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Making the shoe fit: a thematic analysis exploring the journey of adult tic recognition and acceptance in the United Kingdom

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ABSTRACT

Objective: Chronic tic disorders (including tourette syndrome) are typically diagnosed in childhood and characterised by persistent tics that vary in both severity and resolution. This study aimed to explore the journey to recognising tic symptoms in individuals in the United Kingdom who self-reported as having atypically initiated and obtained a confirmed tic disorder diagnosis after the age of 18.

Method: Thirteen semi-structured interviews and one written response were recorded from participants (aged 18-59, median 43) investigating personal adult experiences, early perceptions, diagnostic seeking, and post-diagnosis reflections. Transcripts were analysed through reflexive thematic analysis, with member checks confirming deductive validity.

Results: Analysis revealed three main themes with nine accompanying sub-themes. Minimisation encapsulated challenges in recognising and accepting tic symptoms. Ironic luck and privilege revealed the experiences of diagnosis, emphasising the role of luck, privilege, and personal ownership to recognition and support. Anti-climax examined support mechanisms, impact their condition and diagnosis had on daily activities, reaching acceptance and finding protection.

Discussion: The study highlights the complex journey adults with chronic tic disorders face towards diagnosis and self-acceptance, including social, self and clinical minimisation and limited treatment options. Greater clinical understanding and accessible information is needed to challenge stigma and enhance long-term outcomes.

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Tics; recognition; adulthood; tic disorders; Tourette's; diagnosis

Introduction

Chronic tic disorders (CTDs) and tourette syndrome (TS) have a key unifying symptom of chronic tics. These tics may be brief, rapid, repetitive, non-rhythmic motor and/or vocal expressions that are involuntary or semi-voluntary in nature and have variable degrees of temporary suppression (Ueda et al., 2021). Diagnosing tics is often considered a complex process due to high rates of co-occurring conditions, incomplete understanding of the developmental progression of tics, and challenges in classifying movement types due to other conditions. These factors make their recognition and diagnosis a specialist endeavour, particularly in adults where tics may be less prominent, yet still have a significant impact on one's self-identity, mental well-being and interpersonal interactions (Coleman & Melia, 2024; Stofleth & Parks, 2023; Tseng et al., 2025).

CTDs and TS are recognised as neurodevelopmental disorders, with current medical diagnostic manuals (e.g. Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) American Psychiatric Association [APA], 2013) and International Classification of Diseases, 11th Edition (ICD-11) (World Health Organization [WHO], 2019) advocating a developmental age of initial onset (e.g. ≤ 18 years). Although research into the progression of tics has indicated that around two-thirds to three-quarters of adolescents may experience relief or a dampening to mild presentation from childhood-onset tics (Bloch & Leckman, 2009; Singer, 2006), some adults can experience a persistence or worsening in the severity of tics into adulthood (Black et al., 2021). Importantly, research confirms that adult-onset CTDs can present as de novo cases, albeit as recurrences of previously unrecognised childhood tics or caused by secondary

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external insults such as brain injury, infection or drug toxicity (e.g. de Souza, 2020; Kroeger et al., 2023); yet they remain under-recognised in clinical and research settings.

To complicate identification further, tics are multifaceted, fluctuating between and within individuals, and can wax, wane, enter remission/temporary latency, sustain and/or recur throughout the lifespan (Bloch & Leckman, 2009; Bruun & Budman, 1997). Moreover, the recent emerging and establishing view of some authors of functional tic-like behaviours (FTLB) associated with Functional Movement Disorder (FMD)/ Functional Neurological Disorder (FND) may also add to identification complexity (Berg et al., 2022). The assertion is that FTLBs may visually mimic tics but are considered to have different demographic risk factors, later and rapid onset, female sex-ratio bias, co-occurring conditions and progression profiles and a higher complexity expression than tics (Pringsheim et al., 2023), yet this might be due to the impact of potential greater complexities and stressors presented in life beyond childhood.

Within the United Kingdom (UK), there are currently no dedicated National Institute for Health and Care Excellence (NICE) guidelines for CTDs or TS specifically, although other investigations are in development (e.g. digital therapy value assessment) (NICE, 2025). Instead, the current NICE advice given for CTDS or TS appears under suspected neurological conditions (NG127). Here, the guidance is to deter the notion of referring adults with tics unless they cause trouble, distress, are incapacitating, or the individual shows signs of other progressive neurological symptoms (NICE, 2019). NICE substantiates this by stating that CTDs are fairly prevalent in adults, with mild manifestations often remaining undiagnosed, and that upon clear clarification, adults mainly decide not to pursue treatment unless the impact of their tics becomes severe (NICE, 2019). However, recent findings challenge the assumption that adults are simply choosing to self-identify over a diagnosis. Indeed, focus groups with young people, parents and adults with tic disorders have all highlighted the lack of specialist care and the difficulties that exist in obtaining a diagnosis, with many found to be travelling long distances to secure treatment (Babbage et al., 2025).

For CTDs, the clinical evaluation and communication of diagnosis and outcomes, both in the UK and more globally, can have variations in both quality and consistency (Cavanna & Hale, 2017; Ganos et al., 2021; Marino et al., 2023; Martindale et al., 2023; Rivera-Navarro et al., 2009). Several elements may contribute to this inconsistency, such as a layered cross-disciplinary referral pathway to care and intervention (e.g. from General Practitioner (GP) to psychology and/or psychiatry to neurology), the lack of exposure and perception to tics by medical professionals, the frequent complex interplays with other (often neuropsychiatric) conditions and requirement for diagnosis to be given by a specialist. For example, a cross-country survey of practicing neurologists found many specialists do not frequently come across tics and can vary in their approach to assessment, use of guidelines, validated severity scales and management approaches (Ganos et al., 2021). This was reiterated by Rivera-Navarro et al. (2009) in their qualitative investigation addressing the communication and impact of diagnosis, through focus groups with teenage and adult patients, their relatives and physicians. Whilst all groups agreed that TS was difficult to diagnose, physicians cited the complexity and symptom overlap with co-occurring conditions (particularly those psychological in nature); patients reported feeling that the physicians lacked knowledge of TS; and relatives identified barriers as familial guilt, denial and conflict, for example, over the origin of parental genetic heritability. Additionally, relatives noted misjudgement by physicians, who at times perceived, particularly mothers, as exaggerating or obsessing over patient symptomology.

In terms of treatment, with the focus on childhood onset, psychological therapy or behavioural interventions are often recommended as a first line intervention primarily for stress or anxiety to improve tic management (Ganos et al., 2021; NICE, 2019) and include approaches such as Habit Reversal Therapy (HRT), Exposure Response Prevention (ERP) and Comprehensive Behavioural Intervention for Tics (CBIT), with effectiveness of online and group options being evaluated to widen access (e.g. Bekk et al., 2023; Hollis et al., 2021). Other treatments, such as pharmacological treatments, including antipsychotics and alpha-2 agonists, can help manage severe symptoms but pose risks of side effects and tachyphylaxis (Besag et al., 2021). Neuromodulation approaches, such as Deep Brain Stimulation (DBS), transcranial magnetic stimulation (rTMS) and rhythmic median nerve stimulation (MNS), also show promise but remain limited in their availability (Dyke et al., 2022). NICE guidelines state that the lack of available medicinal interventions, associated side effects and restricted effectiveness means there is *'little value in referring to secondary care except for the confirmation of the diagnosis'*. (NICE, 2019, p. 100) and currently do not recommend a specific source of psychological therapy within their brief inclusion of tic disorders in adulthood.

Lived experience accounts highlight both internal and external blockers to recognition. For example, Keiper (1976) noted how early symptoms are frequently dismissed or deflected as bad habits or odd behaviour. Buckser (2006) further explored the semantic and cultural complexities of illness, describing how CTDs exist at a complicated junction between neurological perceived as involuntary and psychological explanations often inviting stigma, blame and shame. This ambiguous categorisation deeply impacts individuals' self-perception, the ways in which they describe their symptoms and how healthcare professionals interpret and treat them. Healthcare providers decoding these experiences may also respond with differing pathways (neurological and/or psychological) in their pursuit to restore control for the individual and improve outcomes. Within this context, individuals with CTDs become active agents in shaping and controlling how their condition is perceived, navigating the gap between internal experience and public understanding through strategies like displacement, misattribution and contextualisation (Buckser, 2008). The consequences of this perception extend beyond personal identity and medical engagement, adversely impacting on Quality of Life (QoL) (Conelea et al., 2013; Crossley & Cavanna, 2013; Malli & Forrester-Jones, 2022), communication and social interpersonal interactions (including witness misinterpretations of intent and unsolicited attention) (Smith et al., 2015; Stofleth & Parks, 2023), negative depiction, stigma and discrimination in education and employment (Malli & Forrester-Jones, 2022) and pain associated with repetitive tic performance (Taylor et al., 2022).

