantly, two contrasting case studies by Lemelson and Tucker (2017) highlight that culture itself cannot fully explain TD-associated beliefs, stressing the importance of considering individual differences and intersecting identities to understand cross-cultural experiences of stigma in TDs. Though there may be cultural differences in knowledge, beliefs, attitudes and responses to TDs, the extent to which individuals ascribe to dominant beliefs and attitudes will likely influence experiences of stigma, and ascription to cultural beliefs may be influenced by intersecting identities such as gender or caste. For instance, in Taiwan, girls reported higher perceived stress scores than boys. This highlights the importance of considering individual factors and social identities, such as gender, in self-perception of TDs (Chao et al., 2010).

This review was constrained by various limitations. For instance, many studies included in this review are descriptive or cross-sectional in design with few comparisons made across countries and conditions. Findings from studies are therefore tentative and should be reliably retested using statistical measures, between-group measures, and control groups. Studies included were vastly overrepresented by Asian countries which limits an understanding of stigma in other cultures found in Central America and Africa, where fewer studies were identified. Included studies are heterogeneous in sample such as sample size, diagnosis type and age, and measures used which limits comparison across studies and cultures. Development of valid cross-cultural stigma measures and surveys are paramount to conducting cross-cultural research on stigma in TDs. Multi-centre collaborations and sharing of standardised measures

and surveys across countries would facilitate reliable comparison of stigma across cultures. Cross-cultural relationships between components of stigma have not yet been reliably investigated and warrant further study to develop interventions to reduce stigma.

Conclusion

Examining cross-cultural differences in stigma is important to support appropriate adaptation of information and interventions for TDs, rather than assuming a 'one size fits all' approach. In turn, this supports effective clinical care. This review has synthesised current evidence regarding cross-cultural differences in components of stigma in TDs. There is considerable variability across countries in levels of knowledge regarding TDs, beliefs and attitudes regarding TDs such as causal attributions and responses to TDs. Initial evidence highlights the importance of social support in ameliorating stigma. Comparisons across cultures should be interpreted with caution, owing to variation in study designs, lack of statistical methodology and group comparisons. Development of standardised measures which can be shared across countries would support reliable comparison of TD-associated stigma across cultures. Further research is required to interrogate cross-cultural differences in stigma, the relationship between components of stigma, and how individual differences may contribute to experiences of stigma in TDs.

References

Achenbach, T. M., & Edelbrock, C. S. (1978). The child behaviour profile I: Boys aged 6–11. *Journal of Consulting and Clinical Psychology*, *46*, 478–488.

Alalwan, A. A., Alkhamis, M. A., Samman, A. M., Alsharif, E. H., Tarabzoni, O. E., & Khatri, I. A. (2022). The assessment of knowledge about Tourette's syndrome among medical students and primary physicians in Riyadh, Saudi Arabia: A cross-sectional study. *Neurology Research International*, *2022*. https://doi.org/10.1155/2022/3018305

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.

Beck, A. T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, *4*(6), 561-571. https://doi.org/10.1001/archpsyc.1961.01710120031004

Birmaher, B., Khetarpal, S., Brent, D., Cully, M., Balach, L., Kaufman, J., & Neer, S. M. (1997). The screen for child anxiety related emotional disorders (SCARED): Scale construction and psychometric characteristics. *Journal of the American Academy of Child & Adolescent Psychiatry*, *36*(4), 545-553. https://doi.org/10.1097/00004583-199704000-00018

Bloch, M. H., Peterson, B. S., Scahill, L., Otka, J., Katsovich, L., Zhang, H., & Leckman, J. F. (2006). Adulthood outcome of tic and obsessive-compulsive symptom severity in children with Tourette syndrome. *Archives of Paediatrics & Adolescent Medicine*, *160*(1), 65-69. https://doi.org/10.1001/archpedi.160.1.65

Bogardus, E. S. (1925). Measuring social distance. *Journal of Applied Sociology*, *9*, 299-308.

Bronfenbrenner, U. (2000). *Ecological systems theory*. Oxford University Press.

Brook, U., & Boaz, M. (2006). Attitude and knowledge of high school pupils towards adolescents with special needs (Tourette's syndrome). *The Indian Journal of Paediatrics*, *73*, 1099-1104. https://doi.org/10.1007/BF02763054

Budman, C. L., Rockmore, L., Stokes, J., & Sossin, M. (2003). Clinical phenomenology of episodic rage in children with Tourette syndrome. *Journal of Psychosomatic Research*, *55*(1), 59-65. https://doi.org/10.1016/S0022-3999(02)00584-6

Capriotti, M. R., Piacentini, J. C., Himle, M. B., Ricketts, E. J., Espil, F. M., Lee, H. J., Turkel, J. E., & Woods, D. W. (2015). Assessing environmental consequences of ticcing in youth with chronic tic disorders: The Tic Accommodation and Reactions Scale. *Children's Health Care*, *44*(3), 205-220. https://doi.org/10.1080/02739615.2014.948164

Cavanna, A. E., & Rickards, H. (2013). The psychopathological spectrum of Gilles de la Tourette syndrome. *Neuroscience & Biobehavioural Reviews*, *37*(6), 1008-1015. https://doi.org/10.1016/j.neubiorev.2012.10.011

Chao, K. Y., Wang, H. S., Chang, H. L., Wang, Y. W., & See, L. C. (2010). Establishment of the reliability and validity of the Stress Index for Children or Adolescents with Tourette Syndrome (SICATS). *Journal of Clinical Nursing*, *19*(3-4), 332-3340. https://doi.org/10.1111/j.1365-2702.2009.03061.x

Dale, R. C. (2017). Tics and Tourette: A clinical, pathophysiological and etiological review. *Current Opinion in Paediatrics*, *29*(6), 665-673. https://doi.org/10.1097/MOP.0000000000000546

Eapen, V., & Robertson, M. M. (2008). Clinical correlates of Tourette's disorder across cultures: A comparative study between the United Arab Emirates and the United Kingdom. *Primary Care Companion to the Journal of Clinical Psychiatry*, *10*(2), 103. https://doi.org/10.4088/pcc.v10n0203

Eddy, C. M., Cavanna, A. E., Gulisano, M., Agodi, A., Barchitta, M., Calì, P., Robertson, M. M., & Rizzo, R. (2011). Clinical correlates of quality of life in Tourette syndrome. *Movement Disorders*, *26*(4), 735-738. https://doi.org/10.1002/mds.23434

Erenberg, G., Cruse, R. P., & David Rothner, A. (1987). The natural history of Tourette syndrome: A follow-up study. *Annals of Neurology: Official Journal of the American Neurological Association and the Child Neurology Society*, *22*(3), 383-385. https://doi.org/10.1002/ana.410220317

Fiske, S. T. (1998). Stereotyping, prejudice, and discrimination. In D. T. Gilbert, S. T. Fiske, & G. Lindzey (Eds.), *The handbook of social psychology* (4th ed., pp. 357–411). McGraw-Hill.

Fry, M. S., Shircliff, K., Benham, M., Duncan, T., Ladd, K., Gilbert, M. K., Rattermann, M. J., & Cyders, M. A. (2023). Medication assisted recovery: A social ecological approach to understanding how stigma shapes effective use. *Journal of Applied Social Science*, *17*(2), 220-240. https://doi.org/10.1177/19367244231159096

Gadow, K. D., Nolan, E. E., Sprafkin, J., & Schwartz, J. (2002). Tics and psychiatric comorbidity in children and adolescents. *Developmental Medicine and Child Neurology*, *44*(5), 330-338. https://doi.org/10.1017/S001216220100216X

Goffman, E. (1963) *Stigma: Notes on the management of spoiled identity*. Penguin.

Himle, M. B., Woods, D. W., Conelea, C. A., Bauer, C. C., & Rice, K. A. (2007). Investigating the effects of tic suppression on premonitory urge ratings in children and adolescents with Tourette's syndrome. *Behaviour Research and Therapy*, *45*(12), 2964-2976. https://doi.org/10.1016/j.brat.2007.08.007

Hirschtritt, M. E., Lee, P. C., Pauls, D. L., Dion, Y., Grados, M. A., Illmann, C., King, R. A., Sandor, P., McMahon, W. M., Lyon, G. J., Cath, D. C., Kurlan, R., Robertson, M. M., Osiecki, L., Scharf, J. M., & Mathews, C. A. (2015). (2015). Lifetime prevalence, age of risk, and genetic relationships of comorbid psychiatric disorders in Tourette syndrome. *JAMA Psychiatry*, *72*(4), 325-333. https://doi.org/10.1001/jamapsychiatry.2014.2650

Holtz, K. D., & Tessman, G. K. (2007). Evaluation of a peer-focused intervention to increase knowledge and foster positive attitudes toward children with Tourette syndrome. *Journal of Developmental and Physical Disabilities*, *19*, 531-542. https://doi.org/10.1007/s10882-007-9042-z

Hwang, K. K. (2006). Moral face and social face: Contingent self-esteem in Confucian society. *International Journal of Psychology*, *41*(4), 276-281. https://doi.org/10.1080/00207590544000040

Isaacs, D. A., Riordan, H. R., & Claassen, D. O. (2021). Clinical correlates of health-related quality of life in adults with chronic tic disorder. *Frontiers in Psychiatry*, *12*, 619854. https://doi.org/10.3389/fpsyt.2021.619854

Ismail, R., Voss, J. G., Yona, S., Nurachmah, E., Boutain, D., Lowe, C., John-Stewart, G., & Woods, N. F. (2022). Classifying stigma experience of women living with HIV in Indonesia through the social ecological model. *Health Care for Women International*, *43*(1-3), 345-366. https://doi.org/10.1080/07399332.2021.1929989

Jafari, F., Abbasi, P., Rahmati, M., Hodhodi, T., & Kazeminia, M. (2022). Systematic review and meta-analysis of Tourette syndrome prevalence; 1986 to 2022. *Paediatric Neurology*. https://doi.org/10.1016/j.pediatrneurol.2022.08.010

Jatchavala, C., & Pitanupong, J. (2021). Self-perceived incompetence in psychiatric practice of practitioners from southern Thailand: One year following graduation. *Walailak Journal of Science and Technology*, *18*(12), 10408. https://doi.org/10.48048/wjst.2021.10408

Kano, Y., Ohta, M., Nagai, Y., Spector, I., & Budman, C. (2008). Rage attacks and aggressive symptoms in Japanese adolescents with Tourette syndrome. *CNS Spectrums*, *13*(4), 325-332. https://doi.org/10.1017/S1092852900016448

Khalifa, N., & Von Knorring, A. L. (2006). Psychopathology in a Swedish population of school children with tic disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, *45*(11), 1346-1353. https://doi.org/10.1097/01.chi.0000251210.98749.83

Kim, S. Y., & Tak, J. K. (2020). Analyses of psychological stress and coping of parents of children with Tourette's disorder. *The Korean Journal of Health Psychology*, *25*(1), 153-185. https://doi.org/10.17315/kjhp.2020.25.1.009

Knight, T., Steeves, T., Day, L., Lowerison, M., Jette, N., & Pringsheim, T. (2012). Prevalence of tic disorders: A systematic review and meta-analysis. *Paediatric Neurology*, *47*(2), 77-90. https://doi.org/10.1016/j.pediatrneurol.2012.05.002

Kvaale, E. P., Gottdiener, W. H., & Haslam, N. (2013). Biogenetic explanations and stigma: A meta-analytic review of associations among laypeople. *Social Science & Medicine*, *96*, 95-103. https://doi.org/10.1016/j.socscimed.2013.07.017

Lawal T.A., Idowu B.A., Ojo O.O. & Okubadejo N.U. (2012). Knowledge of movement disorders among resident doctors and undergraduate clinical medical students at the Lagos university teaching hospital. *Movement Disorders*, *27*(S1), S295. https://doi.org/10.1002/mds.25051

Leckman, J. F., Riddle, M. A., Hardin, M. T., Ort, S. I., Swartz, K. L., Stevenson, J., & Cohen, D. J. (1989). The Yale Global Tic Severity Scale: Initial testing of a clinician-rated scale of tic severity. *Journal of the American Academy of Child & Adolescent Psychiatry*, *28*(4), 566-573. https://doi.org/10.1097/00004583-198907000-00015

Leckman, J. F., Zhang, H., Vitale, A., Lahnin, F., Lynch, K., Bondi, C., Kim, Y.-S., & Peterson, B. S. (1998). Course of tic severity in Tourette syndrome: The first two decades. *Paediatrics*, *102*(1), 14-19. https://doi.org/10.1542/peds.102.1.14

Lee, M. Y., Mu, P. F., Wang, W. S., & Wang, H. S. (2016). 'Living with tics': Self-experience of adolescents with Tourette syndrome during peer interaction. *Journal of Clinical Nursing*, *25*(3-4), 463-471. https://doi.org/10.1111/jocn.13074

Lee, M., & Park, S. (2019). Beliefs about tic disorders and Tourette's syndrome in South Korea: An online panel survey. *Journal of the Korean Academy of Child and Adolescent Psychiatry*, *30*(3), 109. https://doi.org/10.5765/jkacap.190007

Lee, M. Y., Wang, H. S., Chen, C. J., & Lee, M. H. (2019). Social adjustment experiences of adolescents with Tourette syndrome. *Journal of Clinical Nursing*, *28*(1-2), 279-288. https://doi.org/10.1111/jocn.14564

Lemelson, R. B. (2009). Dissatisfied seekers: Efficacy in traditional healing of neuropsychiatric disorders in Bali. In M. Incayawar, R. Wintrob, & L. Bouchard (Eds.), *Psychiatrists and Traditional Healers* (pp. 179-195) John Wiley & Sons. https://doi.org/10.1002/9780470741054.ch14

Lemelson, R. & Tucker, A. (2017). The bird dancer and the warrior king: Divergent lived experiences of Tourette syndrome in Bali. *Transcultural Psychiatry*, *54*(4), 540-561. https://doi.org/10.1177/1363461517722869

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*(1), 363-385. https://doi.org/10.1146/annurev.soc.27.1.363

Liu, Z., Yang, C., Yu, D., Zeng, L., Jia, Z. J., Cheng, G., & Zhang, L. (2023). Anxiety and depression among parents of paediatric patients with tic disorder in western China: A cross-sectional study. *PLoS ONE*, *18*(7), e0289381. https://doi.org/10.1371/journal.pone.0289381

Lowe, T. L., Capriotti, M. R., & McBurnett, K. (2019). Long-term follow-up of patients with Tourette's syndrome. *Movement Disorders Clinical Practice*, *6*(1), 40-45. https://doi.org/10.1002/mdc3.12696

Ludlow, A. K., Brown, R., & Schulz, J. (2018). A qualitative exploration of the daily experiences and challenges faced by parents and parents of children with Tourette's syndrome. *Journal of Health Psychology*, *23*(14), 1790-1799. https://doi.org/10.1177/1359105316669878

Ludlow, A. K., Cutler, A., & Keville, S. (2022). British teachers' knowledge and awareness of Tourette syndrome in children attending mainstream school. *Journal of Research in Special Educational Needs*, *22*(4), 323-331. https://doi.org/10.1111/1471-3802.12570

Luhalima, R. L., Mulovhedzi, S. A., & Thuketana, N. S., (2023). Understanding Tourette syndrome: An African perspective. In H. R., Maapola-Thobejane & M. In Maguvhe (Eds.), *Handbook of research on shifting paradigms of disabilities in the schooling system* (pp. 259-277). IGI Global. https://doi.org/10.4018/978-1-6684-5800-6.ch018

Malik, O. (2021). Commentary: What is unsought will go undetected–a commentary on Rodin et al. (2020). *Child and Adolescent Mental Health*, *26*(1), 54-55. https://doi.org/10.1111/camh.12401

Malli, M. A., & Forrester-Jones, R. (2022). Stigma and adults with Tourette's syndrome: "Never laugh at other people's disabilities, unless they have Tourette's—Because how can you not?". *Journal of Developmental and Physical Disabilities*, *34*(5), 871-897. https://doi.org/10.1007/s10882-021-09829-2

Malli, M. A., Forrester-Jones, R., & Murphy, G. (2016). Stigma in youth with Tourette's syndrome: A systematic review and synthesis. *European Child & Adolescent Psychiatry*, *25*, 127-139. https://doi.org/10.1007/s00787-015-0761-x

Marcks, B. A., Woods, D. W., Teng, E. J., & Twohig, M. P. (2004). What do those who know, know? Investigating providers' knowledge about Tourette's syndrome and its treatment. *Cognitive and Behavioural Practice*, *11*(3), 298-305. https://doi.org/10.1016/S1077-7229(04)80044-0

Martino, D., Ganos, C., & Pringsheim, T. M. (2017). Tourette syndrome and chronic tic disorders: The clinical spectrum beyond tics. *International Review of Neurobiology*, *134*, 1461-1490. https://doi.org/10.1016/bs.irn.2017.05.006

Mathews, C. A., Amighetti, L. D. H., Lowe T. L., Van De Wetering B. J. M., Freimer, N. B., & Reus, V. I. (2001). Cultural influences on diagnosis and perception of Tourette syndrome in Costa Rica. *Journal of the American Academy of Child and Adolescent Psychiatry*, *40*(4), 456-463. https://doi.org/10.1097/00004583-200104000-00015

Maxwell-Scott, M., O'Keeffe, F., & Eccles, F. J. (2024). Coping with Tourette's syndrome: A meta-ethnography of individual and family perspectives. *Psychology & Health*, 1-23. https://doi.org/10.1080/08870446.2024.2360126

Muller-Vahl K. R., Szejko N., Verdellen C., Roessner V., Hoekstra P. J., Hartmann A., & Cath D.C. (2022). European clinical guidelines for Tourette syndrome and other tic

disorders: Summary statement. *European Child and Adolescent Psychiatry*, *31*(3), 377-382. https://doi.org/10.1007/s00787-021-01832-4

Nussey, C., Pistrang, N., & Murphy, T. (2014). Does it help to talk about tics? An evaluation of a classroom presentation about Tourette syndrome. *Child and Adolescent Mental Health*, *19*(1), 31-38. https://doi.org/10.1111/camh.12000

Nwazor, E., & Okeafor, C. (2019). Knowledge and attitude towards movement disorders among final year medical students in a Nigerian university. *Movement Disorder*, *34*(S2), S608. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed20&NEWS=N&AN=631397163.

Pappert, E. J., Goetz, C. G., Louis, E. D., Blasucci, L., & Leurgans, S. (2003). Objective assessments of longitudinal outcome in Gilles de la Tourette's syndrome. *Neurology*, *61*(7), 936-940. https://doi.org/10.1212/01.WNL.0000086370.10186.7C

Park S., Lee Y. & Kim C. E. (2018). Korean adults' beliefs about and social distance toward attention-deficit hyperactivity disorder, Tourette syndrome, and autism spectrum disorder. *Psychiatry Research*, 269 633-639. https://doi.org/10.1016/j.psychres.2018.08.023

Peterson, B. S., Pine, D. S., Cohen, P. & Brook, J. S. (2001). Prospective, longitudinal study of tic, obsessive-compulsive, and attention-deficit/hyperactivity disorders in an epidemiological sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, *40*(6), 685-695. https://doi.org/10.1097/00004583-200106000-00014

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006) Guidance on the conduct of narrative synthesis in systematic

reviews: A product from the ESRC Methods Programme. Version 1. https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=ed8b23836338f6fdea0cc55e161b0fc5805f9e27

Pring, K., Malli, M., Hardy, B. W., Rapp, S. R., Storch, E. A., Mink, J. W., & Martindale, J. M. (2023). Reframing stigma in Tourette syndrome: An updated scoping review. *European Child & Adolescent Psychiatry*, 1-21. https://doi.org/10.1007/s00787-023-02332-3

Ramteke, A., & Lamture, Y. (2022). Tics and Tourette syndrome: A literature review of etiological, clinical, and pathophysiological aspects. *Cureus*, *14*(8). https://doi.org/10.7759/cureus.28575

Ricketts, E. J., Woods, D. W., Espil, F. M., McGuire, J. F., Stiede, J. T., Schild, J., Yadegar, M., Bennett, S. M., Specht, M. W., Chang, S., Scahill, L., Wilhelm, S., Peterson, A. L., Walkup, J. T., & Piacentini, J. (2022). Childhood predictors of long-term tic severity and tic impairment in Tourette's disorder. *Behaviour Therapy*, *53*(6), 1250–1264. https://doi.org/10.1016/j.beth.2022.07.002

Rivera-Navarro, J., Cubo, E., & Almazán, J. (2014). The impact of Tourette's syndrome in the school and the family: Perspectives from three stakeholder groups. *International Journal for the Advancement of Counselling*, *36*, 96-113. https://doi.org/10.1007/s10447-013-9193-9

Rizzo, R., Gulisano, M., Pellico, A., Calì, P. V., & Curatolo, P. (2014). Tourette syndrome and comorbid conditions: A spectrum of different severities and complexities. *Journal of Child Neurology*, *29*(10), 1383-1389. https://doi.org/10.1177/0883073814534317

Robertson, M. M. (2008). The prevalence and epidemiology of Gilles de la Tourette syndrome: Part 2: Tentative explanations for differing prevalence figures in GTS,

including the possible effects of psychopathology, aetiology, cultural differences, and differing phenotypes. *Journal of Psychosomatic Research*, *65*(5), 473-486. https://doi.org/10.1016/j.jpsychores.2008.03.007

Robertson, M. M., Banerjee, S., Kurlan, R., Cohen, D. J., Leckman, J. F., McMahon, W., Pauls, D. L., Sandor, P., & Van de Wetering, B. J. M. (1999). The Tourette syndrome diagnostic confidence index: Development and clinical associations. *Neurology*, *53*(9), 2108-2108. https://doi.org/10.1212/WNL.53.9.2108

