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Exploring Adults' Experiences of Treatment for Tourette Syndrome and Tic Disorders

Emma Camsey
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School of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

March 2025

University of Glasgow

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Contents

List of Tables 8

List of Figures 9

Acknowledgements 10

Chapter 1: Systematic Review 11

Abstract 12

1. Introduction 13
- 1.1 Background 13
- 1.2 Rationale for this Review 15
- 1.3 Aims & Review Questions 15

2. Method 16
- 2.1 Registration 16
- 2.1 Search Strategy 16
- 2.3 Inclusion & Exclusion Criteria 18
- 2.4 Study Selection 19
- 2.5 Data Extraction and Synthesis 19
- 2.6 Assessment of Quality 20

3. Results 20
- 3.1 Outcome of Selection Process 20
- 3.2 Overview of Included Studies 23
- 3.3 Quality of Included Studies 30
- 3.4 What measures were used and what dimensions do they capture? 32
- 4.5 What reasons were given by authors for the selection of measures used? 42

4. Discussion 42
- 4.1 Overview of the Findings 42
- 4.2 Quality of Life Measures 42
- 4.3 Mental Health Measures 43
- 4.4 Functional Measures 44
- 4.5 ADHD/Impulsivity Measures 45
- 4.6 Limitations of Reviewed Studies 46
- 4.7 Limitations of this Review 47
- 4.7 Future Research Implications 47

5. Conclusion 48

References 50

Chapter 2: Major Research Project 58

Plain Language Summary 59

Abstract 61

1. Introduction 62
- 1.1 Background 62
- 1.2 Aim of current study 64

1.3 Research Questions 64
2. Method 65
2.1 Theoretical framework 65
2.2 Design 65
2.3 Participants 65
2.4 Inclusion Criteria 66
2.5 Recruitment Procedure 67
2.6 Sample 68
2.7 Procedure 68
2.8 Analysis 69
2.9 Research Reflexivity 70
3. Results 70
4. Discussion 84
4.1 Validating the Experiences of Individuals with Tics 84
4.2 Strategies to Manage Tics 86
4.3 Quality of Life 87
4.4 Therapeutic Alliance 88
4.5 Clinical Implications 89
5. Strengths & Limitations 89
6. Future Research 90
7. Conclusion 91
References 92
Appendices 96
Appendix 1: Systematic Review 96
Appendix 1.1- PRISMA 2020 Checklist 96
Appendix 1.2 - Search Strategy 99
Appendix 1.3 – Paper Screening and Selection Tool 102
Appendix 1.4 –Quality Appraisal Tools 103
Appendix 2: Major Research Project 105
Appendix 2.1 – Consolidated Criteria for Reporting Qualitative research (COREQ) Checklist 105
Appendix 2.2 – Research Ethics Committee Approval Letter 107
Appendix 2.3 – NHS Greater Glasgow & Clyde, Research & Innovation Approval Letter 112
Appendix 2.4 – Research Ethics Committee Correspondence Regarding Study Amendments 114
Appendix 2.5 – NHS to NHS letter of Access 120
Appendix 2.6 – Organisation Information Document 123
Appendix 2.7 – Major Research Project Proposal 124
Appendix 2.8 – Invitation Letter to Participant 125
Appendix 2.9 – Participant Information Sheet 126
Appendix 2.10 – Privacy Notice 127
Appendix 2.11 – Participant Consent Form 128
Appendix 2.12 – Interview Confirmation 129
Appendix 2.13 – Semi-structured Interview Schedule 130
Appendix 2.14 – Participant Information Proforma 131

Appendix 2.15 – Post Interview Information 132
Appendix 2.16 – Examples of IPA Analytical Process 133
Appendix 2.17 - NHS Greater Glasgow & Clyde - Institute of Neuroscience Neuropsychology Service Referral Criteria for CBIT Pathway 135
Appendix 2.18 – Participant feedback on initial results 136

List of Tables

CHAPTER 1: SYSTEMATIC REVIEW

Table 1.1 Overview of Studies Included - Pg. 23

Table 1.2 Quality Appraisal Scores (JBI Quasi-Experimental Checklist) – Pg. 29

Table 1.3 Quality Appraisal Score (JBI Randomized Controlled Trials Checklist) - Pg. 30

Table 1.4 List of Measures – Pg.33

CHAPTER 2: MAJOR RESEARCH PROJECT

Table 2.1 Participant Pseudonyms – Pg. 66

Table 2.2 Group Experimental Themes and Sub-themes – Pg. 68

List of Figures

CHAPTER 1: SYSTEMATIC REVIEW

Figure 1: PRISMA Flow Diagram – Pg. 21

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Chapter 1: Systematic Review

A SYSTEMATIC REVIEW OF QUALITY OF LIFE, WELLBEING, MENTAL HEALTH AND FUNCTIONAL MEASURES USED TO ASSESS PSYCHOLOGICAL TREATMENT OUTCOMES FOR TOURETTE SYNDROME AND TIC DISORDER FOR ADULTS.