Complementing other qualitative and thematic analysis on lived experiences of adults with tics (Coleman & Melia, 2024; Malli et al., 2019; Malli & Forrester-Jones, 2022; Marino et al., 2023; Rivera-Navarro et al., 2009; Ross & Rickards, 2015; Smith et al., 2015; Soós et al., 2022; Stofleth & Parks, 2023; Taylor et al., 2022), this study aimed to understand journeys to tic recognition and acceptance for adults in the UK, specifically shining the spotlight on those who only received their confirmed CTD or TS diagnosis in adulthood. This research angle allowed for the investigation of CTD adult-presenting or adult-onset tic experiences and potential reasons behind the underrepresentation of prevalence rates in the adult population.

Methods

Study design

The study used a qualitative approach to explore the journey to validation and the attached meaning of diagnosis for adult individuals to understand the positive and negative impacts of a confirmed diagnosis, and the barriers to obtaining this confirmation. The study also captured the experiential component of adults with tic disorders, exploring their lived experiences, their recognition of tics, as well as highlighting the wider societal, medical and environmental factors contributing to this experience. Our overarching aim was to comprehend the obstacles, facilitators and ramifications (both favourable and unfavourable) regarding symptomatic adults acknowledging their CTD condition. Hence, our study design involved the consideration of creating open-ended semi-structured interview questions, monitoring their impact on participants, adjusting the interview process as needed, faithfully transcribing and multiple reviews of accounts and aiming to employ a reflexive thematic approach to analysis. Reflexive thematic analysis was chosen as the means of data consolidation as it afforded the dynamic ability to explore researcher reflexivity, convergent and divergent narratives, contextual existential significance and acknowledgement of latent and symbolic interactionism in our participants' narratives (Braun & Clarke, 2006, 2019; Smith & Osborn, 2004).

Participants and recruitment

Participants were recruited through opting in for individual interviews after participating in a separate online survey study that explored experiences of self-identification, diagnosis and support for tics. Using both quantitative and qualitative methods, the online survey examined their tic profiles, reasons for seeking diagnosis or self-identifying, and, for those with a formal diagnosis, the support and validation they received. This study, therefore, qualitatively expanded on participant experiences and informed the questions asked within this study. Participant eligibility criteria for the survey (and subsequent interview) were being native to the United Kingdom (UK) (or had resided in the UK for >10 years to allow for sufficient exposure to the UK healthcare system), being English speakers and able to give informed consent.

No other restrictions were placed on participants' gender, ethnicity or other demographic characteristics. Recruitment for the survey and interview was conducted by advertising online through UK representative tic disorder charities and snowballing social media outreach (e.g. Facebook, X/Twitter). Out of the 32 online survey participants with a confirmed late diagnosis (≥ 18 years), 21 expressed an interest in undertaking the interview. Of these, 14 individuals responded to initial contact, and all consented to participation, with 13 participating in an individual one-to-one semi-structured interview and one participant providing a written response to interview questions through encrypted email correspondence.

Participants (see Table 1) were between 18 and 59 years of age (mean = 39; SD = 15.4), with five identifying as female, seven as male, 1 as trans female and 1 as non-binary. All were adults resident in the UK. Although nine (64%) reported tic onset in childhood (< 18 years), all who were interviewed met the inclusion criteria of self-reporting as being formally diagnosed with a CTD (including TS) in adulthood (≥ 18 years). Participants were also asked to self-disclose any other formally diagnosed co-occurring conditions (Table 1).

Data collection

The experiences of participants were explored through semi-structured interviews conducted by the first author. The research team devised and refined the interview questions:

- (1) *What is it like having a tic disorder in adulthood?*
- (2) *What earlier experiences did you have with tics and what thoughts did you have about them?*
- (3) *How do others respond to your tics?*
- (4) *What was your experience of looking for information about your symptoms and what might be causing them?*
- (5) *Was there anything in particular that led you to deciding to seek out diagnosis in adulthood?*
- (6) *Once you had made the decision to seek a diagnosis – what was your experience once you started the process and visited a professional?*
- (7) *What were the most helpful and the most problematic parts of the process for you?*
- (8) *How has having the diagnosis changed things for you?*
- (9) *What recommendations would you give to others about getting a tic disorder diagnosis in adulthood and accessing support?*

The 13 one-to-one interviews were audially/visually recorded via an online video conferencing platform (Microsoft Teams) and transcribed verbatim by the first author. Interviews lasted 25–70 min ($M = 39.98$; $SD = 10.97$). The one written response was conducted over an encrypted email and a Word document, in response to the above interview questions.

Ethics

Ethical approval was granted by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority protocol number LMS/PGR/UH/04921. Prior to the interview, participants were provided with a study brief, regulations, the right to withdraw and intention for their anonymised data to be published, and written informed consent was obtained. Participants received debriefs, including links for additional support after participation. The researchers upheld confidentiality protocols, applied pseudonyms to transcribed data, and interview recordings were deleted after transcription.

Reflexivity and ontology

The primary author's motivation for understanding CTD adults stemmed from their own experiences with a late diagnosis, and their own personal experiences supporting adults with healthcare support need to gain access to services. Being considered a CTD 'insider' researcher (Jones & Phoenix-Kane, 2025), placed more value on reflexivity, supporting the use of reflexive TA (Braun & Clarke, 2020). This enabled the

Table 1. Demographic characteristics of participants.

Participant	Interview format	Age	Gender	Region of the UK	Onset	Diagnosis	Co-occurring conditions (self-reported)	Duration between first provider visit and formal diagnosis*	Final diagnosis provider
1	Videocall	19	Non-Binary	Southeast England	Childhood	Tourette Syndrome	Autism Spectrum Disorder, OCD, Anxiety, Depression, Insomnia, Seizures, PTSD, BPD, Hypermobility Disorder Undiagnosed (suspected); FND	6 months	Private
2	Videocall	22	Female	England, East Midlands	Adult	Chronic Tic Disorder	OCD, Anxiety, Depression	3 years	NHS
3	Videocall	33	Female (Trans)	England, Yorkshire	Adult	Tourette Syndrome	ADHD, Autism Spectrum Disorder, Anxiety, Dyslexia, Dyspraxia, Sensory Processing Disorder, FND	1 year	NHS
4	Videocall	25	Male	England, West Midlands	Childhood	Tourette Syndrome	OCD, Anxiety	10 months	NHS
5	Written (via email)	22	Female	Northwest England	Childhood	Tourette Syndrome	Dyslexia	4 months	NHS
6	Videocall	18	Female	Southwest England	Childhood	Tourette Syndrome	Autism Spectrum Disorder, Depression	1 year	NHS
7	Videocall	55	Male	Southeast England	Adult	Chronic Tic Disorder	ADHD, Autism Spectrum Disorder, Depression, Dyslexia, Insomnia	10 years	NHS
8	Videocall	46	Female	Southeast England	Childhood	Chronic Tic Disorder	None	Less than 1 month	Private
9	Videocall	46	Male	Scotland (Lothian)	Childhood	Tourette Syndrome	Anxiety, Depression, Chronic pain	4 years	NHS
10	Videocall	50	Male	Southeast England	Childhood	Tourette Syndrome	ADHD, Autism Spectrum Disorder, OCD, Anxiety, Insomnia, Dyscalculia	Less than 1 month	Private
11	Videocall	54	Male	Southwest England	Childhood	Tourette Syndrome	Anxiety, Depression, Insomnia Undiagnosed (suspected); ADHD, Autism Spectrum Disorder	15 years	NHS
12	Videocall	59	Male	Northeast England	Adult	Tourette Syndrome	ADHD, Autism Spectrum Disorder, OCD, Anxiety, Depression, Sensory Processing Disorder	9 months	NHS
13	Videocall	39	Male	Southeast England	Childhood	Tourette Syndrome	ADHD, OCD, Anxiety, Depression, Dyslexia, Dyspraxia, Insomnia, Sensory Processing Disorder	Less than 1 month	NHS
14	Videocall	57	Female	Southwest England	Adult	Tourette Syndrome	ADHD, Anxiety, Depression, Insomnia	1 year	NHS

*Estimated time from the first healthcare provider interaction concerning the condition and final diagnosis. Acronyms used in the table: attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD), borderline Personality disorder (BPD) and functional neurological disorder (FND).

consideration of how personal values, experiences and clinical approaches might impact data analysis (Braun & Clarke, 2019, 2020), necessitating reflexive conversations within the research team throughout the study.

A critical realist ontological approach was adopted, which acknowledges the existence of one reality but recognises individuals to have different perspectives and experiences shaped by underlying social structures and forces (Christodoulou, 2023).

Data analysis

The transcripts of all interviews and the written response were collated and read multiple times to gain familiarity with the data by the first author. Iterations of systematic initial and emerging coding and theme definition were led by the first and second authors, with consultation with the rest of the research team, in accordance with thematic analysis principles (familiarisation of data through transcription and repeated reading, initial coding, theme generation and report production) as outlined in Braun and Clarke (2006, 2019). Themes were then identified and tested for fit, linking them to extracts and the entire data set, with the production and finalisation of the report conducted by the research team. For member check validity, all participants were invited to comment on the results (O'Brien et al., 2014). However, this did raise the concern that checking transcripts may be stressful for some participants to relive unpleasant experiences (McKim, 2023). A subset of six participants confirmed that they were happy to read their individual transcripts and corroborated the key themes via verbal and email correspondence.