Robertson, M. M., & Eapen, V. (1996). The National Hospital Interview Schedule for the assessment of Gilles de la Tourette syndrome. *International Journal of Methods in Psychiatric Research*, *6*(4), 203-226. https://psycnet.apa.org/doi/10.1002/(SICI)1234-988X(199612)6:4%3C203::AID-MPR165%3E3.3.CO;2-F

Robertson, M. M., Eapen, V., & Cavanna, A. E. (2009). The international prevalence, epidemiology, and clinical phenomenology of Tourette syndrome: A cross-cultural perspective. *Journal of Psychosomatic Research*, *67*(6), 475-483. https://doi.org/10.1016/j.jpsychores.2009.07.010

Robertson, M. M. (2012). The Gilles de la Tourette syndrome: The current status. *Archives of Disease in Childhood- Education and Practice Edition*, *97*(5), 166-175. https://doi.org/10.1136/archdischild-2011-300585

Robertson, M. M., Eapen, V., Singer, H. S., Martino, D., Scharf, J. M., Paschou, P., Roessner, V., Woods, D. W., Hariz, M., Mathews, C. A., Črnčec, R., & Leckman, J. F. (2017). Gilles de la Tourette syndrome. *Nature Reviews Disease Primers*, *3*(1), 1-20. https://doi.org/10.1038/nrdp.2016.97

Rodin, A., Fleetwood-Meade, K., Gilmour, J., Kasujja, R., & Murphy, T. (2021). Why don't children in Uganda have tics? A mixed-methods study of beliefs, knowledge, and

attitudes of health professionals. *Child and Adolescent Mental Health*, *26*(1), 47-53. https://doi.org/10.1111/camh.12370

Scharf, J. M., Miller, L. L., Gauvin, C. A., Alabiso, J., Mathews, C. A., & Ben-Shlomo, Y. (2015). Population prevalence of Tourette syndrome: A systematic review and meta-analysis. *Movement Disorders*, *30*(2), 221-228. https://doi.org/10.1002/mds.26089

Set, K. K., & Warner, J. N. (2021). Tourette syndrome in children: An update. *Current Problems in Paediatric and Adolescent Health Care*, *51*(7), 101032. https://doi.org/10.1016/j.cppeds.2021.101032

Sheehan, L., Palermo, C. V., & Corrigan., P. (2022). Theoretical models to understand stigma of mental illness. In D. L. Vogel & N. G. Wade (Eds.), *The Cambridge Handbook of Stigma and Mental Health* (pp. 11–30). Cambridge University Press. https://doi.org/10.1017/9781108920995.003

Shiu, C., Chen, W., Kim, B., Ricketts, E., Stiede, J. T., Espil, F. M., Specht, M. W., Woods, D. W., & Piacentini, J. (2023). The roles of lifetime enacted stigma in tic symptoms among young adults with Tourette syndrome. *Movement Disorders Clinical Practice,* 10(12), 1759-1768. https://doi.org/10.1002/mdc3.13900

Smith, H., Fox, J. R., & Trayner, P. (2015). The lived experiences of individuals with Tourette syndrome or tic disorders: A meta-synthesis of qualitative studies. *British Journal of Psychology*, *106*(4), 609-634. https://doi.org/10.1111/bjop.12118

Stangl, A. L., Earnshaw, V. A., Logie, C. H., Van Brakel, W., C. Simbayi, L., Barré, I., & Dovidio, J. F. (2019). The Health Stigma and Discrimination Framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, *17*, 1-13. https://doi.org/10.1186/s12916-019-1271-3

Steinberg T., Harush A., Barnea M., Dar R., Piacentini J., Woods D., Apter A. (2013). Tic-related cognition, sensory phenomena, and anxiety in children and adolescents with Tourette syndrome. *Comprehensive Psychiatry*, 54(5), 462-466. https://doi.org/10.1016/j.comppsych.2012.12.012

Stiede, J. T., Woods, D. W., Anderson, S., Eapen, V., Gev, E., Latimer, R., & Bredesen, A. M. (2021). Cultural differences in reactions to tics and tic severity. *Child & Family Behaviour Therapy*, *43*(3), 161-180. https://doi.org/10.1080/07317107.2021.1940586

Stokes, A., Bawden, H. N., Backman, J. E., Dooley, J. M., & Camfield, P. R. (1991). Peer problems in Tourette's disorder. *Paediatrics*, *87*(6), 936-942. https://doi.org/10.1542/peds.87.6.936

Suh, H. W., Yoon, S. I., Hong, S., Lee, H. W., Lee, M., Kim, J. W., & Chung, S. Y. (2022). How do children with Tourette's syndrome and their parents live with the disorder? A systematic review of qualitative evidence. *Frontiers in Psychiatry*, *13*, 992905. https://doi.org/10.3389/fpsyt.2022.992905

The Tourette Syndrome Association International Consortium for Genetics. (1999). A complete genome screen in sib pairs affected by Gilles de la Tourette syndrome. *The American Journal of Human Genetics*, *65*(5), 1428-1436. https://doi.org/10.1086/302613

Weiner, B. (1995). *Judgments of responsibility: A foundation for a theory of social conduct*. Guilford Press.

Woods, D. W., Piacentini, J., Himle, M. B., & Chang, S. (2005). Premonitory Urge for Tics Scale (PUTS): Initial psychometric results and examination of the premonitory urge phenomenon in youths with tic disorders. *Journal of Developmental and Behavioural Paediatrics, 26*(6), 397–403. https://doi.org/10.1097/00004703-200512000-00001

Yang C., Yang Y., Zhang L. & Zhao L. (2022). Medication choices in children with tic disorders in mainland China, Macao, Hong Kong, and Taiwan: Perspectives of guardians and physicians. *Frontiers in Pharmacology*, *13*, 852414. https://doi.org/10.3389/fphar.2022.852414

Zinner, S. H., Conelea, C. A., Glew, G. M., Woods, D. W., & Budman, C. L. (2012). Peer victimization in youth with Tourette syndrome and other chronic tic disorders. *Child Psychiatry & Human Development*, *43*, 124-136. https://doi.org/10.1007/s10578-011-0249-y

Zung, W. W. (1965). A self-rating depression scale. *Archives of General Psychiatry*, *12*(1), 63-70. https://doi.org/10.1001/archpsyc.1965.01720310065008

Zung, W. W. (1971). A rating instrument for anxiety disorders. *Psychosomatics: Journal of Consultation and Liaison Psychiatry*, *12*(6), 371-379. https://doi.org/10.1016/S0033-3182(71)71479-0

Part 2: Empirical paper

The journey to a functional tics diagnosis and experiences of post diagnostic support: Perspectives from adolescents and their parents

Abstract

Background. From 2020, clinical services noted an unexpected increase in functional tic disorders, which coincided with the timing of the COVID-19 pandemic. Evidence suggests that functional symptoms and tic disorders have a significant impact on family functioning and lower child and parent reported quality of life. However, little is currently known of the impact of a functional tics diagnosis in adolescence, both on the young person and their families. **Methods.** The current qualitative study explores adolescent and parent experiences of a functional tics diagnosis, associated symptoms, and post-diagnostic support. Seven females aged between 12 and 18 years with a formal functional tics diagnosis and eight parents were recruited through Tourette's Action, a UK-based charity for people with Tourette syndrome and their families. Participants took part in individual semi-structured interviews via Microsoft Teams. Transcribed interviews were analysed using a reflexive Thematic Analysis within NVivo 14 and a subsample of transcripts were double coded. **Results.** Themes generated from adolescent and parent interviews included (1) blamed, disbelieved, discounted, (2) fighting for help, (3) professional and community support and (4) changes in identity and relationships. **Conclusions.** The findings emphasise the need for further research into functional tics and how to support young people and their families, in turn to improve service delivery.

Introduction

From 2020, clinical services reported an unexpected increase in functional tic disorders, which coincided with the timing of the COVID-19 pandemic (Heyman et al., 2021; Hull et al., 2021). Tics are sudden, repetitive, non-rhythmic and stereotyped movements or vocalisations that are neurodevelopmental in nature. Functional tics (FTs), otherwise known as functional tic-like behaviour, rapid-onset tics, pseudo-tics or psychogenic tics, are situated within a wider umbrella of functional neurological disorders (FND) and functional movement disorders (FMD; Demartini et al., 2014). Differentiating between the presentation of typical tic disorders and FTs is challenging, though emerging evidence indicates some unique and shared features (see Table 1).

Much remains unknown regarding functional tic pathophysiology. FND literature suggests physical symptoms are a somatic expression of cumulative stress which manifest through complex processes such as changes to the stress system and neurological function (Baizabal-Carvallo & Jankovic, 2013; Pringsheim et al., 2021; Kozlowska, 2017; Pick et al., 2019). A biopsychosocial model has been used to understand the aetiology of FTs (Berg et al., 2022), incorporating biological (such as genetics and aberrant neurological activity), social (such as environmental stressors, adverse experiences, social learning via tic content on social media) and psychological precipitating factors (such as anxiety, depression). Figure one summarises the current conceptualisation of precipitating and maintaining factors.

Given the proposed role of social stressors in FT development, pandemic-associated stress and uncertainty has been considered a key precipitating factor resulting in a rise in FT prevalence (Han et al., 2022). This sudden increase during COVID-19 was also paralleled by higher rates of tics in individuals with pre-existing tic disorders (Robertson et al., 2020). Evidence demonstrates the negative effects of lockdown on the mental health of children and

young people (Newlove-Delgado et al., 2021). Young people with an existing mental health condition and/or neurodevelopmental difficulties may be particularly vulnerable to the negative mental health impact of COVID-19 through disruption in daily routines, social distancing from peers, and family illness (Buts et al., 2022). Equally, the return to socialising and schooling post-pandemic may have increased distress for neurodiverse youth.

Table 1.

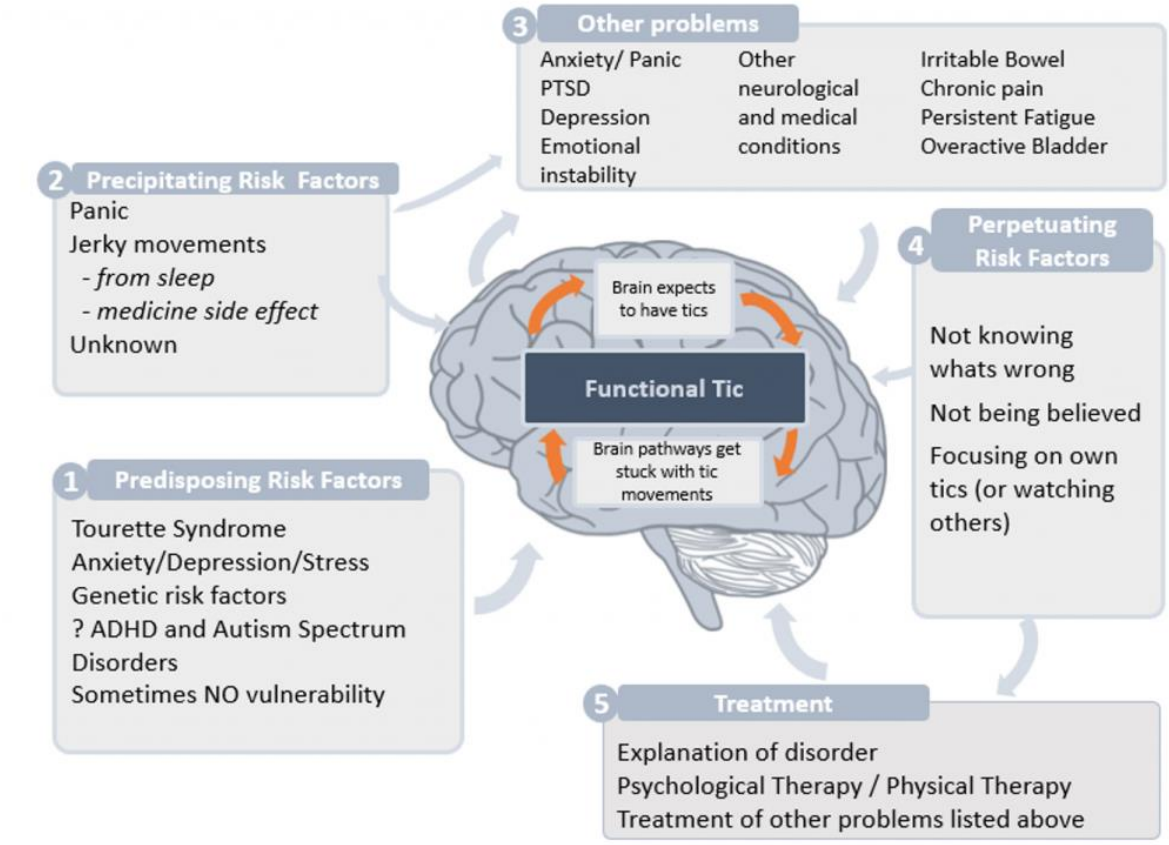
Unique features of functional tics and shared features with typical tic disorders

Unique features of functional tics	**Shared features with typical tic disorders**
Acute and severe onset	Co-occurring autism, ADHD, OCD, anxiety
Later age of onset (typically adolescence)	May benefit from psychological intervention
Female predominance	Individuals with a pre-existing tic disorder can later develop co-occurring functional tics
High frequency of complex tics	Thought to be underpinned by similar neural pathways
Lack of premonitory sensation or unusual premonitory symptoms	Premonitory urges can occur in both
Higher rates of self-injury	Suppressibility
Increased functional impairment	Occur more in the head, face and neck
Co-occurring FND symptoms	
Often do not benefit from typical tic medications	
Suggestibility	
Occur more in trunk and extremities	

Note. Information collated from multiple sources (Buts et al., 2022; McGuire et al., 2021; Müller-Vahl et al., 2022; Pringsheim et al., 2021; Ganos et al., 2019; Hull et al., 2021). *Abbreviations.* Attention deficit hyperactivity disorder *ADHD*, functional neurological disorder *FND*, obsessive compulsive disorder *OCD*.

Figure 1.

Risk and maintaining factors in functional tics.



Note. Figure reproduced from *Functional Tics*, by Hedderly et al. (2022) published on the FND Guide website, sourced at https://neurosymptoms.org/en/symptoms/fnd-symptoms/functional-tics/

Preliminary studies investigating the clinical characteristics of FTs suggest they typically arise in the adolescent period and co-occurring anxiety, depression and undiagnosed neurodevelopmental disorders are common (Heyman et al., 2021; Han et al., 2022; Pringsheim et al., 2021; Buts et al., 2022). An international registry of 294 adolescents and young adults with FTs indicates an 80% psychiatric comorbidity rate with anxiety being most common, and a 24% prevalence rate of autism and 23% prevalence rate of ADHD (Martino et al., 2022). Initial studies linked the increase in FTs to social media use, describing it as a 'mass sociogenic illness' (Olvera et al., 2021; Müller-Vahl et al., 2022; Frey et al., 2022) and some studies

suggest an association between FMDs and COVID-19 infection or vaccination itself (Fung et al., 2022).

Psychosocial stressors are postulated as precipitating factors for FT onset and FMDs more broadly (Hull et al., 2021). Martino and colleagues' (2022) international registry reported an identified stressor in the month prior to FT onset in 64% of cases, including social stressors (34%), pandemic-related stressors (28%), academic-related stressors (25%) and family-related stressors (13%). Evidence suggests that tic disorders and functional symptoms have a significant impact on family functioning, alongside lower child and parent quality of life (Vermilion et al., 2020; McWilliams et al., 2016). Therefore, developing an understanding of the nature of FTs and effective interventions is paramount to improving quality of life in this population. In the UK, the National Health Service (NHS) offers free support to young people through a tiered approach with each tier offering increasingly specialised services based on level of need, from general practitioners (GPs) in tier one, to highly specialist child and adolescent mental health services (CAMHS) in tier four (McDougall et al., 2008).

In the absence of guidelines concerning clinical management of FTs, the FND literature emphasises the role of timely diagnosis and intervention (Vassilopoulos et al., 2022). As part of the diagnostic process, an explanation which draws on the evidence base should be offered to support families to understand the precipitating and maintaining factors underpinning symptoms (Epsay et al., 2018). This is thought to reduce anxiety related to symptoms and promote acceptance. As such, clinical experts emphasise the role of psychoeducation in FT management (Malaty et al., 2022). Evidence indeed indicates the benefit of a FT psychoeducation group in improving knowledge and confidence in FT management (Duncan et al., 2024). Identification and treatment of co-occurring anxiety and depression is thought to be a pathway to reduction in FTs (Pringsheim et al., 2023). Emerging evidence suggests

cognitive behavioural interventions integrated with third-wave cognitive behavioural therapies (CBT) improve daily living function in FTs (Maxwell et al., 2023). A case series suggests that psychological therapy including cognitive behavioural techniques with metacognitive and attention training can be effective in reducing tic severity and anxiety and improving mood and quality of life in children with 'tic attacks' in Tourette syndrome (TS; Robinson & Hedderly, 2016).

Five studies to date have characterised the course and prognosis of young people presenting with FTs, who following diagnosis had often received CBT for anxiety or depression and/or antidepressant medication. In a Canadian sample of 20 adolescents and nine adults with FTs, adolescents demonstrated significant reduction in motor and vocal tics, levels of impairment and global severity scores six months post-diagnosis (Howlett et al., 2022). An Italian sample of 11 adolescents diagnosed with FTs demonstrated a decrease in tic severity and anxiety at 12 months follow-up, though depressive and obsessive-compulsive symptoms did not significantly differ from baseline (Prato et al., 2023). An American sample of youth and adults with FTs demonstrated a significant decrease in tic severity over a period of six to 12 months post-diagnosis (Nilles et al., 2024). Baseline tic severity and presence of additional FND symptoms were associated with higher tic severity scores at six months. Findings suggest that a younger age at diagnosis, receiving CBT for anxiety or depression and antidepressant medication were associated with lower tic severity scores at 6 months follow up. Another American paediatric sample found 79% of those with functional tics improved in tic severity and overall functioning independent of co-occurring conditions, and tic-specific interventions were not found to be superior to other psychological interventions (Tomczak et al., 2024). In a different American sample of 29 paediatric patients with FTs, greater age and longer time to diagnosis decreased the odds of improvement within one month of diagnosis (Mathew et al., 2023).

Qualitative research is a helpful method to develop an understanding of a population's needs and experiences of clinical services (Bradley et al., 2007). Exploring experiences of young people and their parents in other functional symptom populations, such as nonepileptic seizures (McWilliams et al., 2016; Hulgaard et al., 2020), highlighted that individuals diagnosed with FND reported feeling misunderstood and dissatisfied with psychological explanations for the disorder, experiences of stigma and self-stigma (Nielsen et al., 2020; Foley et al., 2024). Young people diagnosed with non-epileptic seizures and their families reported feeling misunderstood by health professionals, had difficulty coming to terms with the diagnosis and found clinicians and education staff were unaware of how to support the young person (McWilliams et al., 2016). A recent study examining mothers' experiences of their child's FTs highlights the severity and intensity of FT symptoms, which have a significant impact on family life, as well as reported difficulties accessing professional services and support for FT management (Ludlow et al., 2024). Further research exploring child and parent experiences of a paediatric FT diagnosis, symptoms, and treatment is necessary to improve clinical services and outcomes for young people and their families.

Research Aims

The purpose of this qualitative study is to explore adolescents with FT and their parents' experiences of a FT diagnosis. The research questions were as follows:

1) How do adolescents with FTs and their parents experience receiving a diagnosis of FTs, including their experiences of pursuing the diagnosis and the impact of the diagnosis?

2) How do adolescents and their parents experience post-diagnostic support for FTs and/or other co-occurring needs?

Methods

Participants and recruitment

Purposive sampling was used to recruit adolescents with FTs and their parents through Tourette's Action, a UK-based charity for TS. Study details were advertised through the Tourette's Action website and associated social media pages (see Appendix A).

Inclusion criteria

Inclusion criteria for adolescents were a) aged between 12 and 18 years old, b) had received a formal diagnosis of FTs, c) not experiencing suicidal ideation or engaging in self-harm during study participation, d) live in the UK, and e) access to the internet and an electronic device. Age limits were selected based on literature which suggests that FTs emerge in the adolescent period (Heyman et al., 2021; Han et al., 2022; Pringsheim et al., 2021). No age limits were applied for parents. All other inclusion criteria were also applied to parents of eligible adolescents. If an adolescent consented to participate, their parent was not obligated to participate and vice versa. Individuals with suicidal ideation and/or self-harm were excluded from the study to minimise risk of harm, as discussing experiences of FTs could be distressing for some.

Sample

Braun and Clarke (2012) recommend a sample size of 10-20 participants for a qualitative doctorate project. Therefore, the intended sample size for the study was 15 to 20 participants, with aims to obtain an equal sample of adolescents and parents. A total of 23

families registered interest in the study, of which eight parents (seven female, one male) and seven female adolescents completed semi-structured interviews. Recruitment closed at a sample size of 15 as data saturation was met. Figure two summarises participant attrition through the process of recruitment.