Prepared in accordance with the author requirements for the British Journal of Psychology

https://bpspsychub.onlinelibrary.wiley.com/hub/journal/20448295/homepage/forauthors.html

Abstract

The objective of the review was to identify and characterise quality of life (QoL), function, mental health and well-being outcome measures used to evaluate adults with Tourette's syndrome and tic disorder (TS/TD) in psychological/behavioural treatment research.

MEDLINE, PsycINFO and EMBASE were searched from inception to March 2024 and papers screened based on inclusion and exclusion criteria. Each study was appraised using a quality assessment tool. A narrative synthesis of pertinent outcome measures was undertaken.

Collectively, 34 outcome measures were employed across 17 eligible studies, assessing 700 participants. The most commonly identified risks of bias were lack of control groups or comparative groups within the studies. Six papers were amalgamated from one original randomised controlled trial, leaving 12 to be synthesised. All but one reported using a specific tool to evaluate outcomes related to QoL, functioning, or well-being. 75% (n=9) of the studies assessed mental health, 33% (n=4) assessed QoL, 42% (n=5) explored impulsivity/attention deficit hyperactivity disorder, and 25% (n=3) used functional measures.

While there is wide variation in outcome measures for adult TS/TD populations, standardising consistently used tools for use in treatment research is essential to improve the quality and applicability to clinical work.

Key words: Tourette's Syndrome, Tic Disorder, Quality of Life, Outcome Measures, and Adult.

1. Introduction

1.1 Background

Tourette’s syndrome and tic disorders (TS/TD) refers to a group of neurodevelopmental conditions that typically manifest in childhood and adolescence that can continue into adulthood, fluctuating in intensity or severity over time (Jafari et al., 2022; Pringsheim. et al., 2019). Motor tics are defined as sudden, rapid, non-rhythmic and recurrent movements (World Health Organisation, 2019a), whereas chronic phonic tic disorder is characterised by the presence of vocal tics (World Health Organisation, 2019b). Tourette's syndrome is a chronic tic disorder characterised by the presence of both persistent motor and phonic tics. Psychoeducation and behavioural interventions are often considered the first line of treatment and are well established treatments for TS/TD (Frey & Malaty, 2022).

Typically, TS/TD has been primarily viewed through a neurological lens, with a focus on understanding the underlying neurobiological mechanisms and symptomatology. This emphasis on the neurological aspects of TS/TDs has often overshadowed the significance of considering broader psychosocial factors. It is imperative for researchers to recognise that the relationship between TS/TD and mental health, as well as overall functioning, can also be bidirectional and considerably affect each other (Freeman-Ferguson, 2022). Similarly, diagnostic criteria for TS/TD primarily emphasise the presence and nature of tics themselves rather than the associated mental health or functional impairments. Consequently, research and clinical practice may prioritise assessing and managing tic symptomology above other aspects of well-being.

Quality of life (QoL) is a multifaceted concept encompassing both health-related and non-health-related aspects of functioning. It pertains to an individual's perceived experiences of the physical, mental, and social impacts of an illness, as well as the effects of associated therapies (Eapen et al., 2016). Previous studies have highlighted that psychiatric symptoms are the primary determinant of health-related QoL for individuals with Tourette Syndrome/Tic Disorders (TS/TD) (Isaacs et al., 2021). Additionally, these comorbid psychiatric symptoms are often considered more problematic than the tic symptoms themselves (Ueda & Black, 2021). Research indicates that approximately 30% of individuals with TS/TD experience comorbid anxiety and depression (Hirschtritt et al., 2015), with comorbid depression positively correlating with tic severity (Rizzo et al., 2017). Research has also shown that while tic severity is associated with an increased risk of depression, this relationship is moderated by factors such as age. It has also been proposed that comorbidities may impact adults differently, with evidence suggesting that comorbidities such as anxiety and depression may be more important determinants for overall quality of life in adults with new-onset tics than in children (Robakis, 2017). A growing but limited body of literature has explored adults' experiences with TS/TD, highlighting that their experiences are often multidimensional and significantly impact various aspects of quality of life (QoL) (Malli et al., 2019). Overall, this information underscores the importance of considering not only tic symptoms but also associated psychiatric symptoms and their effects on QoL when evaluating and managing TS/TD.