Results

Following the thematic analysis of the participants disclosed lived experience, three main themes were identified with nine sub-themes (Table 2).

Theme one: minimisation

This main theme encapsulates the recognition of tic symptomology, the notion of adulthood, control and conforming through minimisation to social norms and the physical and mental toil for those living with a CTD.

Making sense – believing the unbelievable

All but one participant commented on the lack of knowledge, comprehension, and recognition of their tics internally and externally in their earlier experiences during childhood. This shortage had several potential points of external origin, from the backdrop of medical, parental and public understanding:

When as a kid, when I was about seven, I think, well my mom said it was seven, I think it was more like ten I had a lot of throat clearing tics and it was constant we didn't call them tics, it was just me throat clearing, but it used to drive my dad around the twist and I couldn't not do it. So, I was taken to the doctor and this was like 1970 something, and they were like, oh, does he have a feather pillow and we said yes, and said, well try a different one try a sponge pillow and that was all they offered I tried my very hardest notto do the throat clearing around my dad and it turned into sniffing and then it turned into blinking and other things. (Participant 11, aged 54)

Table 2. Themes and sub-themes generated from the data.

Theme	Sub-theme
Minimisation	Making sense – believing the unbelievable Hiding the visible The pain of controlling the uncontrollable
Ironic luck and privilege	Owning the journey Unlocking the gate – A question of luck?
The anti-climax	Quest for deliverance – the medicine-centric trials Mourning loss Reaching acceptance Protecting the tribe

The sentiment of ‘trying my very hardest not to’ echoed throughout most of the accounts, emphasising the acquired personal belief that mitigation, masking and control were possible. Similarly, Participant 4 (aged 25) described:

My parents ... have OCD and a lot of their sort of behaviours to me, it was sort of called like habits [*does air quotes*] and I developed these unusual behaviours and I was told that, you know, don't ... It wasn't intentionally to ... be ... negative about them because there wasn't an understanding ... but there was – it's embarrassing, stop, try and stop yourself from doing it, try your best, it's just a habit.

The repetition of ‘try’ and ‘stop’ alongside the negative minimising response ‘just a habit’ and ‘try your best’ (even unintentionally) from parental figures, highlighted a perceived sense from others of participants control over ‘embarrassing’ tic presentation, adding to the deflection or dismissal of tic recognition involving labelling or identifying the movements and vocalisations as tics.

Indeed, without the acknowledgement of tics, the language in individual accounts predominantly used to describe tics before recognition included ‘twitch’ [Participants 8, 9, 13, 14] and ‘habit’ [Participants 4, 9, 13] and a described inability to regulate movement or speech. With a sense of external pressure, these commentaries often led to an expressed conditioned internal minimisation from a young age to conform to perceived social norms or appropriateness. This was expressed through participant accounts as an acceptance that they were just ‘odd’ [Participants 2, 10, 11, 14], less than ‘normal’ [Participants 3, 10, 14], ‘weird’ [Participants 1, 3, 4, 8, 11, 13] or attributed to deflected causation such as attention seeking or being naughty:

I've been ticing, you know, all my life, but just not enough for it to ever be more than just, I hate to use the expression, attention seeking ... it was ... always been just dismissed as that ... but that's ... at a time when Tourette's was almost unheard of. (Participant 7, aged 55)

When I was a child, I was naughty, but I wasn't ... my whole life has been marked by can't you be serious, can you stop doing that, how about you just stand still for a minute ... and the doctrine that was presented to me throughout my life, throughout my adolescence and into my young adulthood was that I'm a stroppy little so and so, that I like to buck the trend and ... I just can't take things serious, you know and you get told that, you start believing it. (Participant 10, aged 50)

With this potentially misrepresented and internalised belief of not being taken seriously or being described as ‘naughty’, an overarching thread within all accounts was the personal responsibility to hide experiences perceived to be within their control, yet which did not make sense. Additionally, the typical public understanding and perceived rareness of tics influenced individual recognition: *I didn't link the two because in the public domain, it's about swearing and being, you know, that sort of thing. It's not really a reflection of ... my symptoms* (Participant 13, aged 39).

As such, for some, external observation to facilitate initial recognition: ‘... first bit of my onset, my other half knew, and I couldn't quite believe ... darling I think you've got Tourette's, and I was like, no way, not me, no way on earth, and well, she was right’ (Participant 3, aged 33), the reactive repetition of ‘no way’ and initial denial seemed to emphasise their sense of disbelief.

Nevertheless, denial was called into question when individuals had to confront their disruptive or intensifying symptomology – sometimes inexplicably [Participant 2] and sometimes with potential identified factors [Participant 8, aged 46]:

I was absolutely fine the day before and it suddenly exploded and I was at university at the time, so it was very, very disruptive. I had a friend with tics and we were bouncing off each other and a lot of people were confused because I wasn't like that the day before. So mostly it was, I was embarrassed. I didn't know what it was doing or if it could get worse or what was happening. So ... I felt like I didn't have a choice at the time. (Participant 2, aged 22)

I think since I became perimenopausal, my tics have gone through the roof, and I've developed new ones ... I've been getting more tic attacks that are longer, that won't stop, that are really intense ... So, there were some people that have known me that then recently have gone, oh my God, ringing up my partner going, what's up with [K]? ... It's almost like a complete surprise to them. (Participant 8, aged 46)

This confrontation and call to action challenged their established beliefs, and initial personal reactions were often ones of complete surprise, confusion, making it up and of doubting one's sanity:

When I first got diagnosed, I was like, I'm definitely making this up, like, I am faking this ... I'm gonna try really hard not to tic, I'm gonna try really, really hard. And it's sort of not possible when you have an actual tic disorder, right. So, I was trying so hard and using all my energy to suppress my tics and still having tics. (Participant 6, aged 18)

It's nuts this because back when I was 14-year-old, my legs kept collapsing ... and ... I never knew. I used to get ... my mum would hit me saying I were being dramatic, stop being dramatic. In the end they did an exploratory operation and opened my left leg up, 25 stitches and couldn't find anything and I've always had this thing where my legs have given way but never known why. And this started more frequently before my diagnosis, so looking back now ... I can map it all out and understand it, but back then I were just so confused ... I thought I was going insane, I thought going crazy, I thought it was the grief that has pushed me over the top. (Participant 12, aged 59)

Perhaps in contrast to a negative response to tics, Participant 14 (aged 57) was questioned on what they did to be 'blessed' with the condition, potentially showing external minimisation: *'Someone once asked me, oh, what did you do in life ... to be blessed with Tourette's, which was really ... you know, I'm not a mass murderer or anything, so it's not, you know, payback karma or anything'*.

Through hindsight, it was upon gaining a confirmed diagnosis or gleaned more knowledge of tic disorders, individuals could start to change and confirm their new belief system, understand their tics, and identify earlier potential displays of tics:

Once I got the diagnosis and I started to read up ... and learn more about the condition I could then ... sit back and go – alright, yeah, that annoying habit that my parents said I did when I was x age ... that was a tic. (Participant 9, aged 46)

Hiding the visible

Within this context of believability, tics still had a visual and observable quality, sometimes eliciting comedic and tragic reactions. Consequently, embarrassment and self-consciousness were experienced when tics emerged, especially when in public:

In public, a lot of the time I get laughs but like, so yesterday I went out for dinner with an old friend and my partner. We're in a pub. I was ticy as hell and the amount of head turns and dirty looks and stares I got was unreal. And it was like they're looking at you like; you shouldn't be out in public ... particularly the older people were like looking at me with disgust. (Participant 3, aged 33)

As such, many individuals attempted to combat this through suppression, masking or misdirection:

So, most of them ask me things like, oh what you saying no for, cos I shake my head, or are you cold, cos I'll do a shiver. Or ... I will twitch my nose ... there are all sorts of things ... and I've always blamed things away. Like I go, oh yeah, I crooked me neck ... when ... my shoulders are going at 100 miles an hour ... so I've always been able to explain it away. (Participant 8, aged 46)

As Participant 7 suggested, this was to *'get away with it'*. Some, like Participant 14 (aged 57), were questioned as to the validity of having a CTD because of their suppression, and their wish not to be defined by it:

One person said to me, you haven't got proper Tourette's. I thought well walk in my ... shoes for a couple of days and you'll see how ... it can be debilitating, of course it can ... don't use that word very often ... to apply to me ... because ... I don't want it to over affect me in my life. I don't want it to take over and be the be all and end all cos I'm me.

All participants mentioned various mechanisms they employed, such as distraction or concentration – to suppress tics. However, as Participant 10 (aged 50) described, this often came with a significant energy toil and concerted effort to maintain:

Whilst I'm concentrating, because I work as a paramedic ... my brain is so preoccupied with what I'm doing I can even, to some extent, manage the urge to shrug, to do this, to do that but ... it's exhausting ... and after doing 4–5 h of trying to be normal, or what society perceives to be normal, drained, it's like somebody's opened a tap and all my energy is gone.