Measures

Screening questionnaire

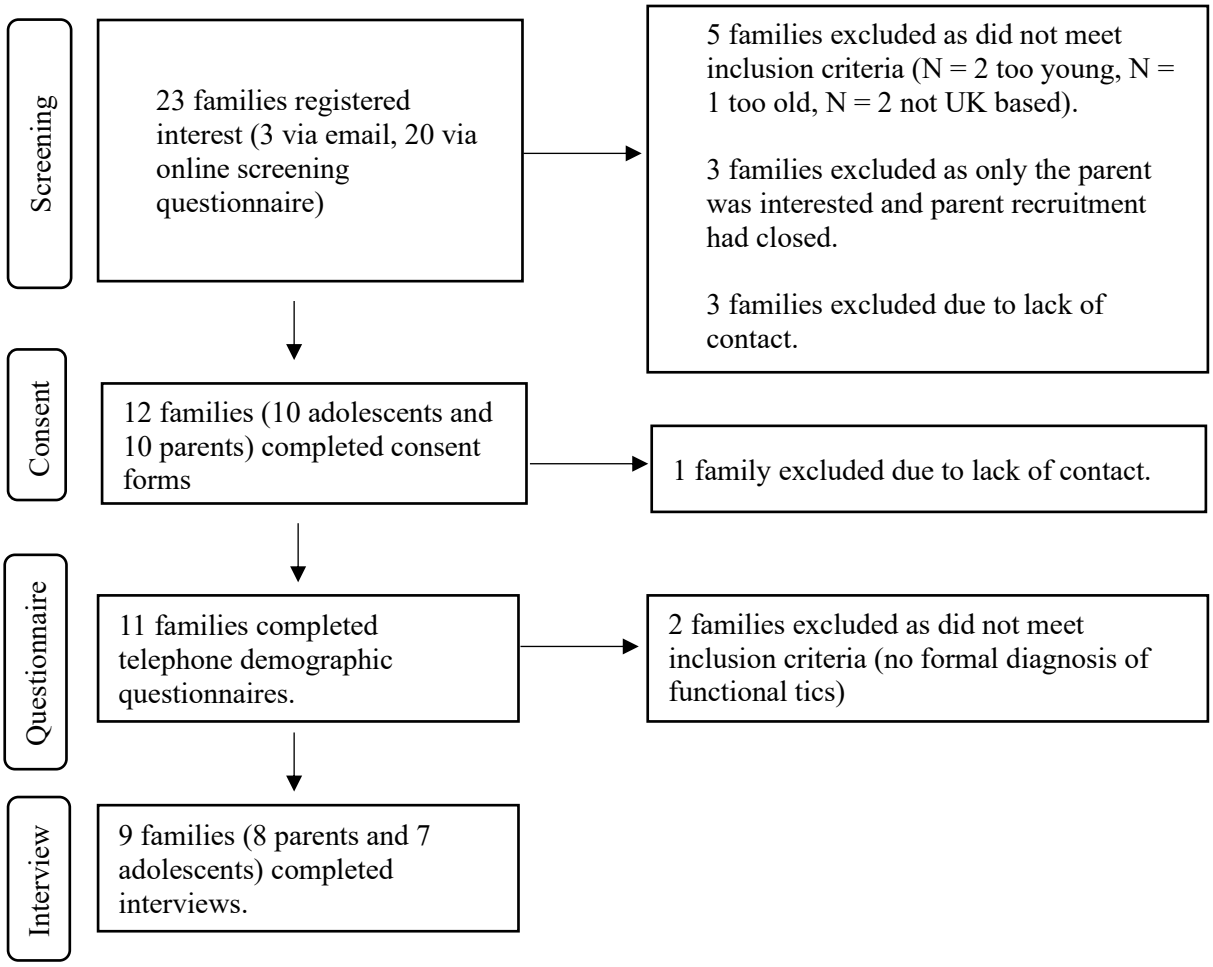
The screening questionnaire (see Appendix D) was designed by the research team and collected data to establish identity of the recipient (parent or adolescent), whether they met inclusion criteria (age and diagnosis), consent to be contacted and email address and telephone number.

Demographic questionnaire

The demographic questionnaire was developed for the purpose of the study with separate questionnaires developed for parents and adolescents over the age of 16 years (see Appendix E). The questionnaires captured data pertaining to age of the child, identified gender and ethnicity, information regarding the child's FT diagnosis and any comorbidities, as well as establishing any self-harm and suicidal ideation. GP contact details were also collected in the instance of risk concerns arising during study participation.

Figure 2.

Participant recruitment



Semi-structured interview

Semi-structured interview schedules (see Appendix F) were developed by the research team, using published examples of interview schedules exploring experiences of a diagnosis in the paediatric FND domain as a template (for example, McWilliams et al., 2016). Bronfenbrenner's social ecological model (1977) and relational recovery frameworks (Wyder & Bland, 2014; Price-Robertson, Obradovic & Morgan, 2016) were used to guide development of separate parent and adolescent interview schedules. The research team comprised a trainee clinical psychologist and four qualified clinical psychologists, three of which had significant

experience working with young people with FTs. Draft interview schedules were developed further in consultation with two young people diagnosed with FTs and their parents from a paediatric hospital in London, who offered feedback on interview schedules and ideas for improvement (discussed further in Part 3 of the thesis). The interview schedule included exploration of adolescent and parent journeys to obtaining a FTs diagnosis including how they experienced and understood the diagnosis, the impact of FTs on the adolescent and the family, triggers and support strategies for FTs and experiences of any post-diagnostic support for FTs and/or comorbidities.

Procedure

The study advert on the Tourette's Action website and social media pages provided a link and QR code to an online screening questionnaire which potential participants could use to access study information sheets (see Appendix B) and register interest in the study. To do so, they were required to provide their contact details and provide consent to be contacted by the research team for study purposes through the screening questionnaire. The lead researcher's email address was included in the study advert as an alternative method to register interest and ask any questions about the study. Participants who registered interest via email were emailed information sheets. Potential participants who met inclusion criteria, as assessed via the screening questionnaire were contacted via telephone or email to discuss participation and were given the opportunity to ask any questions. Once their queries had been answered they were invited to complete an electronic consent and/or assent form (see Appendix C).

Following informed consent and/or assent, participants were contacted via telephone to complete the demographic questionnaire. Parents completed the telephone demographic questionnaire on behalf of children under the age of 16 years or if their child was over the age

of 16 years but was not participating in the study. Adolescent participants over the age of 16 completed the telephone demographic questionnaire with the lead researcher. Once the demographic questionnaire was complete and if participants were still eligible and happy to participate, the interviews were scheduled.

Interviews were conducted virtually using secure UCL domains on Microsoft Teams and lasted between 45 and 90 minutes. Participants were interviewed separately. All interviews were audio recorded and transcribed for analysis, with identifiable information redacted during transcription to preserve anonymity. At the end of the interview, participants were given the opportunity to share any relevant experiences not yet discussed and to ask any questions.

Data Analysis

Thematic Analysis

Thematic Analysis is a qualitative method of analysis which allows for generation of patterns of shared meaning across a dataset, otherwise known as themes (Braun & Clarke, 2006, 2012). The method allows for a greater sample size when compared to other techniques such as Interpretative Phenomenological Analysis (Smith et al., 2022). Thematic Analysis is noted to be a theoretically flexible approach and can be used to answer a range of research questions (Braun & Clarke, 2019). An inductive, reflexive Thematic Analysis was chosen to analyse study data, to allow for exploration of participant perceptions and sense-making whilst staying as close as possible to meanings in the data.

Data analysis was performed using the six-step iterative framework outlined for Thematic Analysis (see Braun & Clarke, 2006, 2012), namely familiarisation, coding,

searching for themes, reviewing themes, defining and naming themes and writing up. N-Vivo 14 was used to support analysis.

Data credibility and reflexivity

Developments in Thematic Analysis have recognised the role of the researcher in knowledge production (Braun & Clarke, 2019). A reflexive approach to Thematic Analysis was therefore utilised to support awareness of the researcher's personal and theoretical assumptions which can impact data collection and analysis. To support this process a reflective journal was kept by the lead researcher during data collection and analysis to aid transparency of their own theoretical position and assumptions. This facilitated reflection on thoughts and feelings which emerged during data collection and awareness of biases which impact what is given attention in the analytic process. In turn, this facilitated changes in interview approach, as well as consideration of alternative interpretations.

To manage researcher bias, three of the 15 transcripts were independently coded by another member of the research team. Similarities and differences in coding were discussed to support reflexivity and to consider alternative perspectives and additional codes. Codes and initial generated themes were discussed within the research team to support querying of the lead researcher's assumptions and allowed for alternative interpretations of the data. This facilitated further consolidation and definition of themes, including reorganisation of themes. Reflexivity is covered in greater detail in part 3 of the thesis.

Ethical Approval

Ethical approval was obtained from the University College London (UCL) research ethics committee (UCL Ethics Project ID Number: 24255/001; see Appendix G for evidence of ethical approval).

Results

Participants

Eight parents participated in the study, of which seven were mothers and one was a father. All adolescents with FTs identified as female, were White British and were aged between 12 and 18 years old (mean age of 15.2 years). Participant information is provided in Table 2. Names were pseudonymised rather than anonymised to facilitate a more personal reading of the findings, whilst preserving confidentiality.

Themes

Analysis of interview transcripts resulted in generation of four themes, each comprising three to four subthemes. An example of a coded transcript extract and codes comprising a subtheme can be found in Appendix H and I, respectively. A thematic map is presented in Figure 3.

Table 2.

Participant characteristics.

Parent name	Adolescent's name	Adolescent's gender, age, and ethnicity	Pre-existing diagnoses	FTs diagnosis date	Diagnosis provider	Concurrent diagnoses received	Subsequent diagnoses received	Additional information
Wendy	Laura	F, 18, White British	Dyslexia, depression, anxiety	2022	Consultant Psychiatrist NHS	TS	Autism, ADHD being assessed.	Waited a year for a diagnosis - confirmed in writing
Angela	Christine	F, 16, White British	None	2022	Consultant Neurologist Private	None	None	Waited a year for a diagnosis - confirmed in writing. Doesn't wish to pursue other diagnoses.
Jacob	Sophie	F, 15, White British	Anxiety	2022	Clinical Psychologist NHS	TS	None	Waited 2 weeks for CAMHS support. Onset of FTs 7-8 months following symptoms of TS tics
Brooke	Abi	F, 17, White British	Autism	2022	Clinical Psychologist and Psychiatrist NHS	None	None	3 months wait for support. Tic onset 7 months prior to diagnosis. Assessed and diagnosed same day. offered a follow up session to discuss in more depth.

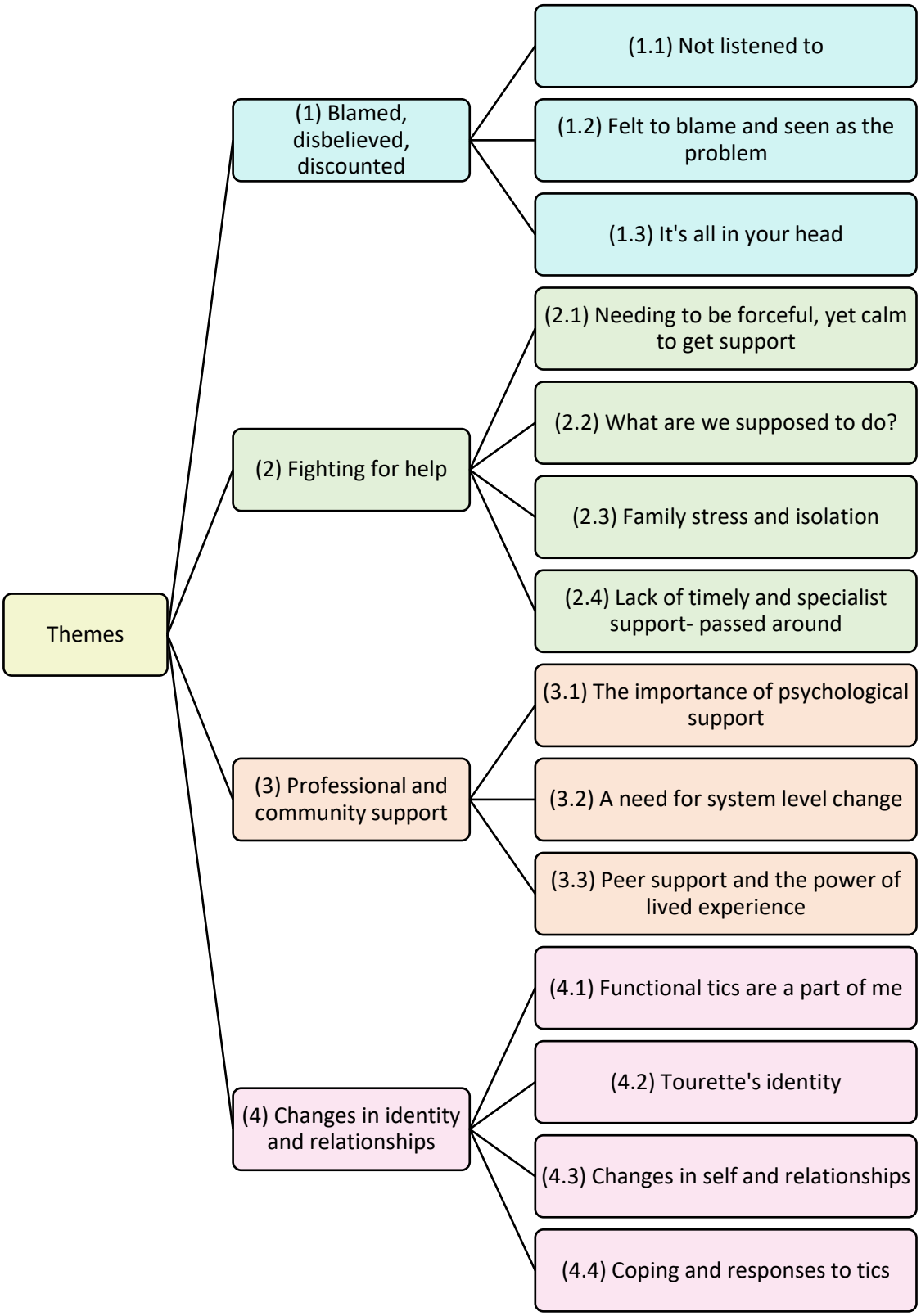
Parent name	Adolescent's name	Adolescent's gender, age, and ethnicity	Pre-existing diagnoses	FTs diagnosis date	Diagnosis provider	Concurrent diagnoses received	Subsequent diagnoses received	Additional information
Kelly	[Holly]	F, 12, White British	ADHD, TS	2021	Psychiatrist and Clinical Psychologist Private	None	Autism	3-4 week wait for support. Assessed and diagnosed in one day
Ella	Jo	F, 17, White British	Prior ED, anxiety, depression, PTSD	2023	Consultant Neurologist Private	FND (NES, dissociative disorder)	None	Seizure onset before FT onset. Sought support from GP and attended A&E twice before seeing a neurologist.
Shelly	Emma	F, 14, White British	TS	2022	Neurologist Private	GAD, OCD, NES	None	4 months between FT onset and diagnosis. Verbal diagnosis. Has been waiting for CBT for a year and a half on the NHS.
Hannah	[Mary]	F, 14, White British	None	2021	Community Paediatrician NHS	None	Autism, Irlen syndrome	3 months between FT onset and diagnosis which was confirmed in writing.
[Aaliyah]	Rachel	F, 14, White British	NES	2022	Consultant Private	PTSD.	None	3 months wait for support. NES started a month before FTs and were diagnosed a few months before FTs.

Note. Parents and adolescents are grouped by family and names are pseudonymised. Square brackets denote a name of a parent or adolescent within a family who did not participate. *Abbreviations.* Attention deficit hyperactivity disorder *ADHD*, accident and emergency *A&E*, child and adolescent mental health services *CAMHS*, cognitive behavioural therapy *CBT*, eating disorder *ED*, female *F*, functional neurological disorder

FND, functional tics *FTs*, general anxiety disorder *GAD*, general practitioner *GP*, non-epileptic seizures *NES*, national health service *NHS*, obsessive compulsive disorder OCD, post-traumatic stress disorder *PTSD*, Tourette syndrome *TS*.

Figure 3.

Thematic map



Note. Theme and subtheme numbers are denoted in brackets.

Notations were used in presentation of quotations:

Omission of material	[…]
Speech emphasis	<u>underlined</u>
Anonymised or explanatory information	[clinic name], [functional tics]
Name and participant type	[Wendy, parent]
Non-verbal communication	*exhales*

Theme 1: Blamed, disbelieved, discounted

This theme explores experiences of feeling blamed, disbelieved, and discounted by professionals whilst seeking support for functional tics, particularly when functional tics started.

1.1 Not listened to

The sudden and explosive onset of FTs were confusing and frightening for families. Acute care was often their initial contact with services due to rapid symptom escalation. Families expressed difficulties with symptoms being acknowledged, whilst not feeling listened to or believed by professionals. This was a barrier to timely support such as onward referrals.

"It was really frustrating that we felt that nobody was taking it seriously […] she also felt frustrated because I think she felt not believed." (Ella, parent)

Some parents suggested that FTs may have arisen out of pre-existing needs not being understood earlier.

"Had somebody listened when I started asking for help then maybe we wouldn't have got to the FTs […] I think because she was autistic and nobody noticed. I think that's the crux of the situation" (Wendy, parent)

The unpredictable nature of FTs, lack of understanding of the condition and how to manage symptoms contributed to feelings of fear and lack of control.

"It kept getting progressively worse and worse and worse to the point I'd have to call on 111 because I got myself so stressed out, because I didn't know what was going on and it wouldn't stop." (Christine, adolescent)

1.2 Felt to blame and seen as the problem

When symptoms started, parents felt blamed by professionals for FTs symptoms.

"I was always made to feel that somehow, it was our fault […] that we were pandering to her and that we were making it worse. […] They were quite accusatory. It was almost about 'what's going on at home?'. You know, 'she's got bruises. What's the bruises?'. She's punching walls and she's hitting herself, that's why she's got bruises." (Wendy, parent)

Young people felt blamed for their tics and seen as the problem. They suggested that people perceived FTs as controllable.

"School were vilifying her tics […] they handled it very much like this is a problem […] I said to the school I did not want Christine being described as abusive at all. Because she had no control over what she was saying." (Angela, parent)

1.3 It's all in your head

Dominant explanations for FTs, such as being psychological in nature and TikTok causing tics, were felt to invalidate symptom severity, contributing to the belief that adolescents were 'faking it' for attention. The transient and, for some, suppressible nature of FTs was thought to perpetuate this belief, with people needing to 'see it to believe it'. Adolescents expressed feeling disbelieved which was internalised, resulting in self-doubt.

*"And I think people then go, 'oh but you're faking it because you got it off that person online'" (*Abi, adolescent)

[Strangers yell] "and imply I'm faking it because I'd be in a wheelchair one week and then not the next" (Sophie, adolescent)

Psychological explanations were experienced as dismissive and blaming which did not acknowledge the physical reality and severity of FTs. Families felt FTs were not seen as severe as medical or neurological conditions and this impacted support availability and accessibility. Rapid medical investigations were offered when professionals were concerned that symptoms could have a neurological cause.

"I would like to think professionals would have an understanding that it is a medical condition. […] If she had a physical disability with her leg chopped off […] it's a bit more obvious" (Ella, parent)

"Because I have a long history of mental health, that any problems […] it's put down to anxiety. […] When you get told it time after time you just think, what on Earth is wrong with me?" (Jo, adolescent)

Theme 2: Fighting for help

2.1 Needing to be forceful, yet calm to get support

Families described having to fight to be seen by professionals to be assessed for FTs, and to access post-diagnostic support.

*"Like banging your head against a brick wall […] we have had to fight for every bit of help that we've had *tears up*"* (Wendy, parent)

Difficulties accessing services, particularly when symptoms started, resulted in high expressed emotion. This had negative consequences and parents found they had to present as calm and articulate to access support. Parents needed to advocate for their child's rights, for example when they lacked support at school. Some underwent courses to understand and advocate for their child's rights.

"I know that people get persistent and vindictive complainer logged against their name, and I'm certain that everybody has that against my name." (Hannah, parent)

"If we go up there screaming and shouting to the odds, that gives them a reason. So we need to do it in a very sensible and calm manner." (Angela, parent)

2.2 What are we supposed to do?

The FTs diagnosis was a relief for some, as it gave clarity to a previously undiagnosed set of symptoms. The diagnosis held different functions for families, such as providing an understanding, normalising experiences, and offering a framework to explain the adolescent's needs. The diagnosis held less meaning for some as they had already researched FTs and the diagnosis did not offer additional information.

"It made me feel like I'm not going crazy" (Jo, adolescent)

"Because we'd kind of already had to look into that and we'd already contacted lots of people I kind of already roughly knew" (Christine, adolescent)

The explanation of FTs made sense to many, often bolstered by families' pre-existing knowledge of mental health difficulties. However, some families conducted post-diagnostic research to understand FTs, as an explanation was not given or was insufficient.

"The letter didn't really change anything at all, except just give it that name" (Hannah, parent)

"I remember I googled it when I got home […]it kind of explained it in a bit more detail" (Rachel, adolescent)

Adolescents were often discharged at the point of diagnosis, without follow-up support. The primary means of professional support was signposting to resources, typically regarding neurodiversity and anxiety rather than FTs.

"The specifics about FTs felt quite light on the ground" (Kelly, parent)

Families needed help in understanding triggers for FTs and developing support strategies. Whilst trying to find suitable support services, parents provided support instinctually without knowing whether strategies were effective. Families found their own understanding of FTs through their own research and lived experience.

"What do we do when we're in crisis? When we're right in the middle of it. When it's two o'clock in the morning and she's punching walls […] I've learned to make decisions based on what I think is the right thing for her, with my gut instinct" (Wendy, parent)

Tourette's Action was a critical resource in learning about FTs, feeling understood, locating suitable support and school liaison to promote professional understanding.

"It was the first time I felt anybody understood what we were going through" (Angela, parent)

2.3 Family stress and isolation

Navigating FTs with minimal understanding of the condition, whilst fighting for support placed a significant strain on the family and dominated parents' lives.

[Fighting for help] "brings a lot of strain on the family, makes everyone very uptight. […] It's very difficult to be that loving family when everyone's very stressed all the time." (Abi, adolescent)

"I was so wrapped up in what was going on […] I spent my entire time trying to find somebody who knew anything about this" (Wendy, parent)

Families described isolation from the outside world, needing to stay at home due to FTs. Adolescents became dependent on parents and the carer role dominated parents' lives, with parents not looking after their own needs.

"I think it takes so much bandwidth and effort to be the carer for someone with FTs that I never really prioritised caring for myself" (Kelly, parent)

FTs impacted the wellbeing of the whole family. They were unable to access activities they previously enjoyed and had limited contact with others.

"It possibly made [husband and youngest child] at times feel very isolated because the focus has been very much [with child]. I think its impacted on all of us" (Angela, parent)

"It took away everything that I loved doing to keep myself… in a good place" (Laura, adolescent)

Many avoided going out in public. Several adolescents feared ticking in front of others, which was compounded by stigma and misunderstanding. Others avoided going out due to environmental triggers for tics.

"Anywhere you're supposed to be quiet, feel apprehensive about going […] going out in public sucks. I have to, like, psych myself up for it. […] You get parents pulling their kids away from you. You get people whispering about you and laughing about you" (Abi, adolescent)

2.4 Lack of timely and specialist support – passed around

Many families sought private care due to long waitlists for NHS support. Families who readily accessed specialist NHS or private support described themselves as fortunate given the scarcity of knowledgeable services for FTs.

"We were just one of the lucky ones that did manage to get in on that clinic after three months […] I know apart from that there is virtually nothing" (Brooke, parent)

Long waitlists resulted in an escalation in psychological distress and tic severity for many. They expressed needing to be in crisis or possess a FT diagnosis to access support.

"I was never really fussed about it or wanted [the diagnosis] in the first place, but […] school weren't going to actually help me or be of any use until they got that sorted" (Christine, adolescent)

Local NHS services lacked an understanding of FTs. Families felt disheartened by the lack of advice and available support which delayed access.

"If when we'd gone to the GP and the GP had said 'talk to these people' we would have been in that direction a lot, lot earlier" (Angela, parent)

Families had difficulty finding appropriate services before and after the diagnosis, as adolescents were not deemed appropriate for CAMHS, or CAMHS lacked knowledge of FTs. They contended with receiving conflicting messages from professionals regarding symptom management. Other families accessed CAMHS quickly or were already under CAMHS when diagnosed. Some were pleased with CAMHS support for FTs whereas others felt more specialist or intensive input was required.

"The initial group of doctors didn't really have much of a clue, but as soon as it was passed on to CAMHS, it sorted out fairly quickly. It was difficult at first because we were sort of being encouraged to tell her to fight it and try to, and that was very uncomfortable for her" (Jacob, parent)

Services were deemed disjointed, and some described falling in the gap between mental health and physical health services, with services 'passing the buck' and making onward referrals (Hardwick, 1991).

*"I was very upset afterwards because I was kind of like… after all this time waiting, just to be told… *sighs* got like another, we've got to refer you here. […] It was just bit of a shambles really. And I just came out really sort of like 'ohh what a waste of time'."* (Jo, adolescent)

Theme 3: Professional and community support

3.1 The importance of psychological support

Psychological support clarified the link between psychological wellbeing and tics in a way that considered adolescent's additional needs. This helped families to understand and manage the underlying causes, contributors, and triggers for tics, such as autism-related stress.

[The therapist] "who we saw agreed a lot of it is to do with the trauma of what happened at school and then the anxiety on top of it" (Brooke, parent)

"It gave us our answer that that stress of COVID had triggered it off." (Shelly, parent)

Psychological support helped families live with FTs through development of personalised strategies such as environmental adaptations. This included distraction techniques and emotion regulation strategies, as well as changing parental responses to tics. Anxiety medication was helpful for many adolescents. Supporting families to cope with tics improved confidence and reduced tic-related anxiety. Psychological intervention such as trauma-focused therapy and CBT for anxiety was also helpful, both for psychological needs thought to cause FTs and psychological needs resulting from FTs. Adolescents also benefited from alternative mind-body interventions or relaxing activities such as reiki, yoga, and Forest school.

"We understood that we were somehow making it worse by our anxiety and by our trying to protect her" (Wendy, parent)

"We're trying to work with her on teaching her to self-regulate, like building Lego or doing some mindfulness colouring […] encouraging her to identify when she's starting to feel anxious and doing something to kind of help that. She's also on anti-anxiety medicine and I think that's probably made a big difference" (Kelly, parent)

3.2 A need for system level change

A limited understanding of FTs was reported across levels of interaction, from one-to-one conversations to school policies. Subsequently adolescents experienced increased anxiety in public and school avoidance.

"A boy came up to me and said, 'are you crippled?' and then walked away. So, I was a bit anxious about just being there" (Emma, adolescent)

[Teachers said] "'The girl in the wheelchair doesn't want you to be making fun of her' in front of a whole assembly. It made me quite embarrassed" (Sophie, adolescent)

Limited understanding resulted in discrimination, such as adolescents being removed from classes and not being allowed to present peer psychoeducation on FTs. Families felt that the onus was on the young person to change their behaviour, rather than the system around them changing.

"Don't decide to take them out of lessons because they're struggling. Help and educate people before". (Christine, adolescent)

"I threatened legal action against [school] because I thought it was discrimination. […] I think a lot of the stress was caused by people not understanding. […] There's a tendency to treat a child like a disruptive child as opposed to thinking, what can we do in this situation?" (Angela, parent)

As part of the diagnosis, an explanation for FTs offered a framework to share and explain the child's needs, which was needed to educate others on FTs given a scarcity of information available. This placed additional responsibility on families. An increased understanding of FTs was deemed essential to improving quality of life, through reducing stigma and increasing awareness of triggers to support tic management.

"It gave us a solid ground to explain to people, this is the situation, this is what's happened, this is why it's happened" (Angela, parent)

The diagnosis and explanation of FTs facilitated adaptations and improved support for adolescents, particularly at school. For example, teachers were aware of their needs and triggers and managed these in the classroom, such as through adapting their approach or having one-to-one support. Adolescents could leave the classroom and have access to quiet spaces in school.

"There was a helper teacher in the classroom and if I told her that I felt something coming on we would go into a different room" (Emma, adolescent)

3.3 Peer support and the power of lived experience

Many participants spoke of the importance of online representation of FTs, and reflected on how representation of TS in the media has been helpful in improving awareness.

"I think it's got a lot easier since Lewis Capaldi, you know, announced about his cos now […] everybody is talking about Tourette's" (Brooke, parent)

Though young people noted that viewing videos of tics can trigger their own tics, they discussed how representation of lived experience online helps to demonstrate what it is like to have FTs and how to manage them. This helped adolescents feel less alone. Several acknowledged the presence of inaccurate portrayals of FTs in the media and called for accurate and positive portrayals to improve FTs awareness. Parents discussed how online groups developed their knowledge of FTs and support strategies. Some families moderated their exposure to online groups as they found content could be negative and disheartening. Listening to lived experience was thought to be an important element of improving the knowledge base

of FTs, with advice by families with lived experience at times thought to supersede professional advice.

"I've found out a lot more information through social media groups than through our community paediatrics" (Hannah, parent)

Tourette's Action was deemed vital in families finding resources and peer support and some adolescents had accessed tic support groups. Peer support helped families feel part of community where they felt understood and connected, in turn supporting wellbeing.

[Peer support] "helped me feel so much better about myself […] You don't have to explain [tics] to anyone because everyone knows, that they do the same" (Sophie, adolescent)

Theme 4: Changes in identity and relationships

4.1 Functional tics are a part of me

FTs were often accompanied by other diagnoses given either before, concurrently, or after FTs.

"I think it helped me realise a lot of things I was struggling with […] I think it's made me aware of actually other things going on." (Christine, adolescent)

An ongoing process was described, of understanding how different aspects of a young person's presentation fit together and interact. For instance, some families understood that underlying neurodiversity had contributed to FT onset and aspects of neurodiversity, such as sensory sensitivities, were triggers for tics.

"Being autistic in a non-autistic world creates a lot of anxiety for her. And it's that anxiety when it reaches a certain point that then triggers the FTs. And so that's the connection" (Kelly, parent)

Families reported that some professionals did not take a holistic approach. Rather, they described a process of diagnostic overshadowing whereby professionals would focus on the adolescent's co-occurring diagnoses or solely focus on FTs, without considering the interaction between needs. This was seen as a barrier to providing effective support.

"I think sometimes people forget that I'm autistic on top of the tics. And forget that […] the trauma was caused by me being autistic which kind of makes the tics even worse. […] I went through something traumatic <u>because</u> of my disability and it then caused <u>another</u> disability. And this new disability is causing <u>more</u> trauma" (Abi, adolescent)

Others described difficulty understanding the difference between their diagnoses, for example how FTs differ from a co-occurring diagnosis of TS. This seemed related to explanations offered by professionals.

"They talked more on the Tourette's bit, not really about FTs, and I'm not sure if FTs is a part of FND or it is FND" (Emma, adolescent)

4.2 Tourette's identity

TS was thought to dominate online representation and public knowledge of tics. Some families felt understood in the TS community, though for others, the FTs diagnosis made them feel different from the TS community. People often misidentified adolescents as having TS which felt invalidating.

"I started telling people that it was just Tourette's because that was easier, people know what Tourette's is rather than FTs" (Laura, adolescent)

Some participants thought that adolescents were being misdiagnosed with TS instead of FTs, which perpetuated feelings of isolation.

"Anyone who applies to [FTs] criteria, aren't getting a FTs diagnosis at the moment. Which is understandable because it's kind of new […] but also really infuriating because it gives you very few people to talk to" (Abi, adolescent)

4.3 Changes in self and relationships

FTs impacted identity as adolescents grieved aspects of their identity and typical adolescent milestones were disrupted.

"She's missed out all that going to house parties and all that stuff that you do between 15 and 18" (Wendy, parent)

Initially, adolescents felt less confident due to FTs, as they struggled with behaving in uncontrollable ways that often contrasted with their personhood.

"I know what my morals are and I'm not rude to people. So when that happens it's so difficult and it's so embarrassing" (Jo, adolescent)

Many described feeling different and isolated from peers. They feared ticking in front of them as this highlighted difference. To manage this, some could suppress tics.

"If I was in class and I really needed to tic, I'd get really anxious about what everyone would think. And now it's kind of come natural to me that I suppress it" (Emma, adolescent)

Young people described an ongoing process of adjustment to FTs as indicated by positive appraisals, such as feeling more confident because of them. Parents and friends demonstrated changes in values and qualities over time such as empathy and advocacy for children with additional needs. Amidst loss of friendships, other relationships and family bonds strengthened which was a coping resource. Some families described finding a new purpose because of FTs which improved confidence and independence.

"It also probably makes us all more empathetic. I'm always amazed by her brother and sister, rather than seeming to resent her for them or anything, they're just protective of her" (Kelly, parent)

"I've got a lot more confidence because I have to be quite outgoing. When you've got tics, you can't be the quiet kid in the corner anymore! […] There's a part of me that I do really like, that has come from the fact that I've just had to be stronger […] Like I can still be the person I wanted to be, I'm just not gonna be doing the stuff I wanted to do. And that changed things for me" (Abi, adolescent)

4.4 Coping and responses to tics

Families described many ways in which they coped and adjusted to FTs. This included offering practical and emotional support to one another. FTs were described as light relief at times, facilitating moments of humour for families which supported coping.

[Vocal tics] "didn't really sound like her, it was slightly different. So, we ended up naming the tics 'Adam' […] - it was our way. Because at that point we were still right in the middle of this absolute trauma of not knowing what was going on […] 'Adam' gave us some light relief because 'Adam' was funny" (Wendy, parent)

Adolescents often stated a preference for responses to tics, such as others ignoring them or laughing at humorous tics. Feeling accepted and safe by others appeared to promote adjustment to FTs and wellbeing. Safety was facilitated in many ways and was unique to the person but included others treating them as the same person and listening to their views.

"Just give them time. Listen to them and try to meet their needs, but as much as possible treat them, treat them as the same person, just the person, not the disorder." (Jacob, parent)

[Friends] "didn't treat me differently at all. It was just like I was the same. […] They kind of just laughed along and join in and not make me feel so like, different" (Rachel, adolescent).

Discussion

The current study explores adolescent and parent experiences of a FTs diagnosis and post-diagnostic support. This is the first known paper to qualitatively explore both parent and adolescent experiences of a FTs diagnosis and post-diagnostic support. Families frequently described a challenging journey to receiving a FTs diagnosis, with many pursuing private assessment and intervention due to long waiting times and scarce NHS resources. They portrayed an isolated experience of fighting for help in the context of feeling invalidated by professionals, whilst navigating an unknown and frightening set of symptoms. This exacerbated distress for the whole family. Services were often described as not set up to cater for the holistic needs of affected adolescents, however there was variability in experiences of post-diagnostic support. These findings are consistent with Ludlow and colleagues' (2024) qualitative study with mothers of children with FTs. The current study extends upon these findings through including adolescent perspectives and exploring experiences beyond the acute phase of FTs. This includes experiences of post-diagnostic support and processes that facilitated adjustment to the diagnosis.

The clinical features of FTs here are in line with existing literature, such as sudden and complex onset, complex functional coprolalia and self-injury and functional limitations associated with FTs. All adolescents presented with FTs during or in the aftermath of the COVID-19 pandemic. This bolsters evidence for the role of pandemic-related stress in FT development (Hull et al., 2021; Heyman et al., 2021). It is important to consider the variation in co-occurring diagnoses within the current sample. Many adolescents had a co-occurring diagnosis of autism and highlighted the role of neurodiversity in their understanding of FTs, such as stress related to the transition back to school post-pandemic. Literature suggests that neurodevelopmental disorders are a risk factor for the development of FTs (Han et al., 2022) and several families understood FTs as a manifestation of cumulative stress resulting from unrecognised autism. A smaller proportion of the adolescent sample presented with co-occurring FND symptoms, typically coupled with psychological needs such as post-traumatic stress disorder, rather than a neurodevelopmental disorder. A third subset presented with pre-existing TS in the absence of other neurodevelopmental conditions or FND symptoms. This could suggest different subgroups with different pathways to FTs, all likely underpinned by diverse anxiety-provoking events (Ludlow et al., 2024). Different pathways to FTs would have important implications for clinical practice, as targets for intervention may differ due to different underlying psychological processes. Randomised controlled trials are required to develop an understanding of effective interventions for FTs and potential adaptations dependent on co-occurring needs.

This study suggests a lack of awareness of FTs has widespread clinical implications, impacting service provision, duration of symptoms prior to diagnosis and availability and suitability of support. This seemingly impacted the extent of and satisfaction with provided explanations of FTs offered at diagnosis (subtheme 2.2), with some families having a reduced understanding of FTs and its relation to co-occurring diagnoses (subtheme 4.1). This is

particularly important given that psychoeducation is recommended as an initial intervention for TDs (Andrén et al., 2022; Duncan et al., 2024). Families were subjected to stigma related to FTs throughout their diagnostic journey and beyond (subthemes 1.3, 2.3, 3.2). Negative attitudes surrounding FTs and its psychological nature appear underpinned by lack of knowledge on the condition, resulting in disparities in healthcare access, instances of institutional discrimination and relationship difficulties, with families feeling that they needed to fight for help (theme 2). This mirrors healthcare experiences in FND, where diagnosed youth are subject to negative attitudes and iatrogenic harm (Kozlowska et al., 2021). Lack of knowledge and misconceptions about TS, such as its controllability, have been found to contribute to stigma in TS which is enacted at the structural level, such as discrimination in education (Cutler et al., 2009; Smith et al., 2015; Malli & Forrester-Jones, 2022). Experiences of education-based discrimination was also reported here (subtheme 3.2). The current study suggests that FTs are conceptualised by others as psychological (subtheme 1.3) and therefore affected youth may be at risk of double discrimination, as evidence suggests psychiatric conditions and TS are two highly stigmatised conditions in youth (Kaushik et al., 2016; Pring et al., 2023).

Variations in professional and community support were evident, whereby some families had contact with physical health services more readily, as well as secondary and tertiary care services such as specialist tic disorder services or CAMHS (subthemes 1.3, 2.4). Other families described difficulties being accepted by services due to not meeting referral criteria and fell in the gap between physical and psychological services. A vicious cycle has been previously described where services make onward referrals due to uncertainty of how to support individuals with FND (Barnett et al., 2020). This is of particular concern given that in the current study, absence of support resulted in greater levels of distress, tic-related impairment, and burden on families.

Disparities in service access could be explained by the intersecting identities of youth in the current example. For example, youth previously known to services for pre-existing psychological concerns may be particularly vulnerable to mental health discrimination, with their symptoms dismissed as 'just anxiety', rather than having access to medical examinations (Hale, 2024). An absence of holistic care was described particularly prior to the diagnosis, as evidenced by dualism, splitting of physical and psychological needs, absence of mind-body links and diagnostic overshadowing (subtheme 4.1). This was experienced as invalidating by many families and was a barrier to effective care provision. The treatment gap between physical and mental healthcare is well established and there have been calls for integrated care within the NHS (Mitchell et al., 2017; Naylor, 2016). Emerging evidence suggests that integrated multidisciplinary treatment is effective in improving quality of life and functioning in adults with FMDs (Palmer et al., 2023). Thus, the clinical implications of this study include a need to develop specialist services with multidisciplinary input, to streamline service access for families and provide targeted, effective support more readily.

The current study presents journeys of families impacted by FTs, from a place of fear and uncertainty to adjustment and acceptance. Psychological support appeared to be paramount to this process, in supporting an understanding of FTs, its relationship to anxiety and other co-occurring needs (subtheme 3.1). Support also offered an understanding of triggers for FTs and support strategies. Interventions were offered both to improve psychological wellbeing and management of tics and varied in focus and modality. Extant literature suggests psychological support for youth with tic disorders promotes acceptance and a sense of control, including the ability to manage tics (Smith et al., 2016). The current study also suggests that psychological intervention supported adjustment to the FTs diagnosis, including acceptance of lifestyle changes, changes to identity and appreciation of positive change (Theme 4). Young people also benefitted from alternative forms of support, such as reiki and anxiety medication.

Families discussed the importance of social support and representation of FTs to promote connectedness and belonging, factors which are protective of psychological wellbeing (subtheme 3.3; Haim-Litevsky et al., 2023). Families noted the predominance of TS in public understanding of tics as well as support available, including peer support. The TS community was described as a place of belonging for some, but for others perpetuated feelings of isolation and difference as they did not identify as part of the community (subtheme 4.2). The negative consequences of not belonging within existing groups has been explored in bisexual youth, who report not feeling accepted within homosexual and heterosexual communities and have reduced access to positive representation which impacts wellbeing (Dunlop et al., 2022). Families expressed a belief that youth presenting with sudden-onset tics were being misdiagnosed with TS, which has been indicated elsewhere (Zea Vera et al., 2022). Misdiagnosis not only reflects and limits professional exposure and knowledge of FTs, but compounds feelings of isolation for individuals with FTs. Improving awareness of FTs and reducing rates of misdiagnosis was considered important in improving positive representation of FTs, reducing stigma and improving the quality of life for people impacted by FTs. An important implication of this study is a need to increase professional awareness of FTs to provide timely, valid and effective assessment and post-diagnostic support.

Families felt an increased awareness of FTs should comprise wider-level system change, promoting an environment which is adaptive and inclusive of youth with FTs (subtheme 3.2). Adolescents stressed the importance of online representation as part of this (subtheme 3.3). The use of public awareness campaigns and psychoeducation to target stigma has had mixed results both for mental health and TS, whereby psychoeducation can improve knowledge and positive attitudes in healthcare and education settings though may have less impact when targeting public education levels (Nussey et al., 2014; Stuart, 2016; Waqas et al., 2020; Carrara et al., 2021). Similarly, concerns have been raised that representation of FTs

online could increase misperceptions (Nilles et al., 2022; Conte et al., 2020). Further research is required to understand the complex relationship between exposure and psychoeducation with stigma and behaviour change in FTs.

Limitations

Sampling and recruitment procedures may have biased study findings. Participants were required to initiate interest in the study; thus, it is possible that families with more challenging healthcare experiences related to FTs were motivated to participate. Efforts were made during the interview process to allow for both positive and negative experiences of FTs to be explored, however findings may not fully represent the spectrum of experiences in healthcare experiences for FTs. Similar findings were found in a recent study (Ludlow et al., 2024), which suggests difficulties establishing support for FTs is a pervasive issue that can affect some individuals more extensively than others.

This study explored experiences of functional tics from the perspectives of parents and adolescents which allowed for potential differences in their experiences to be shared. However, it was decided to combine data from parents and adolescents in one qualitative analysis as similar themes were found across the entire sample. It is important to acknowledge that analysis and subsequent themes would have likely varied if only adolescents or parents were interviewed or if the samples were analysed separately. Studies focusing solely on adolescent experiences of functional tics may give a stronger emphasis to their unique experience.