Similarly, Participant 1 (aged 19) commented that the transition to adulthood brought about a credence, both personal and external, of the expectation of having increased ability to control tics and behave to social norms:

When I broke my hand because of the Tourette's hitting a table ... yeah, it was a bit, trying to explain to someone, oh yeah no, my body decided I'm going to punch a table and they looked at me and their like, you're an adult, why did you do that? Like ... I didn't mean to. And it does feel quite different I think, where I'm an adult, there's sort of like, well why are you doing that? You should be able to just not do that because you're a grown up, you should know what you're doing. It's like ... not how it works.

However, in contrast to the view that tics might wane in adulthood, many recounted that their tics got more observably worse in adulthood and, as such, experienced an augmented incapacity to suppress:

It was starting to become really obvious and harder to sort of ... and it's been like that as I've gotten older, it's become a lot harder to sort of deal with them, they've got a lot worse, and they've become a lot harder to suppress. (Participant 4, aged 25)

Mine's just a reoccurrence of childhood tics which ... I wasn't really fully aware of ... when they started in adulthood aged 46, they were pretty brutal ... came on full force ... I couldn't control them ... I couldn't suppress them ... when I say suppress, it's a tool that I use when I need to, but even back then I didn't have that ability. (Participant 12, aged 59)

Participant 2 (aged 22) highlighted that because some people might have milder tics, this could impact the reported or perceived prevalence within the general population:

Must be more people than we think that have mild tics even in adulthood, and they haven't sought help, because it possibly doesn't bother them as much, and to me that reassures me that perhaps the numbers of reported tics in adults is probably lower than we know.

However, it might be questioned whether suppression and embarrassment might also play a role in the condition not being clinically reported, as Participant 4 (aged 25) said: *'It was this embarrassing thing that I needed to sort of hide ... it wasn't something that I needed to go to the doctor about'*. Yet, this hiding seemed to come at a cost.

Pain of controlling the uncontrollable

As well as masking, controlling, hiding or redirecting tics, participants shared their experiences of the physical and mental strain associated with having CTDs: *'They [tics] just ran roughshod over me and basically ... did a lot of physical damage. And ... I think did a lot of mental damage as well'* (Participant 12, aged 59).

The types of physical challenges reported included the secondary serious physical harm and discomfort that uncontrollable tics could cause, such as fractures, broken bones, pulling of muscles and ligament damage. Participant 3 (aged 33) recounted:

The damaging stuff is the motor tics when I'm hitting things and getting bruises. When I'm, literally break-, fracturing my thumb or breaking my coccyx, you know. And like, some of my friends have been in hospital ... with ligament damage or whatever, and then you try and get an MRI and then you can't stay still for it, and they don't understand how bad it really is.

The lack of understanding and how extreme it could be was also shared by Participant 9 (aged 46), who expanded on other physical consequences, such as problems sleeping or walking, and the need to employ physical disability aids such as wheelchairs:

The drop tics ... there're people that are having to live their life in wheelchairs ... People wouldn't understand and I guarantee 90% of the public wouldn't understand if they said, ... why ... are you in a wheelchair, because I've got Tourette syndrome ... I know someone that's had that problem in the Tourette's community, he spoke online about saying he may ... need to get these operations ... and being told realistically, if it keeps getting worse with your tics ... you may lose half your leg.

The relentless physical challenges were discussed to propagate their mental challenges and impact on well-being. This seemed especially true for those who had to face an exacerbation of tics in adulthood; Participant 12 (aged 59), whose tics escalated at 46, stated: *'I suffer a lot with mental health issues because of the condition, because it's so relentless, it is gonna change your life'*. Participant 7 (aged 55) noted that the outward nature of the condition was potentially more prominent in society's perception, missing the inside bombardment some might experience:

The fact that all people see or hear is the visual stuff . . . and the vocal stuff. And, actually, the fact that90% of the stuff going on is inside intrusive thoughtsand the bombardment of . . . just stuff all the timeand how physically exhausting it can be I don't think the medical profession have any idea let alone society.

Additionally, the variability and random nature of tics and their patterns might have added to the perception of the condition's uncontrollability. Participant 2 (aged 22) talked about this variability and how they attempted to identify and avoid specific sensory inputs to anticipate and not exacerbate tics:

It has mostly affected my walking but I feel like my tics do have their own patterns sometimes and they can join together or they can be separate, they can vary and have different triggers, or they can have worse days. To me, my tics are a bit more random because I know that things like heat can make it worse.

Theme two: ironic luck and privilege

This main theme encapsulates the individual ownership participants underwent in their journey to tic and disorder recognition, and how luck and privilege intertwined with unlocking the (often looping) gate to diagnosis.

Owning the journey

All participants shared the barriers they faced in seeking knowledge and understanding about their CTD. This was particularly true for those who sought answers, for example, before access to the internet. Participant 10 (aged 50) highlighted how hard it was to gain knowledge and find the resources and vocabulary to explain their 'funny movements' and 'random words' to search and explain to others. This barrier sometimes propagated a sense of 'nothing can be done':

Before the internet became a thing, it was very hard to actually gain knowledge. You had to actually have a direction that you could follow to be able to start researching, whatever you wanted to look atit was very, very complicated to try and figure out what on Earth was going on, so I accepted that this was me nothing can be done Prior to that . . . where would you have started, saying rude words or random words coming out or not being able to movethe actual word for tic for example wouldn't have even crossed mymind to actually go and look. Then you've got the issues of when you go to a librarian and you say, have you got books on people who do funny movementsbecause you need to havethe ability to explain . . . have the language to explain what you are looking for With the advent of the internet, especially over the last 15 years where search engines have become very, very adept to actually finding stuff that you didn't know you were looking for even you can actually learn the vocabulary around a variety of conditions.

Some self-explorations and realisations were initiated by chance encounters with stories in media (e.g. documentaries) '*we watched 'I swear I can't help it' saw Jonny on that on there and I'm like, oh shit, maybe I am a bit like that*' (Participant 3, aged 33); and support organisations '*I was absolutely terrified and knew nothing . . . and didn't know where to look I was lucky enough to stumble across [National Charity] very early*' (Participant 7, aged 55). Participant 13 (aged 39) figured out his condition through Higher Education: '*It wasn't until I went to medical school and worked it out for myself and went to seea neurologist I did bits of neurology and I started reading it and I think it sort of twigged, oh my God, this is actually what I've got I sort of figured it out*'.

With acquired knowledge, many recounted their transformation to self-advocating experts, resorting to self-diagnosis and/or re-education of medical professionals before getting medical validation and attention (for tics and co-occurring conditions). Participant 11 (aged 54) remembered how medical professional perception disagreed with his own and support group experiences, and as such did not give him 'any confidence' in their medical opinion:

I saw my neurologistand I wanted totalk to him about various things I think he just wanted to have his lunch actually . . . and I was there for about 20 minwhile we were there, it became apparent that I knew a lot more than he did, and some things I really called into question and I would love to sit down and saylook this isn't right I'm looking to get a diagnosis for this and that, like ADHD and autismand he's like well I doubt that more than 1% of any people with tics have autism I'm in a support group like over 80% of people in this group have other conditions and most of those people in my support groupare autisticafterwards I thought actually . . . there'll be more than 1% of the general public will be autisticso that

was just total rubbish ... he is not a Tourette specialist, he's a tic specialist apparently but ... that does not give me any confidence.

Conversely, a few participants, such as Participant 6 (aged 18), reported having supportive GPs who guided them:

So I didn't really know a lot about Tourette's ... my GP was quite good and she was like, oh, I think this is what's going on ... I was like ... suddenly am in this position where I can't stop moving or things keep happening and I'm not telling my body to do so ... she gave me lots of information, she pointed me towards more information and got me really well informed.

When questioned about tips for individuals seeking a CTD diagnosis in adulthood, some recommended personally accruing proof to present to medical professionals, noting factors that improved or worsened tics:

Get as much evidence as you can- e.g. parental accounts, videos and friends. All these can help with figuring out when your tics started and getting the right care. Write out a list of your motor and vocal tics, that you can hand to your GP and neurologist. As well as things that improve then and make them worse. Ask to be referred to neurology instead of mental health. (Participant 5, aged 22)

Participant 8 (aged 46) also remarked on the cases where the irony of 'can't stop ticing' might cease to 'not moving an inch' when personally presenting in a medical setting, and as such, having videos to mitigate this:

Get someone to video you. That was ... my other tip because ... it's like sod's law, you go, oh yeah, I can't stop ticing and then now I am just sitting there in the office like ... not moving an inch ... I showed him the videos ... and that helped ... I think you need to speak to the people around you as well, people you live with or others getting, sort of, their view on it.