The current study underrepresents experiences of FTs in gender and ethnic minority groups. All adolescent participants identified as White British and female. Though emerging evidence suggests a predominance of FTs in White British adolescents (94% female and 79%

White; Buts et al., 2022) an absence of diversity in this sample is somewhat surprising. Research suggests high rates of functional disorders are found among gender diverse people, with recent prospective studies suggesting 25% to 45% of youth and adults with FTs identify as transgender or non-binary (Lerario et al., 2023; Nilles et al., 2024; Tomczak et al., 2024). As minority groups experience higher rates of healthcare discrimination and disparities in the UK, this could serve as a barrier to study participation as well as help-seeking for FTs (Ayhan et al., 2020; Bentley, 2020). Further research examining the role of minority identities on experiences of FTs would be of benefit for improving clinical services.

The researcher's positioning likely influenced the current study throughout the research process. As a young White British, able-bodied female healthcare professional this may have impacted how participants responded to the researcher during interviews and influenced conversations that felt possible as a result. Use of reflexivity and credibility checks with clinicians with significant clinical experience in relevant areas supported reflection on the interview process and improved the trustworthiness of findings.

Conclusion

The current study explores adolescent and their parents' experiences of a FTs diagnosis and post-diagnostic support. Findings indicate a need for specialist services for FTs which integrate both psychological and neurological aspects of the condition, as well as co-occurring needs. Clear clinical pathways to assessment and intervention for FTs are required to improve the accessibility of care for affected families. Further research is necessary to develop an understanding of psychological pathways to developing FTs and effectiveness of interventions to reduce tic severity and psychological distress. Quantitative and mixed methods methodology could offer additional insights into the needs of this population.

References

Andrén, P., Jakubovski, E., Murphy, T. L., Woitecki, K., Tarnok, Z., Zimmerman-Brenner, S., van de Griendt, J., Debes, N. M., Viefhaus, P., Robinson, S., Roessner, V., Ganos, C., Szejko, N., Müller-Vahl, K. R., Cath, D., Hartmann, A., & Verellen, C. (2022). European clinical guidelines for Tourette syndrome and other tic disorders—version 2.0. Part II: Psychological interventions. *European Child & Adolescent Psychiatry*, *31*(3), 403–423. https://doi.org/10.1007/s00787-021-01845-z

Ayhan, C. H. B., Bilgin, H., Uluman, O. T., Sukut, O., Yilmaz, S., & Buzlu, S. (2020). A systematic review of the discrimination against sexual and gender minority in health care settings. *International Journal of Health Services*, *50*(1), 44-61. https://doi.org/10.1177/0020731419885093

Baizabal-Carvallo, J. F., & Jankovic, J. (2014). The clinical features of psychogenic movement disorders resembling tics. *Journal of Neurology, Neurosurgery & Psychiatry*, *85*(5), 573-575. https://doi.org/10.1136/jnnp-2013-305594

Barnett, C., Davis, R., Mitchell, C., & Tyson, S. (2022). The vicious cycle of functional neurological disorders: A synthesis of healthcare professionals' views on working with patients with functional neurological disorder. *Disability and Rehabilitation*, *44*(10), 1802–1811. https://doi.org/10.1080/09638288.2020.1822935

Bentley, G. R. (2020). Don't blame the BAME: Ethnic and structural inequalities in susceptibilities to COVID-19. *American Journal of Human Biology*, *32*(5), e23478. https://doi.org/10.1002/ajhb.23478

Berg, L., Pringsheim, T. M., & Martino, D. (2022). Sudden onset tic and tic-like presentations in older adolescents and adults. *Current Developmental Disorders Reports*, *9*(4), 146–155. https://doi.org/10.1007/s40474-022-00263-3

Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research*, *42*(4), 1758-1772. https://doi.org/10.1111/j.1475-6773.2006.00684.x

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2012). *Thematic analysis*. American Psychological Association.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597. https://doi.org/10.1080/2159676X.2019.1628806

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, *32*(7), 513. https://psycnet.apa.org/doi/10.1037/0003-066X.32.7.513

Buts, S., Duncan, M., Owen, T., Martino, D., Pringsheim, T., Byrne, S., McWilliams, A., Murphy, T., Malik, O., Liang, H., Heyman, I., & Hedderly, T. (2022). Paediatric tic-like presentations during the COVID-19 pandemic. *Archives of Disease in Childhood*, *107*(3), e17-e17. https://doi.org/10.1136/archdischild-2021-323002

Carrara, B. S., Fernandes, R. H. H., Bobbili, S. J., & Ventura, C. A. A. (2021). Health care providers and people with mental illness: An integrative review on anti-stigma

interventions. *International Journal of Social Psychiatry*, *67*(7), 840-853. https://doi.org/10.1177/0020764020985891

Conte, G., Baglioni, V., Valente, F., Chiarotti, F., & Cardona, F. (2020). Adverse mental health impact of the COVID-19 lockdown in individuals with Tourette syndrome in Italy: An online survey. *Frontiers in Psychiatry*, *11*, 583744. https://doi.org/10.3389/fpsyt.2020.583744

Cutler, D., Murphy, T., Gilmour, J., & Heyman, I. (2009). The quality of life of young people with Tourette syndrome. *Child: Care, Health and Development*, *35*(4), 496-504. https://doi.org/10.1111/j.1365-2214.2009.00983.x

Demartini, B., Ricciardi, L., Parees, I., Ganos, C., Bhatia, K. P., & Edwards, M. J. (2015). A positive diagnosis of functional (psychogenic) tics. *European Journal of Neurology*, *22*(3), 527-e36. https://doi.org/10.1111/ene.12609

Duncan, M., Pearman, Z., Harrold, K., Warren, A., Evans, S., McAllister, E., Heyman, I., Shavel-Jessop, S., Murphy, T., & Liang, H. (2024). Evaluation of a psychoeducation group for children presenting with functional tic-like behaviours. *Clinical Child Psychology and Psychiatry*, OnlineFirst publication, 13591045241237829–13591045241237829. https://doi.org/10.1177/13591045241237829

Dunlop, B. J., Hunter, C., Shafti, M., Coleman, S. E., Hartley, S., & Taylor, P. J. (2022). 'Why is it so different now I'm bisexual?': Young bisexual people's experiences of identity, belonging, self-injury, and COVID19. *Psychology & Sexuality*, 13(3), 756–773. https://doi.org/10.1080/19419899.2021.1924241

Espay, A. J., Aybek, S., Carson, A., Edwards, M. J., Goldstein, L. H., Hallett, M., LaFaver, K., LaFrance, W. C., Lang, A. E., Nicholson, T., Nielsen, G., Reuber, M., Voon, V.,

Stone, J., & Morgante, F. (2018). Current concepts in diagnosis and treatment of functional neurological disorders. *JAMA Neurology*, *75*(9), 1132–1141. https://doi.org/10.1001/jamaneurol.2018.1264

Foley, C., Kirkby, A., & Eccles, F. J. (2024). A meta-ethnographic synthesis of the experiences of stigma amongst people with functional neurological disorder. *Disability and Rehabilitation*, *46*(1), 1-12. https://doi.org/10.1080/09638288.2022.2155714

Frey, J., Black, K. J., & Malaty, I. A. (2022). TikTok Tourette's: Are we witnessing a rise in functional tic-like behaviour driven by adolescent social media use?. *Psychology Research and Behaviour Management*, *15*, 3575-3585. https://doi.org/10.2147/PRBM.S359977

Fung, W. K., Sa'di, Q., Katzberg, H., Chen, R., Lang, A. E., Cheung, A. M., & Fasano, A. (2023). Functional disorders as a common motor manifestation of COVID-19 infection or vaccination. *European Journal of Neurology*, *30*(3), 678-691. https://doi.org/10.1111/ene.15630

Ganos, C., Martino, D., Espay, A. J., Lang, A. E., Bhatia, K. P., & Edwards, M. J. (2019). Tics and functional tic-like movements: Can we tell them apart?. *Neurology*, *93*(17), 750-758. https://doi.org/10.1212/WNL.0000000000008372

Haim-Litevsky, D., Komemi, R., & Lipskaya-Velikovsky, L. (2023). Sense of belonging, meaningful daily life participation, and well-being: Integrated investigation. *International Journal of Environmental Research and Public Health*, *20*(5), 4121. https://doi.org/10.3390/ijerph20054121

Hale, Z. J. (2024). Diagnostic overshadowing of mental health conditions in UK health care. *Mental Health and Social Inclusion*. Advance online publication. https://doi.org/10.1108/MHSI-04-2024-0060

Han, V. X., Kozlowska, K., Kothur, K., Lorentzos, M., Wong, W. K., Mohammad, S. S., Savage, B., Chudleigh, C., & Dale, R. C. (2022). Rapid onset functional tic-like behaviours in children and adolescents during COVID-19: Clinical features, assessment and biopsychosocial treatment approach. *Journal of Paediatrics and Child Health*, *58*(7), 1181–1187. https://doi.org/10.1111/jpc.15932

Hardwick, P. J. (1991). Families and the professional network: An attempted classification of professional network actions which can hinder change. *Journal of Family Therapy*, *13*(2), 187-205. https://doi.org/10.1046/j..1991.00421.x

Hedderly, T., Heyman, I., Ganos, C., Demartini, B., Baizabal-Carvallo, J. F., Edwards, M. J., Joyce, E., & Stone, J. (2022). *Functional tics*. FND Guide. https://neurosymptoms.org/en/symptoms/fnd-symptoms/functional-tics/

Heyman, I., Liang, H., & Hedderly, T. (2021). COVID-19 related increase in childhood tics and tic-like attacks. *Archives of Disease in Childhood*, *106*(5), 420-421. https://doi.org/10.1136/archdischild-2021-321748

Howlett, M., Martino, D., Nilles, C., & Pringsheim, T. (2022). Prognosis of rapid onset functional tic-like behaviours: Prospective follow-up over 6 months. *Brain and Behaviour*, *12*(6), e2606. https://doi.org/10.1002/brb3.2606

Hulgaard, D. R., Rask, C. U., Risør, M. B., & Dehlholm, G. (2020). 'I can hardly breathe': Exploring the parental experience of having a child with a functional

disorder. *Journal of Child Health Care*, *24*(2), 165-179. https://doi.org/10.1177/1367493519864745

Hull, M., Parnes, M., & Jankovic, J. (2021). Increased incidence of functional (psychogenic) movement disorders in children and adults amid the COVID-19 pandemic: A cross-sectional study. *Neurology: Clinical Practice*, *11*(5), e686-e690. https://doi.org/10.1212/CPJ.0000000000001082

Kaushik, A., Kostaki, E., & Kyriakopoulos, M. (2016). The stigma of mental illness in children and adolescents: A systematic review. *Psychiatry Research*, *243*, 469-494. https://doi.org/10.1016/j.psychres.2016.04.042

Kozlowska, K. (2017). A stress-system model for functional neurological symptoms. *Journal of the Neurological Sciences*, *383*, 151-152. https://doi.org/10.1016/j.jns.2017.10.044

Kozlowska, K., Sawchuk, T., Waugh, J. L., Helgeland, H., Baker, J., Scher, S., & Fobian, A. D. (2021). Changing the culture of care for children and adolescents with functional neurological disorder. *Epilepsy & Behaviour Reports*, *16*, 100486. https://doi.org/10.1016/j.ebr.2021.100486

Lerario, M. P., Fusunyan, M., Stave, C. D., Roldán, V., Keuroghlian, A. S., Turban, J., Perez, D. L., Maschi, T., & Rosendale, N. (2023). Functional neurological disorder and functional somatic syndromes among sexual and gender minority people: A scoping review. *Journal of Psychosomatic Research*, *174*, 111491. https://doi.org/10.1016/j.jpsychores.2023.111491

Ludlow, A. K., Anderson, S., Robinson, S., Owen, T., & Hedderly, T. (2024). An investigation into mothers' experiences of their children's functional tic-like behaviour and tic attacks. *Plos One*, *19*(1), e0292742. https://doi.org/10.1371/journal.pone.0292742

Malaty, I. A., Anderson, S., Bennett, S. M., Budman, C. L., Coffey, B. J., Coffman, K. A., Greenberg, E., McGuire, J. F., Black, K. J., Müller-Vahl, K. R., Okun, M. S., Quezada, J., Robichaux-Viehoever, A., & Black., K. J. (2022). Diagnosis and management of functional tic-like phenomena. *Journal of Clinical Medicine*, *11*(21), 6470. https://doi.org/10.3390/jcm11216470

Malli, M. A., & Forrester-Jones, R. (2022). Stigma and adults with Tourette's syndrome: "Never laugh at other people's disabilities, unless they have Tourette's—Because how can you not?". *Journal of Developmental and Physical Disabilities*, *34*(5), 871-897. https://doi.org/10.1007/s10882-021-09829-2

Martino, D., Hedderly, T., Murphy, T., Müller-Vahl, K. R., Dale, R. C., Gilbert, D. L., Rizzo, R., Hartmann, A., Nagy, P., Anheim, M., Owen, T., Malik, O., Duncan, M., Heyman, I., Liang, H., McWilliams, A., O'Dwyer, S., Fremer, C., Szejko, N., … Pringsheim, T. M. (2023). The spectrum of functional tic-like behaviours: Data from an international registry. *European Journal of Neurology*, *30*(2), 334-343. https://doi.org/10.1111/ene.15611

Mathew, A., Abu Libdeh, A., Patrie, J., & Garris, J. (2023). Outcome in paediatric functional tic disorders diagnosed during the COVID-19 pandemic. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *35*(4), 393-397. https://doi.org/10.1176/appi.neuropsych.20220186

Maxwell, A., Zouki, J. J., & Eapen, V. (2023). Integrated cognitive behavioural intervention for functional tics (I-CBiT): Case reports and treatment formulation. *Frontiers in Paediatrics*, *11*, 01-09. https://doi.org/10.3389/fped.2023.1265123

McDougall, T., Worrall-Davies, A., Hewson, L., Richardson, G., & Cotgrove, A. (2008). Tier 4 child and adolescent mental health services (CAMHS) - inpatient care, day services and alternatives: An overview of tier 4 CAMHS provision in the UK. *Child and Adolescent Mental Health*, *13*(4), 173–180. https://doi.org/10.1111/j.1475-3588.2007.00481.x

McGuire, J. F., Bennett, S. M., Conelea, C. A., Himle, M. B., Anderson, S., Ricketts, E. J., Capriotti, M. R., Lewin, A. B., McNulty, D. C., Thompson, L. G., Espil, F. M., Nadeau, S. E., McConnell, M., Woods, D. W., Walkup, J. T., & Piacentini, J. (2021). Distinguishing and managing acute-onset complex tic-like behaviours in adolescence. *Journal of the American Academy of Child and Adolescent Psychiatry*, *60*(12), 1445. https://doi.org/10.1016%2Fj.jaac.2021.07.823

McWilliams, A., Reilly, C., McFarlane, F. A., Booker, E., & Heyman, I. (2016). Nonepileptic seizures in the paediatric population: A qualitative study of patient and family experiences. *Epilepsy & Behaviour*, *59*, 128-136. https://doi.org/10.1016/j.yebeh.2016.03.029

Mitchell, A. J., Hardy, S., & Shiers, D. (2017). Parity of esteem: Addressing the inequalities between mental and physical healthcare. *BJPsych Advances*, *23*(3), 196–205. https://doi.org/10.1192/apt.bp.114.014266

Müller-Vahl, K. R., Pisarenko, A., Jakubovski, E., & Fremer, C. (2022). Stop that! It's not Tourette's but a new type of mass sociogenic illness. *Brain*, *145*(2), 476-480. https://doi.org/10.1093/brain/awab316

Naylor, C., Das, P., Ross, S., Honeyman, M., Thompson, J., & Gilburt, H. (2016). Bringing together physical and mental health. *King's Fund*, *109*(10), 364-366. bringing-together-kings-fund-march-2016_11.pdf (onewestminster.org.uk)

Newlove-Delgado, T., McManus, S., Sadler, K., Thandi, S., Vizard, T., Cartwright, C., & Ford, T. (2021). Child mental health in England before and during the COVID-19 lockdown. *The Lancet Psychiatry*, *8*(5), 353-354. https://doi.org/10.1016/S2215-0366(20)30570-8

Nielsen, G., Buszewicz, M., Edwards, M. J., & Stevenson, F. (2020). A qualitative study of the experiences and perceptions of patients with functional motor disorder. *Disability and Rehabilitation*, *42*(14), 2043-2048. https://doi.org/10.1080/09638288.2018.1550685

Nilles, C., Pringsheim, T. M., & Martino, D. (2022). The recent surge of functional movement disorders: Social distress or greater awareness?. *Current Opinion in Neurology*, *35*(4), 485-493. https://doi.org/10.1097/WCO.0000000000001074

Nilles, C., Szejko, N., Martino, D., & Pringsheim, T. (2024). Prospective follow-up study of youth and adults with onset of functional tic-like behaviours during the COVID-19 pandemic. *European Journal of Neurology*, *31*(1), e16051. https://doi-org.libproxy.ucl.ac.uk/10.1111/ene.16051

Nussey, C., Pistrang, N., & Murphy, T. (2014). Does it help to talk about tics? An evaluation of a classroom presentation about Tourette syndrome. *Child and Adolescent Mental Health*, *19*(1), 31-38. https://doi.org/10.1111/camh.12000

Olvera, C., Stebbins, G. T., Goetz, C. G., & Kompoliti, K. (2021). TikTok tics: A pandemic within a pandemic. *Movement Disorders Clinical Practice*, *8*(8), 1200-1205. https://doi.org/10.1002/mdc3.13316

Palmer, D. D., Gamble, M., Higgins, M., Maley, J., & Watson, E. (2023). Outcomes of an integrated multidisciplinary clinic for people with functional neurological disorder. *Movement Disorders Clinical Practice*, *10*(6), 967-973. https://doi.org/10.1002/mdc3.13757

Pick, S., Goldstein, L. H., Perez, D. L., & Nicholson, T. R. (2019). Emotional processing in functional neurological disorder: A review, biopsychosocial model and research agenda. *Journal of Neurology, Neurosurgery and Psychiatry*, *90*(6), 704–711. https://doi.org/10.1136/jnnp-2018-319201

Prato, A., Saia, F., Milana, M. C., Scerbo, M., Barone, R., & Rizzo, R. (2023). Functional tic-like behaviours during the COVID-19 pandemic: Follow-up over 12 months. *Frontiers in Paediatrics*, *10*, 1003825. https://doi.org/10.3389/fped.2022.1003825

Price-Robertson, R., Obradovic, A., & Morgan, B. (2016). Relational recovery: Beyond individualism in the recovery approach. *Advances in Mental Health*, *15*(2), 108-120. https://doi.org/10.1080/18387357.2016.1243014

Pring, K., Malli, M., Hardy, B. W., Rapp, S. R., Storch, E. A., Mink, J. W., & Martindale, J. M. (2023). Reframing stigma in Tourette syndrome: An updated scoping review. *European Child & Adolescent Psychiatry*, 1-21. https://doi.org/10.1007/s00787-023-02332-3

Pringsheim, T., Ganos, C., McGuire, J. F., Hedderly, T., Woods, D., Gilbert, D. L., Piacentini, J., Dale, R. C., & Martino, D. (2021). Rapid onset functional tic-like behaviours in young females during the COVID-19 pandemic. *Movement Disorders*, *36*(12), 2707. https://doi.org/10.1002%2Fmds.28778

Pringsheim, T., Ganos, C., Nilles, C., Cavanna, A. E., Gilbert, D. L., Greenberg, E., Hartmann, A., Hedderly, T., Heyman, I., Liang, H., Malaty, I., Malik, O., Debes, N. M., Vahl, K. M., Munchau, A., Murphy, T., Nagy, P., Owen, T., Rizzo, R., … Martino, D. (2023). European Society for the Study of Tourette Syndrome 2022 criteria for clinical diagnosis of functional tic-like behaviours: International consensus from experts in tic disorders. *European Journal of Neurology*, *30*(4), 902–910. https://doi.org/10.1111/ene.15672

Robertson, M. M., Eapen, V., Rizzo, R., Stern, J. S., & Hartmann, A. (2020). Gilles de la Tourette syndrome: Advice in the times of COVID-19. *F1000 Research*, *9*, 257. https://doi.org/10.12688%2Ff1000research.23275.2

Robinson, S., & Hedderly, T. (2016). Novel psychological formulation and treatment of "tic attacks" in Tourette syndrome. *Frontiers in Paediatrics*, *4*, 46. https://doi.org/10.3389/fped.2016.00046

Smith, J. A., Flowers, P., & Larkin, M. (2022). *Interpretative phenomenological analysis: theory, method and research.* (2nd ed.). SAGE.