Overall, there seemed to be a consensus amongst participants' accounts of having to take ownership, prepare and arm oneself to approach the medical community to avoid dismissal, disappointment, misdiagnosis or misunderstanding and through this to unlock the potential for diagnosis and treatment.

Unlocking the gate – a question of luck?

Participant 2 (aged 22) shared their experience of feeling like '*you have to go through a lot of hoops to be able to ... reach the people who are most likely to be able to help you because you're ... a bit older*'. This often seemed to lead to diagnostic dismissal, which Participant 1 stated '*too mentally ill for us [Doctors] ... dismiss it because you're an adult or you have other issues*'.

The encountered resistance and sometimes delayed diagnosis till adulthood was exacerbated by the requirement to find professionals with competency and appropriate diagnostic understanding:

I can understand why GP's and other allied health professionals would have struggled potentially to be able ... to categorise patients. And the very few fortunate ones that were sent to neurology, then it all boils down to whether the neurologist you'd see ... is competent ... in movement disorders and even believes in it. Because quite a few discussions I've had with some of the GPs that I actually work with now are coming up to retirement, they said for years we actually didn't believe that GTS was ... a real thing because we didn't have much to go by. (Participant 10, aged 50)

Participant 11 (aged 54) emotionally recounted their progression to counter dismissive, acceptance of weirdness or other suspected causes, sharing the majority consensus of 'pushing' for diagnosis and treatment:

And then they finally agreed, after me really pushing I went to see one person ... and she's like why do you need to see a neurologist ... can't you just accept that you're a bit weird ... and I'm like, no I can't I need help with this. Sorry I'm getting a bit teary about it.

Participant 11 (aged 54) also reflected, when thinking of others' diagnostic journeys, that gaining access to specialists and the support received varied:

I found some people actually recently ... who've developed tic disorders like in the last two or three years. Some of those have ... got them diagnosed very quickly ... I'm quite jealous of them actually ... in some areas of the country they seem to be better at doing that sort of stuff ... Like a guy ... over in [East Anglia] ... he developed it a couple of years ago and he's already got a diagnosis and his doctor was very supportive ... but then there's

other people I talk to ... someone in [Southern England] and she is so frustrated that everything you know is just ... constant, constant brick walls.

The repetition ('very supportive', 'very quickly'; 'constant, constant brick walls') accentuated the dichotomy in experiences of diagnostic accessibility and support. Participant 13 (aged 39) recounted the difficulty accessing a specialist for adult presentations:

My first mode of attack was to find someone and that's really the most difficult bit and it's like, how do you find someone who is a specialist in Tourette's full stop ... difficult, let alone how do you find someone who can see adults with Tourette's which is like really hard as far as I can figure out.

Likewise, Participant 3's (aged 33) journey also emphasised having to go through multiple iterations of specialists to gain diagnostic clarification:

Eight neurologists for FND and Tourette's in less than three years. I'm going through them like the country goes through prime ministers ... there's no consistency ... I shouldn't need to go to hospital, and a neurologist, I think it's this, go away and see another one, I think it's this as well, we'll diagnose you, then you need to see someone else. They should know.

Conversely, several participants expressed the luck of being in a good location to access specialists:

As the area I live in has a really well funded neurology department I have no problematic parts, I just wish everyone could access the same care that I did. (Participant 5, aged 22);

I got a little bit more insistent ... I needed to push it ... but actually ... they were fairly good ... and the waiting time to see ... a psychiatrist was I think, two or three months ... I think that was pure luck really. (Participant 7, aged 55); and

I had a good rapport with him before ... and ... he seen the change from ... thinking I had mental health issues to like ... this isn't ... this needs investigating. So, I pretty much got fast tracked through ... and I went to see somebody ... I saw him once and he gave me the diagnosis. (Participant 12, aged 59)

Finally, the reality was that once the appropriate diagnostician was seen, validation could be breathtakingly fast:

... so it must have been about 15 min going over this stuff and he just sat, he just more or less said right you have Tourette syndrome. And it's like could I not have seen you at the start. It's like 15 min with you and I had a diagnosis. After about two or three years of fighting with doctors and everything just to get to the neurologist. Had I been referred to them from the very start, I would have known right away. (Participant 9, aged 46)

Several participants discussed having the privilege or fortune of being able to afford private healthcare, which allowed them to receive faster diagnoses or treatment and validation without relying on the National Health Service (NHS) and its enduring lengthy waiting times:

Everyone has such a unique experience of seeking diagnosis ... and I am aware that I was just really privileged to be able to go private ... long way to go before people are full comfortable and feel believed, which they should have to in the first place, it should be ... we should be just listened to straight away. (Participant 2, aged 22)

Some advised others facing similar situations to consider going private if possible:

Book yourself in and expect a long wait. I think the NHS as an organisation has a massive failure when it comes to the ability to send people for diagnosis ... because for them it ranks really quite down at the bottom of the pit of conditions ... worst case scenario, if you can afford it, pay for it privately. (Participant 10, aged 50)

Lastly, Participant 2 (aged 22) stressed the importance of not being dismissed when gaining support and validation:

You shouldn't be dismissed ... even if, because it's an unusual position to be an adult with tics and it doesn't follow the usual pattern ... if you're dismissed, you might never get help, or you might delay getting help, which isn't any good.

Whilst diagnosis seemed an important key to unlocking understanding and potential interventions, it did not seem to lead to resolution, explored now in the final theme.

Theme three: the anti-climax

This main theme looks at the medical and therapeutic support mechanisms encountered pre- and post-diagnosis, and their availability and effectiveness from the participant's perspective. The participants also reflected on their journey to acceptance, recognising missed opportunities or limitations imposed by the condition and embracing and protecting a '*community of difference*' (Participant 3).

Quest for deliverance – the medicine-centric trials

Pre- and post-diagnosis, some participants recounted their medicine-centric offering by medical professionals to alleviate their tics and other aspects of their conditions. The medicines offered were often described as 'strong':

I was straight on ... antipsychotics and I had bad reactions to that ... would have preferred to go the psychotherapy side of things before trialling really strong medications to try and tackle something that we didn't even know the cause of. I wasn't really that happy about that, but I didn't feel like I had much of a choice. (Participant 2, aged 22)

There was also a sense of trial-and error, with a lack of choice, no guarantee of success yet significant side effects:

The anxiety medication I was on didn't help ... they tried me with different medication, I've seemed to be very sensitive to medication and it always causes a lot of side effects and ... I think virtually every time it wasn't worth ... it. There was one I was on for a while and just felt like, it sort of calmed me down quite a bit, but I felt like I was behind a glass wall all the time and I just didn't feel me and I put a lot of weight on. (Participant 11, aged 54)

Participant 3 (aged 33) mentioned an extreme case in which 'pre-formal diagnosis I was put on Tetrabenzine. Which destroyed me. I lasted five days on them and I was about to kill myself.

Participant 10 (aged 50) recounted his accidental discovery when experiencing a back injury that Gabapentinoid medications helped his tics. However, they still had to start on antidepressants, rather than initially being able to go back to his preferred medication route:

Whether a low grade Pregabalin or Gabapentin, so Gabapentinoid, should be the first line of ... pharmaceutical ... intervention to suppress tics ... it would be beneficial if I didn't have to have the argument, I want this drug, no, you'll start on Sertraline. Why should I start on an SSRI, when actually I know that a Gabapentinoid can do the work.

For Participant 4 (aged 25), even the medical professional advised against pharmaceutical intervention, with the comment of 'crazy sphere' and 'serious' corroborating this sense of strength of medications on offer:

I wanted to go to university ... I'd spoken to him [diagnosing professional] about any sort of ... minor sedative medications to sort of help at times when they're, when my tics are bad or any other sort of more serious medications. And he actually said ... because I'm like young ... and ... it's not like crazy sphere, he didn't want, he wanted to avoid that sort of medication for me ... he knows what he is talking about so I just listen, I didn't really try and go against it.

Along with the lack of choice of medications, perhaps in contrast, some participants like Participant 12 (aged 59) noted that medicines could be used more positively as a gatekeeper to diagnosis:

I think you're told when you go in for a diagnosis that we are ... medically run services and we are pro-medicines and then you've more or less got to agree that you're gonna take medication ... Medication should be an option. It should be a personal choice that you make between yourself and the doctor ... because you've gotta live your life ... take my dopamine away from me, takes my creativity away from me, takes my lust for life away from me.