Smith, H., Fox, J. R., & Trayner, P. (2015). The lived experiences of individuals with Tourette syndrome or tic disorders: A meta-synthesis of qualitative studies. *British Journal of Psychology*, *106*(4), 609-634. https://doi.org/10.1111/bjop.12118

Smith, H., Fox, J. R., Hedderly, T., Murphy, T., & Trayner, P. (2016). Investigating young people's experiences of successful or helpful psychological interventions for tic disorders: An interpretative phenomenological analysis study. *Journal of Health Psychology*, *21*(8), 1787-1798. https://doi.org/10.1177/1359105314566647

Stuart, H. (2016). Reducing the stigma of mental illness. *Global Mental Health*, *3*, e17. https://doi.org/10.1017/gmh.2016.11

Tomczak, K. K., Worhach, J., Rich, M., Swearingen Ludolph, O., Eppling, S., Sideridis, G., & Katz, T. C. (2024). Time is ticking for TikTok tics: A retrospective follow-up study in the post-COVID-19 isolation era. *Brain and Behaviour*, *14*(3), e3451. https://doi.org/10.1002/brb3.3451

Vassilopoulos, A., Mohammad, S., Dure, L., Kozlowska, K., & Fobian, A. D. (2022). Treatment approaches for functional neurological disorders in children. *Current Treatment Options in Neurology*, *24*(2), 77-97. https://doi.org/10.1007/s11940-022-00708-5

Waqas, A., Malik, S., Fida, A., Abbas, N., Mian, N., Miryala, S., Amray, A. N., Shah, Z., & Naveed, S. (2020). Interventions to reduce stigma related to mental illnesses in educational institutes: A systematic review. *Psychiatric Quarterly*, *91*(3), 887-903. https://doi.org/10.1007/s11126-020-09751-4

Wyder, M., & Bland, R. (2014). The recovery framework as a way of understanding families' responses to mental illness: Balancing different needs and recovery journeys. *Australian Social Work*, *67*(2), 179-196. https://doi.org/10.1080/0312407X.2013.875580

Zea Vera, A., Bruce, A., Garris, J., Tochen, L., Bhatia, P., Lehman, R. K., Lopez, W., Wu, S. W., & Gilbert, D. L. (2022). The phenomenology of tics and tic-like behaviour in TikTok. *Paediatric Neurology*, *130*, 14–20. https://doi.org/10.1016/j.pediatrneurol.2022.02.003

Part 3: Critical Appraisal

Critical Appraisal

This critical appraisal concerns my experiences in deciding this topic of research and issues which arose during the process, including personal assumptions and how challenges were managed. The appraisal covers my personal background and experiences, including how I consider these to have shaped my assumptions and beliefs about functional tics (FTs). I will discuss my reflections on the process of producing this research, including challenges and how these were addressed, alongside a consideration of future steps.

How personal and professional experiences have shaped my assumptions

Thematic Analysis is not deemed a passive process; indeed, Braun and Clarke (2012) emphasise the role of the researcher's personal and theoretical assumptions in qualitative research, which interact with data to create meaning through the construction of themes. My personal and professional experiences will have undoubtedly influenced my perceptions, beliefs, interactions, and responses throughout the research process. This in turn, will have shaped the topic chosen, research design, the process of recruitment, the interview process, and the sense I made of the data during analysis. Though procedures were put in place to alleviate the effects of researcher bias, the assumptions held by the researcher cannot be fully eliminated. The consequences and potential benefits of researcher subjectivity will be discussed throughout this paper.

To set the context for my reflections, it is important to name my own identities and experiences. I am a White, middle-class female in my late 20s. I am able-bodied and do not have children. I am a trainee clinical psychologist with experience of working with neurodiverse individuals and people with various health and neurological conditions. I started

my psychology career in learning disability and autism services and have since gone on to work with adults with brain injuries, young people with brain tumours and other health conditions, alongside youth with autism and ADHD. Through my professional career I have developed an understanding of neuropsychological and psychological theories that may underpin neurodevelopmental and psychological needs, as well as psychological models of adjustment and help seeking behaviour. In addition, previous research I have conducted has focused on the interaction between physical and mental health via the gut-brain axis (Johnstone et al., 2021). This interest in exploring mind-body links has been furthered through working in paediatric settings with young people with a physical health condition.

I believe my clinical experience of working with individuals in various National Health Service (NHS) settings has had most impact. As a trainee clinical psychologist, I have witnessed the many discriminations and stigmas faced by individuals with physical or psychological health needs. This is paralleled by personal experience of having had a close relative experience stigma related to a neurodegenerative condition and the impact this can have on wider systems, such as the family. In clinical practice my theoretical orientation centres systemic and narrative models, viewing 'problems' as co-constructed through interactions between individuals, rather than being internal to one person (Dallos & Draper, 2015). Systemic models also place focus on the existence of multiple perspectives, relationships, relationships to help, intersecting identities and power (Dallos & Draper, 2015; Reder & Fredman, 1996; Burnham, 2012). Narrative therapy supports individuals and groups to tell preferred stories about their life in ways that make them stronger (Portnoy, Girling & Fredman, 2016). I believe that this has shaped my interest in the family system and how they navigate challenges together. In turn, through the research process I hoped to allow space for discourse to emerge around resilience and coping during experiences with FTs. From my position as a psychologist, I have an innate interest in how psychological interventions can be of value to

people. Taken together, my personal and professional experiences likely shaped the decision not only to decide this project for my thesis but have also resulted in my analysis of data through the social ecological model (Bronfenbrenner, 1977).

Prior to conducting this research, I had not had personal or professional experiences of tic disorders (TDs). On reflection, a lot of my pre-existing beliefs and assumptions about TDs had origins in media representations of Tourette syndrome (TS). For example, I held an assumption that most people with TS present with coprolalia when research suggests coprolalia is prevalent in only 20-30% of TS cases (see Robert et al., 2024). Entering this research topic, I felt apprehensive about my lack of knowledge on TDs. I believe that this resulted in some uncertainty on how to approach clinical interviews with youth with TDs, and perhaps a personal discomfort with 'not knowing'. On reflection however, I believe a position of 'not knowing' benefitted my approach as a researcher as I was more curious about participant experiences. I believe this facilitated a 'bottom up', inductive approach, which was less guided by a clinical and academic knowledge of TDs.

Working with assumptions – the role of reflexivity

Throughout the research journey, reflexivity was paramount to support my ability to reflect on how my personal contexts and subsequent beliefs and assumptions were shaping the research process. This allowed me to explore alternative perspectives and hold my beliefs tentatively, rather than becoming wedded to my initial approach and interpretations. I kept a reflective journal throughout the process to engage with my personal values and consider how they were influencing the research process and decisions made. Examples of how reflexivity contributed to the research process will be discussed in greater depth in the following section of the appraisal.

Reflexivity and credibility of the research were greatly bolstered by being part of a research team who had significant clinical and academic experience of TDs and qualitative research. This ensured that the research was clinically and academically relevant, as informed by academic knowledge of TDs and FTs, and that findings were in line with experiences shared by families in clinical settings. Team experience in conducting qualitative research also supported me in my learning of Thematic Analysis as I had not completed a qualitative study prior to this thesis. For instance, meeting with the research team to examine transcripts supported me in developing my interview technique alongside my coding and analysis skills. This also offered ample opportunity for credibility and bias checks, through comparing how my perspective and approach may differ from others in the team. On reflection, regular discussion with the research team about developing themes was crucial in supporting me to take different perspectives, to not become committed to themes and thus being prepared to discard potential themes (Braun & Clarke, 2013). For instance, this process supported me to notice when there were overlaps across themes which resulted in changes in structure so that themes were more distinct.

Reflections on the research process

Study design and public and patient involvement (PPI)

The current study was born out of practice-based evidence in a paediatric hospital that noted a sudden rise in FT presentations. I did not develop the idea for the study; however, the project underwent substantial developments in design prior to seeking ethical approval.

The design of the interview schedule was initially developed based on a pre-existing interview schedule for paediatric non-epileptic seizures (McWilliams et al., 2016) which was

subsequently developed through PPI. Members of the research team invited attendees of a FT psychoeducation group in a paediatric hospital to review the study's information sheets and consent forms. Two families offered their perspectives on these documents and highlighted important ways that they could be improved. For example, they advised that some of the wording in the information sheets for young people be simplified (such as not using the word 'pseudonymised') and shortening of the document. With regards to the interview schedules, focus was placed on making the questions more specific to support engagement of autistic young people. For instance, one family noted that many adolescents receive other diagnoses before the FTs diagnosis and therefore they suggested referring to the 'FT diagnosis' rather than 'diagnosis' more broadly in interview questions. Families noted that there are multiple stages leading up to the diagnosis, and therefore the interview schedule was amended to reflect a journey to receiving the FTs diagnosis. Families also suggested asking participants explicitly about their mental health, their experiences of waiting lists and of support strategies for FTs. They noted multiple forms of support for FTs such as medication which led to the interview schedule including questions about other forms of support. An example of how interview schedules were amended based on PPI feedback can be found in Appendix J.

Consultation from families supported tailoring the study to increase relevance to affected families whilst also improving study accessibility through changes in language. On reflection, PPI involvement could have been extended further so that the study was co-produced with families affected by FTs. For instance, families could have been involved in the development of the study research questions and the design, actively contributing to ideas rather than being consulted once the study was in a draft design stage. This could be ambitious however within the constraints of a DClinPsy.

Recruitment

A key change in study design prior to ethical approval was the decision to recruit participants through Tourette's Action, a UK-based charity for TS rather than through a paediatric hospital which would require NHS ethics. It is important to consider the implications of this decision. The decision to recruit through Tourette's Action facilitated a faster ethical approval process which allowed more time for recruitment. Though recruitment through an NHS site may have been faster, it is argued that recruiting nationally through Tourette's Action allowed for diversity in healthcare experiences to be shared, rather than perspectives of a diagnosis through one NHS paediatric hospital. This gave insight into how understandings of FTs can vary across services, resulting in diverse outcomes for families. In turn, this improves generalisability of the findings.

Recruiting through an advertisement on a charity website compared to contacting NHS patients from a paediatric hospital will likely have resulted in different participant samples. Families who participated in this study needed to be aware of Tourette's Action, respond to the advertisement and be motivated to participate. Negrin et al. (2022) note a lack of literature on why individuals may volunteer for research, though participants in the current study highlighted a wish to contribute to information available on FTs. This form of recruitment will likely have been a barrier to participation for families with fewer resources, time constraints or connections to TD charities. The study sample demographics were homogeneous with regards to gender and ethnicity, meaning that the voices of individuals with gender and ethnic minority identities were not heard. Perhaps recruitment through NHS services would have increased the likelihood of participation from minority groups, as families would have been directly contacted about the study and would have already received support from a paediatric hospital.

However, this is with the assumption that families with marginalised identities access NHS support for a FTs diagnosis.

Evidence suggests that individuals from minority ethnic groups are less likely to participate in medical research compared to White British individuals (Smart & Harrison, 2015) The absence of representation of gender and racially diverse people in the study sample may be a result of social inequality resulting in fewer resources and lack of awareness of research, inequality of service access to receive a diagnosis, poor experiences of help seeking from professionals resulting in mistrust as well as fears of being identified through research (Hussain-Gambles et al., 2004; Owen-Smith et al., 2016). It is therefore unknown how youth from ethnic minority backgrounds and/or who identify as transgender may experience seeking a FT diagnosis. Inequalities in service access have been demonstrated in other paediatric conditions. For example, the autism literature suggests that families from racially diverse groups and families from low-income households are diagnosed with autism later than White children and children of higher socioeconomic status (see Stahmer et al., 2019). Participants in the current study noted a need to be proactive in navigating services to access support and the benefit of being able to pay for private support. This highlights the potential role of social determinants in experiences of a FTs diagnosis, which require further study.

Anxiety also appeared to be a barrier to study participation for young people. For instance, one potential participant provided consent for the study but then ceased contact when informed that the interview would take place via video and could not be completed via email. Experiences shared through the current study may not reflect the extent of impairment experienced by young people who experience greater levels of anxiety, which likely has a significant impact on their activities of daily living. Providing alternative means to participate, for example through writing, will have likely made the study more accessible to youth

experiencing anxiety. Likewise, exclusion criteria meant that individuals currently experiencing suicidal ideation or engaging in deliberate self-harm could not participate in the study due to ethical issues concerning increasing risk through study participation. Different experiences of FTs and healthcare experiences may have been shared had this exclusion criteria had not been implemented.

Interviews

Interactions with participants during interviews will have been shaped by how participants and I perceived one another, including perceived similarities and differences in identities. This will likely have influenced what participants felt it was possible to discuss during the interview and will have shaped my approach to the interview. For instance, participants were aware that I was a trainee clinical psychologist completing research as part of my doctorate in clinical psychology. As a result, they may have felt that it was important or relevant to discuss experiences with psychological services and psychological support, rather than alternate forms of support. I considered this in my reflective log and as a result decided to ask families explicitly about other forms of support that they had experienced. This led to conversations around alternative therapies such as reiki as well as hobbies and groups such as horse riding. During the interview process I was also completing my scoping review examining stigma in TS across cultures and I reflected on how this was shaping my approach to interviews with participants, whereby I was focused on challenges experienced navigating services for FTs. From such I ensured that I also asked about positive experiences and stories.

I believe that my experience as a psychological practitioner was a positive contribution to the interview process in many ways. For example, I believe that my developed skills in engagement may have resulted in participants feeling more comfortable to discuss difficult

experiences. Simultaneously, my position and experience as a psychologist also posed a challenge in the interview process as I was required to take a researcher stance with participants. Examination of interview transcripts with a member of the research team highlighted that at times I had taken a practitioner's stance. For example, I would begin to start formulating the young person's difficulties through asking about their history, which was not relevant to the research question. This tendency was likely exacerbated by my wish for participants to have a positive experience of sharing their experiences in context of perhaps not feeling heard before. This insight supported me to notice when tendencies to formulate arose during subsequent interviews and to refocus on the research question and the interview schedule.

Reflexivity throughout the interview process supported development of my approach as an interviewer, including development of the interview schedule. This included discussion with the research team to reflect on issues arising during the process and strategies to overcome issues. For instance, in an interview with an adolescent I wondered whether they felt uncomfortable expressing their tics. This led to conversations with the research team about ways that I could introduce and set up the interview to support adolescents in feeling comfortable expressing their tics. I also noticed that for some families, experiences of other co-occurring needs such as non-epileptic seizures were being discussed in the interview, and at times it was difficult to determine whether the families were discussing experiences of FTs or another co-occurring need. As a result, I would ask families to clarify which condition they were referring to. I also asked enquired about participants' perspectives on the relationship between co-occurring conditions and FTs.

Analysis

My perspective, assumptions and theoretical orientations will have impacted how transcripts were coded and the subsequent generation of themes. Analysis was guided by the social ecological model (Bronfenbrenner, 1977), meaning that I was conscious of relationships between people and between individuals and institutions. This model felt beneficial for the topic given that pursuing and receiving a diagnosis does not occur in isolation and enquiring about experiences of services can offer suggestions for service improvement. Had I arrived at the project with a different theoretical model such as cognitive behavioural theories, I might have taken a more individualised approach to analysis, perhaps paying more attention to individuals' thoughts and how these interacted with their feelings and behaviours.

During analysis I initially developed a significant number of codes which perhaps highlighted my desire to encapsulate all the data and anxiety to 'get it right' in the context of reduced familiarity with qualitative methodology. I felt privileged to have witnessed participant experiences of FTs. Given the scarcity of research in this area I felt a significant responsibility to develop an impactful paper with aims to improve awareness and service provision for this population. My biases as a researcher were supported by a member of the research team independently coding a sample of transcripts. The member of the research team had significant experience in working with FTs and TDs. This allowed for cross-examination of biases and blind spots that can lend to differences in coding and whether emerging codes and subsequent themes were relevant to clinical practice. From this experience I learnt that I was perhaps coding in too greater detail. However, codes generated by a member of the research team and I illustrated similar themes.

Themes underwent significant change during the analysis process. Involvement of the research team was invaluable in supporting me to notice overlap between subthemes and to

contextualise developing themes within academic and clinical knowledge of FTs. I found the process of amending themes challenging as I felt emotionally tied to the results, whilst being passionate about including as much data as possible in the write up. From this experience I learnt that a concise synthesis of participant experiences can hold significantly more impact than a long and detailed description.

It is important to acknowledge that the decision to interview both parents and adolescents and combine their data into one qualitative analysis will have influenced the results and study findings. It was decided to recruit both adolescents and parents to allow for possible differences in experiences of functional tics to be shared, which could complement one another and enrich a holistic understanding of the experience of functional tics. For example, parents may have a greater understanding of challenges navigating the healthcare system, and young people may have shared their experiences of navigating school and friendships in the context of functional tics. Similar patterns in the data were noted across adolescent and parent datasets and therefore it was decided to analyse their data in one analysis. This was also felt to improve readability. However, a greater emphasis on the experiences specific to adolescents and/or parents may have resulted from analysing the samples separately.

Conclusion

To conclude, the process of conducting empirical qualitative research was a highly rewarding experience. The process challenged and developed my research skills, from navigating ethical approval applications to the write-up of the findings. Reflexivity and support from the research team was paramount to manage issues related to researcher bias and subjectivity, in turn improving the quality of the research. I feel honoured to have been involved in an important and novel research area and hope that the research can help to raise awareness of FTs, support for affected families as well as instigating further research.

References

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. SAGE Publications.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, *32*(7), 513. https://psycnet.apa.org/doi/10.1037/0003-066X.32.7.513

Burnham, J. (2012). Developments in Social GRRRAAACCEEESSS: Visible–invisible and voiced–unvoiced. In *Culture and Reflexivity in Systemic Psychotherapy* (1st ed., pp. 139–160). Routledge. https://doi.org/10.4324/9780429473463-7

Dallos, R., & Draper, R. (2015). *An introduction to family therapy: Systemic theory and practice* (4th ed.). McGraw-Hill Education. https://ebookcentral.proquest.com/lib/ucl/detail.action?docID=6212224.

Hussain-Gambles, M., Leese, B., Atkin, K., Brown, J., Mason, S., & Tovey, P. (2004). Involving South Asian patients in clinical trials. *Health Technology Assessment*, *8*(42), 1-109. https://doi.org/10.3310/hta8420

Johnstone, N., Milesi, C., Burn, O., van den Bogert, B., Nauta, A., Hart, K., Sowden, P., Burnet, P. W. J., & Cohen Kadosh, K. (2021). Anxiolytic effects of a galacto-oligosaccharides prebiotic in healthy females (18–25 years) with corresponding changes in gut bacterial composition. *Scientific Reports*, *11*(1), 1-11. https://doi.org/10.1038/s41598-021-87865-w

McWilliams, A., Reilly, C., McFarlane, F. A., Booker, E., & Heyman, I. (2016). Nonepileptic seizures in the paediatric population: A qualitative study of patient and family

experiences. *Epilepsy & Behaviour*, *59*, 128-136. https://doi.org/10.1016/j.yebeh.2016.03.029

Negrin, K. A., Slaughter, S. E., Dahlke, S., & Olson, J. (2022). Successful recruitment to qualitative research: A critical reflection. *International Journal of Qualitative Methods*, *21*, 16094069221119576. https://doi.org/10.1177/16094069221119576

Owen-Smith, A. A., Woodyatt, C., Sineath, R. C., Hunkeler, E. M., Barnwell, L. T., Graham, A., Stephenson, R., & Goodman, M. (2016). Perceptions of barriers to and facilitators of participation in health research among transgender people. *Transgender Health*, *1*(1), 187–196. https://doi.org/10.1089/trgh.2016.0023

Portnoy, S., Girling, I., & Fredman, G. (2016). Supporting young people living with cancer to tell their stories in ways that make them stronger: The Beads of Life approach. *Clinical Child Psychology and Psychiatry*, *21*(2), 255-267. http://dx.doi.org/10.1177/1359104515586467

Reder, P., & Fredman, G. (1996). The relationship to help: Interacting beliefs about the treatment process. *Clinical Child Psychology and Psychiatry*, *1*(3), 457–467. https://doi.org/10.1177/1359104596013012

Robert, C., Weiblen, R., Wagner-Altendorf, T. A., Paulus, T., Müller-Vahl, K., Münchau, A., Krämer, U. M., Heldmann, M., Roessner, V., & Münte, T. F. (2024). Slips of the tongue in patients with Gilles de la Tourette syndrome. *Neurological Research and Practice*, *6*(1), 25–25. https://doi.org/10.1186/s42466-024-00324-5

Smart, A., & Harrison, E. (2017). The under-representation of minority ethnic groups in UK medical research. *Ethnicity & Health*, *22*(1), 65-82. https://doi.org/10.1080/13557858.2016.1182126

Stahmer, A. C., Vejnoska, S., Iadarola, S., Straiton, D., Segovia, F. R., Luelmo, P., Morgan, E. H., Lee, H. S., Javed, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., Hassrick, E. M., Smith, T., & Kasari, C. (2019). Parent voices: Cross-cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities*, *6*, 752-773. https://doi.org/10.1007/s40615-019-00575-y

Appendices

Appendix A. Study advert

Version 2; Date: 03.03.23; Ethics no: 24255/001

Experiences of a functional tics diagnosis in adolescents, and their caregivers: A qualitative study

Are you a young person (aged 12-18) with a diagnosis of functional tics?

OR

Are you a parent or carer of a young person (aged 12-18) with a diagnosis of functional tics?

We would like you to share your experiences of a **functional tics diagnosis** and any **support** you might have had.

The interview will last up to 1 hour and will take place on Microsoft Teams.

Young people will be entered into a £30 prize draw for taking part!

For more information, please scan the QR code or visit this link:
https://redcap.idhs.ucl.ac.uk/surveys/?s=F9NJ8MLLTPMLTHKF

Or contact **Olivia Burn:**
O.Burn@ucl.ac.uk

Appendix B. Information sheets

UCL Research Department of Clinical, Educational & Health Psychology
1-19 Torrington Place
University College London

Information Sheet for Young People (12–15-year-olds)

Title of Project:	**Experiences of a functional tics diagnosis in adolescents, and their parents: A qualitative study**
Project ID No:	**24255/001**
Department:	**Clinical, Education and Health Psychology**
Student Researchers:	**Olivia Burn** **Email address: o.burn@ucl.ac.uk** **Corin Whitfield** **Email address: corin.whitfield.21@ucl.ac.uk**
Principal Researcher:	**Dr Alana Loewenberger** **Email address: alana.loewenberger.09@ucl.ac.uk**

We are researchers, clinical psychologists, and trainee clinical psychologists at University College London (UCL). We are inviting you to take part in a research project. This study is being carried out by two trainee clinical psychologists undertaking the Doctorate in Clinical Psychology at UCL

Please read this information sheet if you are interested in taking part. Please take time to read the information carefully and speak to your family about it. Ask us if anything is not clear or you would like more information.