However, due to strength, side effects and efficacy, many participants avoided or subsequently discounted medication as a viable deliverance mechanism, preferring to manage tics through psychotherapy or lifestyle changes:

There are options for medication, but ... it's not really a route I want to go down. Because, like antipsychotics have a lot of ... side effects and ... they're not something ... I was willing to take ... my tics I don't think are bad enough or they do not affect my life enough to warrant taking medication ... I tend to manage them more with lifestyle things. So, sleep has a massive impact on my tics, if I've not slept that's a big issue for me ... exercise

... reducing stress levels, I think for me those are easier things than to deal with more medication and more side effects. (Participant 6, aged 18)

The sort of fallout from it, and the medication made me feel terribly anxious and horrible and so I didn't take their medication for very long. I stopped the medication, and I've never touched medication since because it's scared me off. (Participant 13, aged 39)

As such, with the denial of medicines or lack of available treatments (particularly on the NHS), many participants recounted that they or others hit the end of the line; being dismissed or discharged, with no direction to other interventions, follow-up, or support mechanisms:

I was diagnosed on the day, and he said to me, I'm really sorry, I'm going to diagnose you with Tourette's, and I said, why are you sorry? He said, because there's nothing I can do to help you. (Participant 3, aged 33)

The only treatment on the NHS is medication. And if you don't want any medication you're discharged as there's nothing else that they can help you with. Privately the options are also pretty slim, but a little more holistic. (Participant 5, aged 22)

I would say that at no point was anybody actually helpful ... the diagnosis was fairly straightforward, but ... nobody pointed me in the direction of ... any support or advice or help ... and I've always been surprised that ... there is never any follow up. (Participant 7, aged 55)

Participant 12 (aged 59) commented that this could lead to potentially unhelpful self-medication efforts and significant consequences: *'I've had friends who've ... lost their lives because ... they've hated the condition ... they've been chasing a dream of medication. They've self-medicated; alcohol, drugs, food ... just been totally unhappy with how they are'*.

Despite the lack of potential deliverance, many participants still valued obtaining a diagnosis, to be able to provide evidence for employers and self-assurance:

Withholding a diagnosis because you don't want someone to have a label, it's really unhelpful because a label can be, can really open doors in terms of ... if you need reasonable adjustments from your employer, like how are you going to evidence that ... you've actually got Tourette's, how would you do that. (Participant 6, aged 18)

Having a word ... I think makes a huge difference to me, in so far as a) ... I have some idea ... what's going on because ... I can relate it to other people because I can make that connection ... but b) I can turn to somebody else and say ignore me if I make stupid noises, it's only Tourette's ... it's about ... being able to give context ... without context ... suddenly tics become much more frightening. (Participant 7, aged 55)

Mourning loss

Confronting the realisation of having a CTD could evoke a profound sense of loss and negative consequences. For Participants 12 and 14, the exacerbation of the disorder ultimately meant the loss (or partial loss) of their careers and other daily activities:

I think how my tics manifested themselves put me in a bad position for work. I couldn't get any work. I had my own business which I couldn't do any longer because I kept falling off the ladders ... saying, telling, explaining to somebody I had Tourette's ... I can understand why people don't want to disclose it because the stigma that goes about ... it just puts you in the firing line. Puts a big cross on your back, you know, as a target. (Participant 12, aged 59)

Huge shock ... I was working and I lost my job ... I can't drive now, I'm terrified in a car now ... by the time I got to the swearing episodes, there was no way that I could work with children, and not be able to, you know, control myself with them ... At that point I was lashing out as well, hands and legs were, which is why I was sort of banned from driving because ... I had a tic and I drove an automatic car and slammed on the brake by accident and swerved into the curb with my son in the car. (Participant 14, aged 57)

Participant 14 (aged 57) even recounted the unsuitability of alternative careers offered to her:

I worked for the City Council ... they offered me a position within the City Council as an organist at the crematorium. I can't play an organ and it would not have been the right job ... even if I could play the organ.

For Participant 10 (aged 50), due to the condition not being taken seriously, incidents at work led to enduring disciplinary action:

This is also the same with GTS because they didn't take it seriously in my disciplinary case, which I'm still under investigation by the HCPC for it. But work has exonerated me completely, entirely, and the HCPC said, well, you could insult the member of the public. Ok, fantastic, so this is ongoing for a year, so that puts stress on me, and I feel victimised.

Several participants could consequently have an almost mournful reflection of previously missed opportunities, and the consequences the condition now had on themselves. Participant 13 (aged 39) recounted how this manifested as depression:

I ended up ... being told yes, it's Tourette's and I felt that was validation. But ... I then very quickly went into quite a depression ... his [Doctor] opinion on it was this is common after adults get a diagnosis ... I don't know if that's true ... that ... suddenly ... the release of it ... they ... often go into a depression. I had sort of depression anxiety episode for about three or four months where I was really unwell and had to take time off work, and I think maybe my tics got worse and I think just that being told OK, it's OK now.

Conversely, beyond this sense of loss, Participant 12 (aged 59) reflected that having the condition required an ability to accept limitations for work and adapting to practice through acknowledgement and compromise, which seemed more productive:

You've not gonna let it stop you, but ... there's gotta be a realisation that ... there's gonna be things that you can't do ... the world doesn't owe us anything ... You want reasonable adjustments at work if it means that you go into an office at a quiet time ... then that's fine. But ... if you wanna be a chef and you've got a problem with stabbing with knives or throwing knives, you can't expect people to reasonably adjust to that part, wearing chain armour suits. So, it's being realistic about what the challenges are ... I can no longer hold a pen ... or paint like I used to or draw. But ... I use my creativity through photography so ... it's having that ability to chop and change.

As such, this grieving might then come with a sense of reinvention to re-understand their sense of self:

I think having a diagnosis when you get to a certain age is a failed blessing because all of a sudden, you're faced with ... having to ... not reinvent yourself, but re-understand yourself. Figuring out who you are, what is this condition that you've read about. (Participant 10, aged 50)

Perhaps, this was a process that happened over time, where eventually diagnoses enabled acceptance and a more compassionate stance towards themselves.

Reaching acceptance

Most participants seemed to reach a form of acceptance of the impact, limitations and chronic nature of their conditions. For Participant 12 (aged 59), diagnosis confirmation was a tool for education, understanding one's identity and forgiveness:

Having a diagnosis is just, it's been ... like Saint Paul on the road to ... Damascus ... it's been ... massive ... and so important because I were able then to start to understand, educate myself about the condition. Given me a bit of an identity ... because I were just some mixed up jumbled up person with ADHD, OCD ... I mean I got the diagnosis for the other conditions, the cooccurring ones pretty much right away, but it's been a valuable tool ... been able to forgive myself ... for a lot of the chaos in my life.

Whilst there were variable ideas amongst participants of the amount of impact diagnosis had, Participant 10 (aged 50) commented that *'it gives you a little bit of empowerment about who you are and what your behaviours have or have not done. It takes away the feeling to some extent of the blame that has been forced upon you'*. On the other hand, Participant 13 (aged 39) stated:

It didn't bring the closure that I was hoping for, I thought it would close this feeling of I'm making it up or faking it, which hasn't completely gone away, but it is far, far better and I feel much more reassured ... Day-to-day it doesn't make a difference.

The time period to acceptance sometimes seemed to be exacerbated by external factors, judgement and internalisation. Participants referred to external attitudes when comprehending their own acceptance:

People are surprised by my level of acceptance ... that they're like ... why aren't you taking any steps to manage this ... why aren't you doing anything about this. And I'm like well, the options I've got ... aren't great for me either, don't fit with my lifestyle, they don't really work and I'm managing my tics as best as I can ... I mean it's other people they affect rather than me. (Participant 6, aged 18)

One aspect that seemed to hinder the ability to accept was the experiences of professionals minimising the severity of the condition and the impact tics had on them:

The hard thing that came out of it was ... at one point he [Specialist] said to me that he classified me as very mild ... which was probably fair enough. I mean from his aspect, because he said to me ... I see people with Tourette's who ... their tic is to set fire to the house or their tic is to steal a car, which I think is the real extreme end ... I sat there thinking well I tic every 20 s every day that I'm alive and I'm awake and it causes me severe pain chronically, and I'm not sat here smashing things up or shouting fuck, but it's horrible ... I don't class it as mild personally ... I'd be happy with moderate ... but ... that got to me. (Participant 13, aged 39)

When acceptance came, it helped them to manage even deteriorations in their condition, which arose through less masking and suppression:

Ironically, I see my condition to a degree has got worse. And I think that's partly from knowing what it is and now, sort of, not fighting ... my body. I tend to find there's an element of right so if I feel this is gonna happen let it happen kind of thing now. (Participant 9, aged 46)

Participants 3 and 12 also offered the narrative of recommending that others with the condition embrace, accept and not compare their manifestation with others, particularly in terms of severity:

Be prepared that you're gonna meet people that are more complex than you. And it's probably going to hit you like a ton of bricks, mentally. But also, be prepared that people might not be as bad as you and just learn the differences in the community and accept them, but become, allow yourself to become part of the community. Try not to deny it or hate yourself for it. (Participant 3, aged 33)

It might sound a bit extreme to say ... to somebody right at the beginning to embrace it, it would be a difficult task but knowing the fact that it's not gonna go anywhere ... the only way it's gonna get easier is if you learn to live with it and not, if you hate Tourette's syndrome it's gonna turn around and bit your arse ... you don't have to love it and by embracing it you're not loving it, you're just accepting it and learning to live along with it ... what I'm saying is don't make a big deal out of it ... Tics are tics, they come and they go, some stay, some don't. The more comfortable you are inside your own shoes the better. (Participant 12, aged 59)

For Participant 12 (aged 59), their created metaphor of shoes – to which this paper derives its name 'making the shoe fit' and was verified by member checks, extends this idea of 'fitting into' their shoes from initial presentation leading to discomfort and 'resentment', to acceptance and potential attenuation through familiarisation of symptoms over time:

Initially, it's like having ... a new pair of shoes that you're forced to wear ... they're very, very uncomfortable, err, a lot of resentment, why do I have to wear these ... But as time goes on, I start to fit into it and I become more relaxed having the condition ... that's my little metaphor ... And I think the older I get ... as my age is creeping on and the condition ... hasn't lessened, people say oh your tics have lessened, they haven't lessened, I'm just, I'm fitting into them like a pair of old shoes.

This acceptance, and finding a better fit, seemed to enable space to be given to considering themselves as a protector, providing advice on how to navigate hurdles and negative responses. This is explored now in the final sub-theme.

Protecting the tribe

Given that Tourette's and CTDs were often misunderstood in the public domain and were, in some respects, an oxymoronic hidden and visible disability, many participants detailed the obligation to disclose and to spread awareness about the condition for their own and others' benefit:

I suppose it is sort of to pre-warn them of that this is going to happen, kind of, throughout our conversation. And I likened it one time ... I done an interview for a podcast for Tourette's and like I was saying to the person that being a gay man and same for like gay women ... you don't just come out once, you spend your entire life coming out to every new group of people you meet ... so, it's kind of put me in a situation where I need to come out twice to people. (Participant 9, aged 46)

I'm happy to talk to people about it because the more awareness you can spread ... I know I'm in a 10% sort of group of people that swear ... and not all Tourette's is about swearing ... we all know ... I'm a minority in that respect. (Participant 14, aged 57)

Having a confirmed diagnosis allowed participants to better articulate the condition to others:

When you're trying to explain to people why things are going on, everyone's heard of Tourette's ... A lot of the time they're like, oh, but why aren't you swearing ... there are misconceptions ... but it's like ... a word that everyone's heard of. When you say ... I've got tics, they're like oh, you've ... got bugs. (Participant 6, aged 18)

For Participants 1, 10 and 12, each detailed the 'bad' reactions and lack of acceptance of explanation by others when being challenged about the condition and how they approached disclosure. Participant 12 (aged 59) seemed to corroborate a responsibility to explain:

I generally find I have a bad response ... my condition's my responsibility right. So, I've gotta prepare myself for the worse-case scenario when going out ... So usually what happens is, I'll startle somebody. So right away, they're in a fight or flight response where their like, what was that noise ... why is he shouting loud, why has he swore, why has he punched himself in the face ... so the responsibilities back on me to explain to people or put them at ease ... I've gone through the full experience of being followed ... laughed at, mistaken as someone on drink and drugs ... someone had put the children behind them to ... project them from me, thinking I were a threat ... to being actually physically assaulted on a number of occasions and also receiving abuse off the police who said, yeah, I know you've got Tourette's but I'm telling you now to shut up.

Participant 1 (aged 19) utilised deflection when dealing with 'mean' or 'arse-y' people or responses:

If it's someone who is asking because they genuinely don't understand it then I'll sort of go – ok I have Tourette's, it means I do weird things and say stuff I don't mean. I can't control it, suppressing is not fun, don't make me do that please because I can't do that well ... but the people that are doing it in a really mean way, I've taken to just going – oh yeah no, I'm possessed. Like I have a badge not that says – Not possessed, just Tourette's – because someone accused me of being possessed. So now I have just taken to whenever anyone questions it in an arse-y way, I'm like no I'm just possessed. Like that's all, don't you worry. Despite the fact I have this massive badge on me that says quite the opposite.

Participant 10 (aged 50) considered the diagnosis as 'ammunition to fire back' against challenges:

There are times when people actually challenge you. And I think well hang on a minute, I'm not challenging you because you're walking on crutches ... I can understand that walking on crutches is socially acceptable because you've got a visible injury. But having an ... unseen disability doesn't mean to say that it's stressing me the less to compare to the guy with the crutches ... I personally think this is quite terrible. And knowing that there is something that I have been diagnosed with doesn't make it better. It just gives me ammunition to fire back and say, look, I've got XYZ.

Similarly, Participants such as 3 and 4 seemed to feel a diagnosis aided in counteracting potential detrimental situations or consequences, relating this to protection when interacting with authority figures such as the police:

I think the biggest thing for me with diagnosis was protection. Protection from the law. When I, cos police are a real trigger for me, so are nurses, nurses and police are like, yeah, I'm, I'm gone when I see either of them in uniforms, even carers that wear uniforms that look like nurses, that's, that's me gone ... if I'm in A&E and I'm shouting and screaming tics, at least I can say look I'm formerly diagnosed with Tourette's, don't arrest me, don't kick me out for harassment. (Participant 3, aged 33)

A big thing for me was the, er, [National Charity] ID card ... I wear, like everywhere ... even if I pop out to the shop ... but just in case, for whatever reason, I was stopped by the police, I just have it as like that's my, you know, please don't Taser me kind of thing ... so it was that protection of having [a diagnosis] ... you know, if anything did happen. (Participant 4, aged 25)

There was also a sense of protecting the tribe – forming a community of adults with the same condition, often through social media or networking through charities. These links were considered vital to obtain coping mechanisms and to supplement – or often compensate – for the minimised experiences of medical support:

It ... changed everything really. Not immediately in terms of like support but, just felt validated ... And because of that, I've then been able to ... connect with [National Charity] ... and they were able to send me along to like weekly meetings which previously ... I wouldn't have been able to access that if I didn't have this [a confirmed diagnosis] ... and that's led ... to a level of support which is just like life changing really. You know, my best friends are all people with Tourette's. (Participant 11, aged 54)

Seemingly, through these connections, life-changing friendships evolved, which contrasted with the more difficult responses and interactions they encountered in their wider everyday lives.

Discussion

There is a growing body of qualitative research capturing the lived experience of those with CTDs. This study takes a unique angle, delving into the journey to personal identification and recognition of tics for those who received a late confirmatory diagnosis in adulthood in the UK.

In line with participants' attempts at making sense of their symptoms, CTDs and TS have visible elements, which can be misinterpreted, socially compromising and interrupting social norms coupled with sensationalism towards obscene behaviour in societal perception and media (Malli et al., 2019; Smith et al., 2015; Stofleth & Parks, 2023). As such, the adults in the current study described their pain of controlling the uncontrollable and concerted efforts of minimalisation. With believing the unbelievable, our participants described how external negative deflection ('just a habit'), dismissal and othering ('weird', 'odd', 'cursed'), particularly in childhood, led to a conflict of striving to change their behaviour, subsuming these external beliefs into their own self-perception. Challenges ensued when exacerbation in adulthood occurred, with many initial reactions still hailing disbelief – ('making it up', 'faking' and 'going crazy') echoing similar experiences described by others (e.g. Coleman & Melia, 2024; Malli et al., 2019). When confronted with these belief structures, many of our adults with a CTD engaged in the assumed persona of adaptability, denial and undetectability, hiding the visible through suppression to get 'away with it' and facing increased and implied expectation in the ability to control oneself in adulthood (Coleman & Melia, 2024; Malli & Forrester-Jones, 2022; Smith et al., 2015). However, this would often incur physical and mental pain, which could affect aspects of performance (such as tasks that require concentration) in daily life.

The effects and strain of voluntary tic suppression, particularly the concern of rebound tics, which increase tic frequency, has previously been explored (Himle & Woods, 2005; Meidinger et al., 2005; Verdellen et al., 2007). Most research has concluded that no significant rebound effect occurs under researcher observation, with tics typically returning to or remaining below baseline levels (Himle & Woods, 2005; Meidinger et al., 2005), even before or after therapeutic intervention (Verdellen et al., 2007). While some children in these studies reported heightened premonitory urges during suppression (Himle & Woods, 2005), findings were inconsistent. Similarly, Specht et al. (2013) found no notable changes in urge intensity during or after extended suppression in young adolescents (aged 10–17). Long-term outcomes of behavioural or support therapies also appear favourable. For example, Barber et al. (2024) reported that most adults did not report tic worsening or substitution from tic management strategies, 11 years after participating in such interventions. Self-initiated coping and perceived satisfaction with tic control have also been found to positively correlate with life satisfaction and quality of life (Matsuda et al., 2016). Nevertheless, premonitory urges remain a key subjective factor in tic disorders, even as suppression appears to function as an effective short-term strategy. Brandt et al. (2023) found that approximately 85% of tics associated with premonitory urges were followed by a sense of relief but also that lower quality of life was linked to the presence of premonitory urges, complex vocal tics and co-occurring conditions. As reiterated by Taylor et al. (2022), in some cases, suppression may intensify tics or lead to persistent physical discomfort. These findings, including ours, point to a potential disconnect between subjective and internal experiences (e.g. premonitory urges) and externally observable outcomes, a gap that future research should aim to bridge. Despite this, many adults with CTDs, including TS, opt to suppress tics for the sake of social harmony.