Why are we doing this study?
We want to find out what it is like to have functional tics. Not much is known about how young people and their families experience a functional tics diagnosis, and how they find living with functional tics.

With you and other young people, we would like to understand what it is like to be given a diagnosis of functional tics and any support you might have had after the functional tics diagnosis. We would like to understand how functional tics have impacted you and what might or might not help to support people with functional tics.

We are also asking parents or carers of young people with functional tics to take part. If your parent or carer takes part in the study, they will take part in a separate interview.

Why have I been invited?
You have been invited to take part in this study as you have been given a diagnosis of functional tics.

Do I have to take part?
No. It is completely up to you if you would like to take part. You will be able to ask any questions you may have about the study.

If you would like to take part, we will ask you to sign a consent form. We will also ask your parent or carer to sign a consent form, to say that they are happy for you to take part. You don't have to take part if your parent or carer would like to take part.

If you decide to take part in the study, you are still free to stop taking part within a month of your interview. You don't have to give a reason. You can let us know by asking your parent or carer to contact us. Or you can email us at o.burn@ucl.ac.uk or corin.whitfield.21@ucl.ac.uk.

What will I be asked to do?
You will be asked to complete a consent form, to make sure that you understand what you are being asked to do and are happy to take part.

Your parent or carer will be asked to answer some questions over the phone. You can do this with them if you would like. We will ask about your age, gender, ethnicity, if you live in the UK, mood, date of your functional tics diagnosis, who gave you the diagnosis, any other diagnoses you might have and your GP details. This is to help give some background information about the people who take part in the study. You don't have to give this information if you don't want to.

You will then be asked to take part in a one-to-one interview with one of the doctoral student researchers, to explore your experience of a functional tics diagnosis and any treatment or support you may have received for functional tics. If your parent takes part, they will have a separate interview with one of the student researchers. They will be asked similar questions.

Interviews will last up to 60 minutes and will take place online, via Microsoft Teams. Interviews will be recorded through a password-protected audio device so that they can be typed up afterwards.

You will be entered into a £30 prize draw to thank you for your interest in the study.

What are the good things about taking part in this study?
You will have a chance to talk about your experiences of having a functional tics diagnosis and any support you may have received for functional tics. We hope that this will help us to know more about functional tics and improve the support given to young people with functional tics.

Will taking part in the study be difficult?
Talking about functional tics can be upsetting for some people. The interview might be very upsetting for people already experiencing a lot of distress. We will ask your parent

or carer about your wellbeing over the phone to make sure that you feel well enough to take part in the study.

During your interview, we will ask for an adult to be in the same building as you. This is so they can support you if you become upset. One of the doctoral researchers will also be there to support you. The interview can be paused at any time and can be changed to another time. We will give you and your parent/carer with information about services that can support you if needed. Details of services that can offer support are also found later in this information sheet.

The interview could raise some concerns about your well-being or safety. If so, we would create a plan together to help support you. We will ask for you and your parent/carer's consent to contact your GP if there are any concerns. Only people who live in the UK will be able to take part. This is so we can create a plan if there are concerns about your well-being.

If you become upset after the interview has finished or if you have any concerns, you can talk to your family or contact the research team. You can contact the researchers by emailing o.burn@ucl.ac.uk, corin.whitfield.21@ucl.ac.uk, or the Principal Investigator, Dr Alana Loewenberger, by emailing alana.loewenberger.09@ucl.ac.uk.

If you would like to speak with a clinician outside of the research team, Dr Marc Tibber is a clinician who works with young people. He can be contacted if needed by emailing m.tibber@ucl.ac.uk. He can also suggest some services that support young people.

What information will I be asked to provide and how will my information be kept private?

We will ask for some information about you –your age, gender, when and who provided your functional tics diagnosis, and any other diagnoses you may have received. This information will be made anonymous so no one except the student researchers will know that it is you.

One of the student researchers will record the interview using a password-protected audio recorder. Only the student researchers will have access to the recording and will be the only person who will be able to identify you. The interview will then be typed up into a script by the student researchers and the audio recording of the interview will then be deleted. We will remove any personal information from the script so that nobody reading it will be able to identify you.

What happens to the information that I provide?

Information about you will be stored on a secure storage facility to keep it safe. The audio recording of the interview will be stored securely whilst the interview is being typed up. After the script is typed up the audio recording will be deleted.

We will delete any information about you on the scripts (e.g. your name) so no one knows that it is you. Scripts will be securely stored through password-protected documents. The research team will be able to see the scripts. All information we collect will be used according to the Data Protection Act 1998 and will be kept private. All data will be destroyed 12 months after the study ends.

We will ask for you and your parent/carer's consent to use quotes in any reports of the study. Quotes won't use your real name and people won't be able to identify you.

What will happen with the results of this study?
Once the study is finished the results will be typed up in a report as part of a thesis project. The results will also be sent to peer review journals. Nobody will know who you are from reading it as we won't use your real name.

At the end of the interview, you will be asked if you would like to be told about any of these reports, or if you would like to be sent a summary of the report.

Sources of support
If you would like support for your mental health then please do talk to a parent or carer, or you can contact the following services:

- Tourette's Action website and helpdesk (https://www.tourettes-action.org.uk/)
- Your registered GP
- Your local CAMHS service. The NHS website can help you to find local mental health services (https://www.nhs.uk/nhs-services/mental-health-services/how-to-find-local-mental-health-services/)
- A teacher or other professional at school/college
- The Young Minds website has information on where you can find support: (https://www.youngminds.org.uk/young-person/)

What if there is a problem?
If you are not happy about this research and want to complain then please speak to your family, or email the Principal Researcher, Dr Alana Loewenberger on alana.loewenberger.09@ucl.ac.uk. If you are still unhappy, you can contact the Chair of the UCL Research Ethics Committee on ethics@ucl.ac.uk.

Data Protection Privacy Notice
The controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this study. Further information on how UCL uses participant information can be found in our 'general' privacy notice here.

For participants in health and care research studies, click here.

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data is: 'Public task'.

Information about you will be used as long as it is required for the study. If we can remove information about you (remove your name, date of birth or give you a false name) then we will do this where we can.

If you are worried about how your information is being used, or if you would like to contact us about your rights, please contact UCL at data-protection@ucl.ac.uk.If you are still worried, can contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Who is organising the funding of this study?
The UCL Research Department of Clinical, Educational and Health Psychology has given £30 to the study for the prize draw.

You will be given a copy of this information sheet to keep. If you are happy to take part, we will ask you to complete a consent form which you will also be given a copy of to keep.

Thank you for reading this information sheet and for your interest in this research study.

Please do ask any questions about the study. Please let us know if anything is not clear or if you would like any further information.

If you have any questions about this study, please contact Olivia Burn at o.burn@ucl.ac.uk or Corin Whitfield at corin.whitfield.21@ucl.ac.uk.

UCL Research Department of Clinical, Educational & Health Psychology

1-19 Torrington Place

University College London

Information Sheet for Young People (16–18-year-olds)

Title of Project:	**Experiences of a functional tics diagnosis in adolescents, and their parents: A qualitative study**
Project ID No:	**24255/001**
Department:	**Clinical, Education and Health Psychology**
Student Researchers:	**Olivia Burn** **Email address: o.burn@ucl.ac.uk** **Corin Whitfield** **Email address: corin.whitfield.21@ucl.ac.uk**
Principal Researcher:	**Dr Alana Loewenberger** **Email address: alana.loewenberger.09@ucl.ac.uk**

We are researchers, clinical psychologists, and trainee clinical psychologists at University College London (UCL). We are inviting you to take part in a research project. This study is being carried out by two trainee clinical psychologists undertaking the Doctorate in Clinical Psychology (DClinPsy) at UCL

Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives and friends if you wish. Ask us if anything is not clear or you would like more information.

This study has been approved by the Clinical, Educational and Health Psychology Research Department's Ethics Chair.

What is the purpose of this study?

We want to find out what it is like to have functional tics. Not much is known about how young people and their families experience a functional tics diagnosis, and how they find living with functional tics.

With you and other young people, we would like to explore and understand what it is like to receive a diagnosis of functional tics and the support or treatment you may have received after the diagnosis. We are interested in understanding how the functional tics diagnosis has impacted you and what might or might not help to support people with functional tics.

We also hope to recruit parents or carers of young people with functional tics, to find out about their experiences of their child receiving a diagnosis of functional tics and of

any support and treatment received. If your parent or carer is recruited for this study, they will take part in a separate interview.

Why have I been invited?
You have been invited to participate in this study as you have received a diagnosis of functional tics.

Do I have to take part?
No. You are under no obligation to take part in this study. You will be given the opportunity to ask the investigator any questions you may have before giving your consent to take part in the study.

We are inviting both young people and their parents or carers to take part in the study. However, if you would like to take part but your parent or carer does not, they do not need to take part too. The same applies if your parent or carer would like to participate but you do not.

If you decide to participate, you are still free to withdraw from the study within a month of your interview. Any information you have provided will be deleted. If you no longer want to take part in this study, please let the researchers know by emailing o.burn@ucl.ac.uk or corin.whitfield.21@ucl.ac.uk. You do not need to give a reason for withdrawing from the study.

What will I be asked to do?
You will be asked to complete a consent form to make sure that you understand what your participation involves, and to evidence that you are happy to take part.

Your participation will involve completing a short questionnaire with us over the phone. You can complete it with a parent or carer if you would like to. We will ask you about your age, gender, ethnicity, your mood, date of your functional tics diagnosis, who gave you the diagnosis, any other diagnoses you might have been given and your GP details. This is to help provide some background information about the people who take part in the study. You don't have to give this information if you don't want to.

You will then be asked to take part in a one-to-one interview with one of the doctoral student researchers, to explore your experience of receiving a functional tics diagnosis and any treatment or support you may have received for functional tics.

If your parent participates in the study, they will take part in a separate one-to-one interview with one of the student researchers. They will be asked about their experiences of your functional tics diagnosis and any support or treatment since the diagnosis.

Interviews will last up to 60 minutes and will take place online, via Microsoft Teams. Interviews will be audio recorded through a password-protected audio device so that they can be transcribed (typed up). For you to participate, we will need your consent to audio record the interview.

You will be entered into a £30 prize draw as an acknowledgement of your interest in the study.

What are the benefits of participating in this study?
Participating in this study will give you the opportunity to reflect on your experiences of having a diagnosis of functional tics and any support you may have received for functional tics.

We expect that the findings from this study will be used to improve our understanding of functional tics. This will help to improve services to support people who have a diagnosis of functional tics.

What are the risks of participating in this study?
Discussing experiences of functional tics may be distressing for some young people. The interview might be very upsetting for people already experiencing a lot of distress. We will ask about your well-being over the phone to make sure that you feel OK to take part in the study.

Before starting the interview, we will check that you feel well enough to take part. If you feel upset during the interview, the student researcher will be there to support you. The interview can be paused at any time and can be rescheduled. The research team is experienced in assessing and managing psychological concerns. We can also direct you to the appropriate healthcare service if we think that further support is needed. In addition, we have provided you with details of services and resources to access later in this information sheet.

During your interview, we will ask for an adult to be in the same building as you. This is so they can support you if you become upset.

It is possible that the interview could raise some concerns about your wellbeing or safety. If so, we would create a plan together to help manage these concerns and think about what would help to support you. We will ask for your consent to contact your GP if there are any concerns.

If you become upset after the interview has finished or if you have any concerns, you can contact the researchers by emailing o.burn@ucl.ac.uk, corin.whitfield.21@ucl.ac.uk, or the Principal Investigator, Dr Alana Loewenberger, at alana.loewenberger.09@ucl.ac.uk.

Please note, if you would like to speak with a clinician outside of the research team, Dr Marc Tibber is an external clinician specialised in working with young people and he can be contacted if needed by emailing m.tibber@ucl.ac.uk. He is also in a position to direct you to the appropriate healthcare service if further support is needed.

What information will I be asked to provide and how will my information be kept confidential?
We respect your privacy and are committed to protecting your personal data.

We will ask you to provide some personal information - your age, gender, when and who provided your functional tics diagnosis, and any other diagnoses you may have received. This information will be made anonymous - it will be attached to a code so

that nobody except the student researchers will be able to identify you from the data we keep.

One of the student researchers will audio record the interview using a password-encrypted audio device. Only the student researchers will have access to the audio recording and will be the only person who will be able to identify you. The interview will then be transcribed (typed up) by the student researchers and the audio recording of the interview will then be deleted. We will remove any personal information from the transcription so that nobody reading it will be able to identify you.

What happens to the information that I provide?
Forms that you complete that include personal information about you will be stored on UCL Data Safe Haven, which is a secure storage facility for UCL research data. Whilst the audio recording of the interview is being transcribed it will be kept on UCL Safe Haven. After transcription is complete the audio recording will be deleted.

Anonymised interview transcripts containing no personal information (e.g., name, email) will be securely stored through password-protected documents on UCL OneDrive. Anonymised interview transcripts will be accessible to the research team through UCL OneDrive, to support analysis of the data. All data will be handled according to the Data Protection Act 1998 and will be kept confidential. All data will be destroyed 12 months after the study ends.

We will ask for your consent to use quotes from your interview in any resulting reports or publications of the study. Quotes will be anonymous – this means that we won't use your real name, and it will not be possible for others to identify you.

What will happen with the results of this study?
Once the study has been completed, the results will be published in a report as part of a thesis project. The results will also be submitted to peer review journals, and you will be asked at the end of the interview whether you would like to be informed about any such publications, or if you would like to be sent a summary of the report. Confidentiality and anonymity will be maintained, so it will not be possible to identify you from any publications.

Sources of additional support
If you would like additional support for your mental health then please do talk to a parent or carer, or you can contact the following services:

- Tourette's Action website and helpdesk (https://www.tourettes-action.org.uk/)
- Your registered GP
- Your local CAMHS service. The NHS website can help you to find local mental health services (https://www.nhs.uk/nhs-services/mental-health-services/how-to-find-local-mental-health-services/)
- A teacher or other professional at school/college
- The Young Minds website has information on where you can find support: (https://www.youngminds.org.uk/young-person/)

Who is organising the funding of this study?
The UCL Research Department of Clinical, Educational and Health Psychology has awarded £30 funding for the prize draw.

Who has reviewed the study?
The study has been peer-reviewed within UCL's Research Department of Clinical, Educational and Health Psychology and has been approved by the UCL Research Department's Ethics Chair (ethics number: 24255/001).

What if there is a problem?
If you wish to complain or have any concerns about any aspect of the way you have been approached or treated by members of staff, you may have experienced due to your participation in the research or UCL complaints mechanisms are available to you. If you would like to make a complaint, please email the Principal Researcher, Dr Alana Loewenberger on alana.loewenberger.09@ucl.ac.uk. Should you feel that your complaint has not been handled well enough, you can contact the Chair of the UCL Research Ethics Committee on ethics@ucl.ac.uk.

Who is the Sponsor for this Study?
University College London (UCL) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and UCL will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Data Protection Privacy Notice
The controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice here.

For participants in health and care research studies, click here.

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data is: 'Public task'.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise the personal data (removing your name, date of birth etc.) or pseudonymise the personal data (give you a false name) you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the

Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at:

https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

You will be given a copy of this information sheet to keep. If you are happy to participate, we will ask you to complete a consent form which you will also be given a copy of to keep.

Thank you for reading this information sheet and for considering taking part in this research study.

You are encouraged to ask any questions about the study. Please let us know if anything is not clear or if you would like any further information.

If you have any questions about this study, please contact Olivia Burn at o.burn@ucl.ac.uk or Corin Whitfield at corin.whitfield.21@ucl.ac.uk.

UCL Research Department of Clinical, Educational & Health Psychology
1-19 Torrington Place
University College London

Information Sheet for Parents and Carers

Title of Project:	**Experiences of a functional tics diagnosis in adolescents, and their parents: A qualitative study**
Project ID No:	**24255/001**
Department:	**Clinical, Education and Health Psychology**
Student Researcher:	**Olivia Burn** **Email address: o.burn@ucl.ac.uk** **Corin Whitfield** **Email address: corin.whitfield.21@ucl.ac.uk**
Principal Researcher:	**Dr Alana Loewenberger** **Email address: alana.loewenberger.09@ucl.ac.uk**

We are researchers, clinical psychologists, and trainee clinical psychologists at University College London (UCL). We are inviting you and your child to take part in a research project. This study is being carried out by two trainee clinical psychologists undertaking the Doctorate in Clinical Psychology (DClinPsy) at UCL

Before you decide whether to take part, it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

This study has been approved by the Clinical, Educational and Health Psychology Research Department's Ethics Chair.

What is the purpose of this study?
There has been a reported increase in young people experiencing functional tics yet there has not been much research into functional tics. Little is known about how young people and their families experience a functional tics diagnosis and how they have found living with functional tics.

We want to find out about what it is like to have functional tics, both from young people diagnosed with functional tics and their parents or carers. We will be interviewing parents and young people separately. We are interested in understanding you and your child's experiences of a functional tics diagnosis, how it has impacted you and what might or might not help to support people with functional tics.

Why have I been invited?
You have been invited to participate in this study as your child has received a diagnosis of functional tics.

Do I have to take part?
No. You are under no obligation to take part in this study. You will be given the opportunity to ask the investigator any questions you may have before giving your consent to take part in the study.

We invite both you and your child to take part in the study. However, if you would like to participate but your child does not, they do not need to take part too. The same applies if your child would like to participate but you do not.

If you decide to participate, you are still free to withdraw from the study within a month of your interview. Any information you have provided will be deleted. If you no longer want to take part in this study, please let the researchers know by emailing o.burn@ucl.ac.uk or corin.whitfield.21@ucl.ac.uk. You do not need to give a reason for withdrawing from the study.

What will I be asked to do?
You will be asked to complete a consent form to make sure that you understand what your participation involves, and to evidence that you are happy to take part. If your child is under the age of 16, we will require your written consent for them to take part.

Your participation will involve you completing a short questionnaire with us over the phone if your child is under 16 years old. If your child is over 16 years old and would like to take part, we will ask them to complete the questionnaire with us over the phone. We will ask about your child's age, gender, ethnicity, their mood, who provided the diagnosis, any other diagnoses they might have been given and their GP details. This is to help provide some background information about the people who take part in the study. You don't have to give this information if you don't want to.

You will then be asked to take part in a one-to-one interview with one of the doctoral student researchers, to explore your experiences of your child receiving a functional tics diagnosis and any treatment or support your child may have received for functional tics.

If your child participates in the study, they will take part in a separate one-to-one interview with one of the doctoral student researchers. They will be asked about their experiences of a functional tics diagnosis and any support or treatment they may have received for functional tics.

Interviews will last up to 60 minutes and will take place online, via Microsoft Teams. Interviews will be audio recorded through a password-protected audio device so that they can be transcribed (typed up). We will need your consent to audio record the interview for you to take part in the study.

If your child takes part they will be entered into a £30 prize draw as an acknowledgement of interest in the study.

What are the benefits of participating in this study?
Participating in this study will give you the opportunity to reflect on your experiences of your child having a diagnosis of functional tics and what support they may have received for functional tics.

We expect that the findings from this study will be used to develop an understanding of functional tics. This will help to improve services to support people who have a diagnosis of functional tics.

What are the risks of participating in this study?
Discussing experiences of functional tics can be distressing and might be particularly difficult for young people who are already experiencing high levels of distress. We will ask about your well-being and your child's well-being (if they are under 16 years old) over the telephone to make sure that both you and your child feel OK to take part in the study. We will directly ask your child about their well-being if they are over 16 years old.

Before starting the interview, we will check that you or your child feel well enough to take part. If you or your child feels distressed during the interview, the student researcher will be there to support you. The interview can be paused at any time and can also be rescheduled. The research team is experienced in assessing and managing psychological concerns. We can also direct you to the appropriate healthcare service if we think that further support is needed. In addition, we have provided you with details of services and resources to access later in this information sheet.

During your child's interview, we will ask you or another adult to be in the same building as them. This means that if they do become upset, we can ask for your support, or if any concerns are raised these can be discussed with you.

It is possible that the interview could raise some concerns about your child's wellbeing or safety. In this instance we would create a plan together to help manage any risks. We will ask for your consent to write to your child's GP if any concerns arise.

If you or your child become upset after the interview has finished or if you have any concerns, you can contact the researchers by emailing o.burn@ucl.ac.uk, corin.whitfield.21@ucl.ac.uk or the Principal Investigator, Dr Alana Loewenberger, by emailing alana.loewenberger.09@ucl.ac.uk.

Please note, if you would like to speak with a clinician outside of the research team, Dr Marc Tibber is an external clinician specialised in working with young people and he can be contacted if needed by emailing m.tibber@ucl.ac.uk. He is also in a position to direct you to the appropriate healthcare service if further support is needed.

What if I no longer want to take part in this study?
If you no longer want to take part in this study, please let the researchers know by emailing o.burn@ucl.ac.uk or corin.whitfield.21@ucl.ac.uk. Any data collected within

the past 4 weeks of your withdrawal will be removed from the study. You do not need to give a reason for withdrawing from the study.

What information will I be asked to provide and how will my information be kept confidential?

We respect your privacy and are committed to protecting your personal data.

We will ask you to provide some personal information about your child - their age, gender, when and who provided the functional tics diagnosis, and any other diagnoses your child may have received. This information will be made anonymous - it will be attached to a code so that nobody except the student researchers will be able to identify your child from the data we keep.