Stofleth and Parks (2023) highlighted several forms of unwanted attention and verbal and physical harassments that can manifest due to misinterpretations of intent in interpersonal interactions resulting from tics. As such, the enactment and external imposition of minimisation may have broad consequences. Our results also echo Buckser (2008), who described the presentation management of CTDs through strategies such as displacement (expressing tics in private), misattribution (reframing tics as socially insignificant actions) and contextualisation (shaping how tics are perceived through disclosure). Additionally, both adults with childhood-onset and adult-onset CTDs may struggle to identify exactly when tics commenced and what constituted a tic and even through fear or embarrassment, delaying presentation to clinicians until adulthood. This also undoubtedly has implications on the subjective threshold at which individuals perceive clinical distress of CTDs, as many attempt to 'make the shoe fit' by rationalising or downplaying their symptoms.

When self-identifying or seeking diagnostic validation and support for CTDs in adulthood, participants expressed the notion of personally owning the journey to recognition. What should not be underappreciated, and is represented in this study, is how advances in technology, and CTD understanding has adversely affected the journey for some. For those who grew up when medical understanding and general exposure to CTDs were more limited, and especially before the advent of the internet, these adults were likely to be subjected to minimisation and dismissal, as well as struggle to acquire the descriptive language of the condition and of ‘tics’. Even, contrasting with younger adults within our participants, individual recognition often was initiated by chance encounters, which highlights an ongoing need for better public availability of accurate and reliable information on the symptoms of CTDs in adults. Yet, the act of acquiring knowledge and diagnostic validation aided in better recognising that tics had manifested earlier in their lives.

Akin to previous research (e.g. Malli & Forrester-Jones, 2022; Marino et al., 2023), adults perceived and experienced substantial barriers to diagnosis and post-diagnostic support through a lack of professional clinical understanding and compassionate empathy within primary care (i.e. GPs) and secondary care (e.g. neurologists). This seemed to encourage adults with CTDs to arm themselves with their own research when approaching healthcare providers, assuming the role of advocator. However, the fight for a diagnosis seemed to hasten deflection towards the diagnosis of other mental health causes (such as anxiety), long waiting times or in some cases dismissal, due to being an adult. Nevertheless, perhaps there was a question of luck with diagnosis being a dichotomous lottery – where positive ‘lucky’ experiences included supportive medical professionals who shared and took the effort to gain information from, and for, the enquiring adult, being fast-tracked to specialist services, and having the financial ability to seek private healthcare.

Once tic recognition was achieved both personally and medically, many encountered an anti-climax in the conclusion, with the effort taken to gain validation outweighing the impact of being presented with a road to nowhere. Pharmaceutical options were often considered by both participants and knowledgeable clinicians as being ‘strong’ or extreme, involving a trial-and-error process with uncertain efficacy and serious consequential side effects. The most common pharmaceutical options offered were antipsychotics, and these, along with other medications, were sometimes offered as a compulsory precursor to a CTD diagnosis – or else face diagnostic dismissal. Although Malli et al. (2019) reported participants found these medicines beneficial, most of our sample did not; rather, there was the unifying finding of reported distress, aversion and dampened affect because of use. It is also of note that very few participants were initially offered psychoeducation or behavioural therapy – despite this being the recommended preferred first line for intervention (NICE, 2019); this might be due to atypical presentation or tic exacerbation in adulthood. As Ganos et al. (2021) have indicated, the best intervention practices within movement disorder management should be harmonised and publicised on a global level.

With wide-ranging and diverse co-occurring conditions already self-reported in this sample, facing tic and disorder recognition in adulthood led to mournful reflection further impacting their daily life and mental wellbeing. Further, some faced workplace challenges, with others encountering an upheaval, reconstruction or growth of their personal narrative, their sense of placement or purpose (Coleman & Melia, 2024; Malli et al., 2019; Malli & Forrester-Jones, 2022). Diagnosis, a process that provided a facilitated explanation for visibly problematic symptoms also had the perceived effect of protecting or arming participants against adverse interrogation (such as potentially negative public reaction and police/law interaction). With participants reaching acceptance, some participants recommended that others embrace their condition to alleviate their symptoms and their impact on their life. Through this, they called for others to take collective action, the potential for this is to support the establishment of a community of difference, and greater societal acceptance of CTDs. Thus, a handful of our participants further extended this to educating and advocating for CTDs to protect their tribe in the clinical and public domain (Ross & Rickards, 2015). The support from communities through social media and national charities was predominantly expressed as multi-beneficial (Soós et al., 2022), though access is often limited to those who have a confirmed diagnosis. Perhaps this emphasises the importance of this current study in also embracing those with a late diagnosis in adulthood, and prior to diagnosis, adults who self-identify. Additionally, all participants in the adult-onset group except one could remember childhood behaviours or indicators which they now believe might have been initial, albeit, mild signs of tics.

While we include some of the first accounts of experiences accessing a diagnosis or just self-identifying with a CTD in adulthood (including those with adult-onset and previously undiagnosed child-onset), there

are some limitations to note. For example, despite attempts to recruit across the UK, our study lacks geographic spread, with minimal representation in Scotland, and none in Wales or Northern Ireland. Clinical outcomes and approaches to CTDs may differ in these areas, especially with the subdivided nature of the NHS (e.g. NHS Wales) and in areas with limited guidance (e.g. no current guidelines for CTDs in the Scottish Intercollegiate Guidelines Network (SIGN)). As such, future research should broaden the current England-focused scope to investigate and fully incorporate practices across the UK. This includes exploring more diverse recruitment strategies, such as in-person engagement through clinics or relevant charities, to better reach and diversify the adult demographic. Additionally, this study involved both insider (i.e. with lived experience of tic disorders) and outsider researchers who finalised the semi-structured interview questions. Future work should place greater emphasis on co-creation and pilot testing with individuals with lived experience. This might include collaboratively developing research methodologies (e.g. interview questions, data collection methods) to ensure a more inclusive and authentic representation of the lived experience of adults with chronic tic disorders (CTDs) (Jones & Phoenix-Kane, 2025). It is our hope that adult experiences of CTDs continue to be further explored both qualitatively and quantitatively, including tic and clinical recognition in adult-onset and older adults, including those aged over 65 years (e.g. Qualls & Appenzeller, 2019; Robakis, 2017; Voitsidis et al., 2019).

The current findings have important implications for how tic disorders are understood, diagnosed and treated in adulthood. As echoed recently by Babbage et al. (2025), our data highlights the profound personal and social toll of delayed recognition, misdiagnosis and the expectation of adult self-control, often resulting in suppression, distress and concealment. Clinically, this calls for a greater awareness of atypical or subtle presentations in adults, and an emphasis on compassionate, informed responses within primary and secondary care. Enhancing public and professional understanding of adult CTDs, especially through accessible, relatable information and early psychoeducation, may help reduce diagnostic delays and improve patient outcomes. Importantly, the disconnect between subjective experiences (e.g. pain, shame, emotional fatigue) and objective observations (e.g. tic frequency) underlines the need for more holistic assessment frameworks that validate lived experience. Future research should explore therapeutic approaches tailored for adults, especially beyond pharmacological options, and evaluate the long-term impact of late diagnosis. These findings also reinforce the value of peer support and community networks in navigating identity, acceptance and advocacy. Ultimately, centring the adult perspective in CTD research can help shift the narrative from invisibility and minimisation to recognition and empowerment across the lifespan.

Conclusion

In summary, our study provides an in-depth analysis corroborating preceding studies of lived experience accounts from adults with CTDs, from the perspective of those with late adult-initiated CTD diagnosis within the UK. We found that adults with CTDs encounter historic and ongoing quandaries of social acceptability (minimisation), difficult diagnostic journeys, disparaging barriers to validation mediated by personal advantage and circumstance and adverse outcomes for treatment and prognosis, creating an anti-climax in line with participants' experiences. This evidences the ongoing struggle adults face with late diagnoses in CTDs, perhaps made even more difficult for participants in this sample, given their additional co-occurring issues – potentially necessitating additional diagnostic journeys for these disorders. Therefore, we highlight needed improvements to access, clinical investigation practices and comprehension when dealing with adult-presenting cases of CTDs.

Overall, our study showcases the external and internal barriers that adults may need to overcome in order to recognise tic symptomology and obtain a CTD diagnosis. Although this may not provide a gateway to intervention, at least it can afford the ability for self-identification, realisation, reconciliation, acceptance, self-management and understanding for a population underrepresented in clinical prevalence and understanding.

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Author contributions

All authors contributed to the study concept and design. Material preparation, data collection and analysis were performed by Danni Phoenix-Kane. Iterations of analysis were performed by Danni Phoenix-Kane and Saskia Keville. The first draft of the manuscript was written by Danni Phoenix-Kane, and all authors commented/contributed to subsequent versions of the manuscript. All authors read and approved the final manuscript.

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