The student researcher will audio record the interviews using a password-encrypted audio device. Only the student researchers will have access to the audio recording and will be the only person who will be able to identify you. The interview will then be transcribed by the student researchers and the audio recording of the interview will then be deleted. We will remove any personal information from the transcription so that nobody reading it will be able to identify you.

What happens to the information that I provide?

Forms that you complete that include personal information about you and your child will be stored on UCL Data Safe Haven, which is a secure storage facility for UCL research data. Whilst the audio recording of the interview is being transcribed it will be kept on UCL Safe Haven. After transcription is complete the audio recording will be deleted.

Anonymised interview transcripts containing no personal information (e.g., name, email) will be securely stored through password-protected documents on UCL OneDrive. Anonymised interview transcripts will be accessible to the research team through UCL OneDrive, to support analysis of the data. All data will be handled according to the Data Protection Act 1998 and will be kept confidential. All data will be destroyed 12 months after the study ends.

We will ask for your consent to use quotes from your interview in any resulting reports or publications of the study. Quotes will be anonymous - this means that we won't use your real name, and it will not be possible for others to identify you.

What will happen with the results of this study?

Once the study has been completed the results will be published in a report as part of a thesis project. The results will also be submitted to peer review journals, and you will be asked at the end of the interview whether you would like to be informed about any such publications, or if you would like to be sent a summary of the report. Confidentiality and anonymity will be maintained, and it will not be possible to identify you from any publications.

Sources of additional support

If you or your child would like additional support for your mental health, then you can contact the following services:

- Tourette's Action website and helpdesk (https://www.tourettes-action.org.uk/)

- Your registered GP
- Your local CAMHS (for young people) or IAPT (for adults). The NHS website can help you to find local mental health services (https://www.nhs.uk/nhs-services/mental-health-services/how-to-find-local-mental-health-services/)
- A teacher or other professional at school/college
- The Young Minds website has information on where you can find support: (https://www.youngminds.org.uk/young-person/)

Who is organising the funding of this study?
The UCL Research Department of Clinical, Educational and Health Psychology has awarded £30 funding for the prize draw.

Who has reviewed the study?
The study has been peer-reviewed within UCL's Research Department of Clinical, Educational and Health Psychology and has been approved by the UCL Research Department's Ethics Chair (ethics number: 24255/001).

What if there is a problem?
If you wish to complain or have any concerns about any aspect of the way you have been approached or treated by members of staff, you may have experienced due to your participation in the research or UCL complaints mechanisms are available to you. If you would like to make a complaint, please email the Principal Researcher, Dr Alana Loewenberger on alana.loewenberger.09@ucl.ac.uk. Should you feel that your complaint has not been handled well enough, you can contact the Chair of the UCL Research Ethics Committee on ethics@ucl.ac.uk.

Who is the Sponsor for this Study?
University College London (UCL) is the sponsor for this study based in the United Kingdom. We will be using information from you to undertake this study and UCL will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Data Protection Privacy Notice
The controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted at data-protection@ucl.ac.uk.

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice here.

For participants in health and care research studies, click here.

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data is: 'Public task'.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise the personal data (removing your name, date of birth etc.)

or pseudonymise the personal data (give you a false name) you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at:

https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

You will be given a copy of this information sheet to keep. If you are happy to participate, we will ask you to complete a consent form which you will also be given a copy of to keep.

Thank you for reading this information sheet and for considering taking part in this research study.

You are encouraged to ask any questions about the study. Please let us know if anything is not clear or if you would like any further information.

If you have any questions about this study, please contact Olivia Burn at o.burn@ucl.ac.uk or Corin Whitfield at corin.whitfield.21@ucl.ac.uk.

Appendix C. Consent forms.

UCL Research Department of Clinical,

Educational & Health Psychology

1-19 Torrington Place

University College London

Consent Form for Young People (aged 12-15)

Experiences of a functional tics diagnosis in adolescents, and their parents: A qualitative study

Please complete this form after you have read the Information Sheet.

I confirm that I understand that by selecting each box below I am consenting to this element of the study. I understand that it will be assumed that an unselected box means that I DO NOT agree to that part of the study. I understand that by not giving consent for any one element that I may not be able to continue with the study.

Please initial box

1. I confirm that I have read and understand the information sheet version 2.0, dated 05.03.23 for the above study. I have had the chance to ask questions about the study. ☐

2. I understand that I do not have to take part in this study unless I want to and that I am free to withdraw from the study within a month of the interview without giving any reason. I know that if I do not take part in the study, it will not affect the healthcare I receive, or my relationship with Tourette's Action. ☐

3. I understand that my participation will be audio recorded and I consent to the use of this material as part of the project. ☐

4. I understand that if I no longer want to take part in this study I should inform the researcher. Any data that has been collected will be deleted. ☐

5. I consent to the use of anonymised quotes or information in any resulting reports or publications. I understand that confidentiality will be maintained, and it will not be possible for others to identify me. ☐

6. I am aware of who to contact if I am unhappy about the study, or want to complain about the study. ☐

7. I consent to the research team contacting my GP and a parent, if concerns about my well-being arise during the study. ☐

8. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

UCL Research Department of Clinical,

Educational & Health Psychology

1-19 Torrington Place

University College London

Consent Form for Young People (aged 16-18)

Experiences of a functional tics diagnosis in adolescents, and their parents: A qualitative study

Please complete this form after you have read the Information Sheet.

I confirm that I understand that by selecting each box below I am consenting to this element of the study. I understand that it will be assumed that an unselected box means that I DO NOT agree to that part of the study. I understand that by not giving consent for any one element that I may not be able to continue with the study.

Please initial box

1. I confirm that I have read and understand the information sheet version 2.0, dated 05.03.23 for the above study. I have had the opportunity to consider the information, ask questions and have had these fully answered. ☐

2. I understand that my participation is voluntary and that I am free to withdraw within a month of the interview. I know that if I do not take part in the study, it will not affect the healthcare I receive, or my relationship with Tourette's Action. ☐

3. I consent to take part in both the questionnaire and interview ☐

4. I understand that my participation will be audio recorded and I consent to the use of this material as part of the project. ☐

5. I understand that if I no longer want to take part in this study I should inform the researcher. Any data that has been collected will be deleted. ☐

6. I consent to the use of anonymised quotes or information in any resulting reports or publications. I understand that confidentiality will be maintained, and it will not be possible for others to identify me. ☐

7. I am aware of who to contact if I am unhappy about the study, or want to complain about the study. ☐

8. I consent to the research team contacting my GP and a parent, if concerns about my well-being arise during the study. ☐

9. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

UCL Research Department of Clinical,

Educational & Health Psychology

1-19 Torrington Place

University College London

Consent Form for Parents

Experiences of a functional tics diagnosis in adolescents, and their parents: A qualitative study

Please complete this form after you have read the Information Sheet.

I confirm that I understand that by selecting each box below I am consenting to this element of the study. I understand that it will be assumed that an unselected box means that I DO NOT agree to that part of the study. I understand that by not giving consent for any one element that I may not be able to continue with the study.

Please initial box

1. I confirm that I have read and understand the information sheet version 2.0, dated 05.03.23 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that myself and/or my child are free to withdraw within a month of the interview without giving any reason. I know that if I do not take part in the study, it will not affect the healthcare that myself or my child receives, or our relationship with Tourette's Action. ☐

3. I consent to completing the questionnaire regarding my child's background information (please write 'NA' in the box if your child is over the age of 16). ☐

4. I understand that my participation will be audio recorded and I consent to the use of this material as part of the project. ☐

5. I understand that if I no longer want to take part in this study I should inform the researcher. Any data that has been collected will be deleted. ☐

6. I consent to the use of anonymised quotes or information in any resulting reports or publications. I understand that confidentiality will be maintained, and it will not be possible for others to identify myself or my child. ☐

7. I am aware of who to contact if I am unhappy about the study, or want to complain about the study. ☐

8. I consent to the research team contacting my child's GP if concerns regarding the well-being of my child arise during the study. ☐

9. I give permission for my child to take part in this study (please write 'NA' in the box if your child is over the age of 16) ☐

10. I agree to take part in the above study. ☐

Name of Participant	Date	Signature

Name of Researcher	Date	Signature

Appendix D. Screening questionnaire

Items in brackets denote whether recipients are required to give a forced response or whether they can type a response freely.

Screening questionnaire

Are you a parent of a young person with functional tics, who is 12 to 18 years old? [YES/NO]

Are you a young person with functional tics, aged between 12 to 18 years old? [YES/NO]

Do you live in the United Kingdom? [YES/NO]

Have you or your child been given a diagnosis of functional tics by a professional involved in your care? (e.g., paediatrician, GP, psychologist) [YES/NO]

How old are you? [free text]

If you are a parent completing this form, how old is your child? Please leave this blank if you are a young person completing this form. [free text]

I consent to being contacted for the purposes of this research study [YES/NO]

If you are over the age of 16, what is your email address? [free text]

If you are over the age of 16, what is your telephone number? [free text]

If you are under the age of 16, what is your parent's/carer's email address? [free text]

If you are under the age of 16, what is your parent's/carer's telephone number? [free text]

Appendix E. Demographic questionnaires

<u>Demographic questionnaire</u> - to be completed via telephone with 16–18-year olds

How old are you?

How would you describe your gender identity?

What is your ethnicity?

Have you received a formal diagnosis of functional tics?

When did you receive a formal diagnosis of functional tics?

Who provided the diagnosis of functional tics?

Have you received any other diagnoses from a professional? (e.g. anxiety, depression, autism, ADHD)

As you would have seen in the information sheet, sometimes it can be challenging to talk about health experiences, and we would like to make sure you feel OK to take part in the study. Do you experience times of high distress? Are you able to keep yourself safe during these times?

Have you ever experienced any thoughts about harming yourself? Have you ever harmed yourself?

If yes: Have you discussed this with anyone, or is anyone supporting you with this?

What are your GP details? (name, address, telephone number)

<u>Demographic questionnaire</u> – for parents/carers to complete via telephone for children aged 12-15.

How old is your child?

How would you describe your child's gender identity?

What is your child's ethnicity?

Has your child received a formal diagnosis of functional tics?

When did they receive a formal diagnosis of functional tics?

Who provided the diagnosis of functional tics?

Has your child received any other diagnoses from a professional? (e.g. anxiety, depression, autism, ADHD)

As you would have seen in the information sheet, sometimes it can be challenging to talk about health experiences, and we would like to make sure both you and your child feels OK to take part in the study.

Does your child experience times of high distress? Are they able to keep themselves safe during these times?

Has your child ever experienced any thoughts about harming themselves? Have they ever harmed themselves?

If yes: Have they discussed this with anyone, or is anyone supporting them with this?

Do you experience times of high distress? Are you able to keep yourself safe during these times?

Have you ever experienced any thoughts about harming yourself? Have you ever harmed themselves?

If yes: Have you discussed this with anyone, or is anyone supporting you with this?

What are your child's GP details? (name, address, telephone number)

Appendix F. Interview schedules

The interview schedule created by McWilliams et al. (2016) was used as a template to further develop the interview schedules below.

Interview schedule: 12–18-year-olds.

I want you to think about the day you found out that you had been diagnosed with functional tics. What do you remember about it?

Prompts if needed:

- How did you find out about the diagnosis?
- Did someone explain the diagnosis to you? How did they explain it?
- Do you remember where you were?
- What name did they use for the diagnosis?
- How did they explain functional tics/why these happened for you?
- What did you think about their explanation?
- What did the diagnosis mean to you?
- What support did they suggest would help you? (e.g., treatment of anxiety or further assessment)

Now I'd like you to talk me through what happened before then, and your journey to getting a functional tics diagnosis. What was your life like before the functional tics diagnosis?

Prompts if needed:

- Did you see any different doctors, nurses, psychologists, or other professionals before then? What was this like?
- Did you receive any other diagnoses before the functional tics diagnosis?
- How did you feel during this time?
- What about school - how did they understand the problem?
- Did you have other difficulties at school?

Could you tell me about how functional tics have affected your life?

Prompts if needed:

- Have functional tics affected your friendships or relationships you have with people in your family or your teachers?
- Have functional tics affected how you feel about yourself or the things that you do?
- Have functional tics affected your mental health?
- Have functional tics affected the life of your family or your friends?

Have you noticed any things that trigger functional tics? Is there anything that helps to manage the functional tics?

Prompts if needed:

- Have you noticed any particular times when functional tics happen?
- Have you noticed any particular places where functional tics happen?
- Is there anything that you use to help manage functional tics? (e.g. holding ice, distraction)

- Is there anything that other people do that helps you manage functional tics?

Could you tell me about any support or further treatment you have received since the diagnosis of functional tics?

Prompts if needed:

- What type(s) of support have you had since the diagnosis? (e.g., psychotherapy, medication)
- Did you have any more assessments (e.g., for autism, ADHD, learning disability) or diagnoses?
- What was it like trying to get support?
- Have there been any changes in support from school/college/professionals/family and friends?
- Has this helped to improve the functional tics or helped you to live with them?
- Has this helped with other difficulties?
- Also, what sorts of things have not helped?

I'd like you to think about how people can help with functional tics. What do you think is important for them to know about functional tics?

Prompts if needed:

- How would you describe functional tics?
- How can professionals help young people with functional tics?
- How can teachers help young people with functional tics?
- How can family and friends help young people with functional tics?

Interview schedule: Parents/carers

I want you to think about the day you found out that your child had been given a diagnosis of functional tics. What do you remember about it?

Prompts if needed:

- How did you find out about the diagnosis?
- Do you remember where you were?
- Did someone explain the diagnosis to you? How did they explain it?
- What name did they use for the diagnosis?
- How did they explain functional tics/why these happened for your child?
- What did you think about the explanation?
- What support did they suggest would help? (e.g., treatment for anxiety or further assessment)

I'd like you to talk me through what happened before then and the journey to getting a functional tics diagnosis. What was life like for you, your child, and your family?

Prompts if needed:

- What sorts of health professionals did you see? What was this like?
- Did your child receive any other diagnoses before the functional tics diagnosis?
- How did you/your family feel during this time?
- What about school - how did they understand the problem?
- Did your child have other difficulties at school?

Could you tell me about how functional tics have affected your life?

Prompts if needed:

- Have functional tics affected your child, their behaviour, or the things that they do?
- Have functional tics affected your mental health or your child's mental health?
- Have functional tics affected how you feel about yourself or the things that you do?
- What is it like supporting a young person with functional tics?
- Are there any strategies that you find helpful to support your child with functional tics?
- Have functional tics affected the life of your family or your friends?
- Have functional tics affected your friendships or relationships you have with people in your family?
    - How have others understood or responded to the diagnosis?

Could you tell me about any support or further treatment you have received since the diagnosis of functional tics?

Prompts if needed:

- What type(s) of support have you or your child had since the diagnosis? (e.g., psychotherapy, medication)
- Did your child have any more assessments (e.g., for autism) or diagnoses?
- What was it like trying to get this support?
- Have there been any changes in support from school/college/professionals/family and friends?

- Has this helped to improve the functional tics or helped you or your child to live with them?
- Has this helped with other difficulties?
- Also, what sorts of things have not helped?

I'd like you to think about how people can help people with functional tics. What do you think is important for them to know about functional tics?

Prompts if needed:

- How would you describe functional tics to other people?
- How do you think professionals should explain functional tics?
- How can professionals help young people with functional tics?
- How can teachers help young people with functional tics?
- How can family and friends help young people with functional tics?

Appendix G. Evidence of ethical approval

UCL RESEARCH ETHICS COMMITTEE
OFFICE OF THE VICE-PROVOST (RESEARCH, INNOVATION & GLOBAL ENGAGEMENT)

10th March 2023

Dr Alana Loewenberger
Research Department of Clinical, Educational and Health Psychology
UCL

Cc: Olivia Burn and Corin Whitfield

Dear Dr Loewenberger

Notification of Ethics Approval with Provisos
Project ID/Title: 24255/001: Experiences of a functional tics diagnosis in adolescents, and their caregivers: A qualitative study

Further to your satisfactory responses to the Committee's feedback, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **1st July 2024.**

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Research Ethics Service
Office of the Vice-Provost (Research, Innovation & Global Engagement)
University College London
Email: ethics@ucl.ac.uk
www.ucl.ac.uk/research-ethics/

Final Report

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research;
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix H. Extract from a coded transcript

Transcript	Codes
P: It had kind of been on long enough and we thought, kind of, that was the main reason for going to see them. Because school weren't really going to actually help me or be of any use until they got that sorted to a degree, so yeah. Kind of expected it, and it wasn't like a big surprise or anything.	Diagnosis needed to get support Not surprised by the diagnosis
I: And did, did someone explain the diagnosis to you?	
P: A little bit, but because we'd kind of already had to look into that and we'd already contacted lots of people I kind of already roughly knew.	Did own research when tics started
I: You kind of already knew what it was, yeah. Do you remember how they explained it?	
P: Not really I don't think. I think I'd been talking to da-da-da-da-da and also kind of roughly had her understanding of everything so I kind of went with it	
I: Yeah, sure. And who was the person that kind of gave you an understanding originally?	
P: Probably originally, got it from [THERAPIST NAME] from [SERVICE].	
I: Yeah, OK. And how did they explain it to you? Can you-	
P: It was a bit like some sort of boiling pots, how I was a person who just, it got too much for my brain to cope with and it was the way to get some of the stress out	Explanation for functional tics given by professionals Functional tics described as a pressure cooker - body releasing built up anxiety
I: Yeah. And what did you think of that explanation?	
P: It does make quite a lot of sense because there was a lot going on and everything just went pff [*moves hands outwards*].	Explanation gave answers and made sense
I: Yeah, it was all just quite a lot. And what did you think about the diagnosis, the functional tics diagnosis?	
P: Not like... I was never really fussed about it or kind of wanted it in the first place, but I kind of had no choice	Diagnosis needed to get support

	because of school. And I think that's what annoys me the most, I didn't really get like a lot of… what I wanted about it. It was more, oh school are gonna keep treating you like an idiot until you have it so there's no other way around it.

Abbreviations. I, interviewer; P, participant.

Appendix I. Example codes within a subtheme

Below is a screenshot of codes comprising the subtheme ‘lack of timely and specialist support – passed around’ within the theme ‘fighting for help’. ‘Files’ refers to the number of participants endorsed and ‘references’ refers to the number of times each code was endorsed throughout the data.

Name	Files	References
Blamed, disbelieved, discounted	15	307
Fighting for help	15	539
Needing to be forceful to get support (but also calm)	12	37
Family stress and isolation	15	230
What are we supposed to do	15	115
Lack of timely and specialist support - passed around	15	141
Lack of professional knowledge of functional tics and support services a barrier to timely support	4	4
Took a long time to get the right information, support and acceptance	4	5
A need for joint professional working and MDT input (e.g. shared understanding)	5	7
Feeling lucky to access support quickly	6	8
Disjointed services - passing the buck, gatekeeping and onus on parent	7	13
Need to be in crisis to get support - reduced distress a barrier to accessing support	7	8
Support needs to be more readily accessible - long waiting times resulting in escalation of distress	7	10
Lack of timely support - a need to access private support	8	16
Limited support available and difficulties accessing support	8	25
Explanation given by professionals for functional tics	10	16
Specialist professionals important - understanding of functional tics and confidence in diagnosis	13	29
Who am I now	15	295
Professional and community support	15	436

Appendix J. Amendments to an interview schedule based on feedback from patient and public involvement (PPI)

The interview schedule created by McWilliams et al. (2016) was used as a template to further develop the interview schedules for the current study.

Example interview schedule: 12–18-year-olds
(Amendments based on PPI feedback are in red)

I want you to think about the day you found out that you had a diagnosis of functional tics. What do you remember about it?

Prompts if needed:

- How did you find out about the diagnosis?
- Did someone explain the diagnosis to you? How did they explain it?
- Do you remember where you were?
- What name did they use for the diagnosis?
- How did they explain functional tics/why these happened for you?
- What did you think about their explanation?
- What did the diagnosis mean to you?
- What support did they suggest would help you? (e.g., treatment of anxiety or further assessment)

Now I'd like you talk me through what happened before then and your journey to getting a functional tics diagnosis. What was your life like before the functional tics diagnosis?

Prompts if needed:

- Did you see any different doctors, nurses, psychologists, or other professionals before then? What was this like?
- Did you receive any other diagnoses before the functional tics diagnosis?
- How did you feel during this time?
- What about school - how did they understand the problem?
- Did you have other difficulties at school?

Could you tell me about how functional tics have affected your life?

Prompts if needed:

- Have functional tics affected your friendships or relationships you have with people in your family or your teachers?
- Have functional tics affected how you feel about yourself or the things that you do?
- Have functional tics affected your mental health?
- Have you noticed any things that trigger the functional tics? Are there any strategies that help with the functional tics?
- Have functional tics affected the life of your family or your friends?

Could you tell me about any support or further treatment you have received since the diagnosis of functional tics?

Prompts if needed:

- What type(s) of support have you had since the diagnosis? (e.g., psychotherapy, medication)

- Did you have any more assessments (e.g., for autism, ADHD, learning disability) or diagnoses?
- What was it like trying to get support?
- Have there been any changes in support from school/college/professionals/family and friends?
- Has this helped to improve the functional tics or helped you to live with them?
- Has this helped with other difficulties?
- Also, what sorts of things have not helped?

I'd like you to think about how people can help with functional tics. What do you think is important for them to know about functional tics?

Prompts if needed:

- How would you describe functional tics?
- How can professionals help young people with functional tics?
- How can teachers help young people with functional tics?
- How can family and friends help young people with functional tics?