A previous systematic review has been conducted focusing on exploring tic measures and rating psychometric quality of severity and screening instruments for tics across both child and adult populations (Martino et al., 2017). Based on evidence from 106 studies across all age groups, they recommended several measures and concluded that developing new tic severity or screening instruments was unnecessary. However, they identified potential opportunities to create a rating tool encompassing the full spectrum of tic-related behaviours and to develop patient-reported outcome measures. While their evaluation offers a useful summary regarding the assessment of tic severity, it overlooks the measurements of other types of impacts e.g. function and wellbeing, that hold significance for this group of individuals. Therefore, an opportunity exists to carry out a review that centres on alternative outcomes such as QoL, mental health, well-being, and overall functioning, all of which have been employed in research studies involving this specific clinical population.

Interventions and research for TS/TD have historically assumed that improving the severity or frequency of tics will positively impact QoL (McGuire et al., 2015). Studies incorporating QoL measures assess a broader impact of the condition by exploring social functioning, emotional well-being, academic performance, and daily activities. These measures can help understand the individual's overall well-being and the interventions' effectiveness. It has been noted that often QoL measures are not incorporated into TS/TD research - when they are, they are unlikely to be sensitive to specific features which are central to individuals with TS/TD and are liable to underestimate difficulties (Cavanna et al., 2013). These issues within research may have arisen out of the complexity of assessing individuals with TS/TD. Often assessing mental health, overall functioning, and quality of life in individuals with TS/TD can be challenging due to the heterogeneity of symptoms and the potential presence of comorbid conditions such as attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), or mood disorders.

1.2 Rationale for this Review

Due to the scarcity of research exploring the range of measures utilised beyond tic frequency/severity, the rationale guiding their selection, and the presence of consistent patterns in their usage across studies, this review aims to address these gaps. Specifically, our focus will be on QoL, mental health, wellbeing, and general functional measures employed to assess outcomes in studies examining psychological and behavioural interventions for TS/TD, along with the reasoning behind their selection.

By undertaking this review, we aimed to provide some clarity and consistency around what is being measured and why, highlighting what aspects are being evaluated and the motivations driving their selection. To our knowledge there are no previous systematic reviews with a focus on this area.

1.3 Aims & Review Questions

In line with the rationale above, the review aimed to identify and characterise the various QoL, functional, mental health and well-being outcome measures being utilised to evaluate adults with TS/TD within research studies of psychological and behavioural interventions (including psychoeducation). Specifically, three research questions were addressed;

1. Which other measures, apart from those focused on tic severity/intensity, are being utilised in empirical studies of psychological and behavioural interventions for TS/TD?
2. What are the QoL, mental health and well-being dimensions (e.g. ratings of depression, anxiety, wellbeing etc.) and functional dimensions (e.g. physical impairments, occupational etc.) captured within these other measures?

3. What reasons did the study authors give (if any) for choosing those measures?

2. Method

2.1 Registration

A protocol for this systematic review was uploaded to the Open Science Framework (OSF) on the 19th April 2024 (https://osf.io/69f5s). No amendments have been made to this document. This review adheres to the PRISMA reporting guidelines, as outlined in the PRISMA 2020 checklist (Appendix 1.1).

2.1 Search Strategy

All searches were completed between the 4th to the 5th March 2024. Limits including only studies published in English, and involving human participants were placed on the searches. MEDLINE, PsycINFO, and EMBASE (appendix 1.2) were searched, see example below. Search terms were identified through a review of similar search strategies and with guidance from the librarian. No date limits were imposed. Forward searching (identifying articles that cite the original relevant article after it had been published), and backward searches (identifying and examining the references cited in relevant papers) were conducted for eligible papers. Publication bias is highlighted as a significant flaw within systematic reviews and potentially threatens the validity of any conclusions (Siddaway et al., 2019). Therefore, we contacted the available corresponding authors of papers eligible for the review to request forthcoming papers or unpublished papers. This contact was made via email and one month was allotted for responses. Ten authors were contacted in total, and three responses were received, and no additional papers were identified.

Search term example

1. *Medline (Ovid)*

Date of Search: 25.03.24

1	Tourette syndrome.tw.
2	tic disorder.tw.
3	(tic* or tourette* or TS or GTS).tw.
4	gilles de la Tourette syndrome.tw.
5	tic*.tw.
6	1 or 2 or 3 or 4 or 5

7 psycholog* intervention*.tw.
8 psychotherap*.tw.
9 Psychotherapy/
10 Psychotherapy, Group/
11 cognitive therap*.tw.
12 Cognitive behavio*ral therapy/
13 Psychotherapy/
14 psycho* treatment.tw.
15 psycho* education.tw.
16 cognitive behavio*ral therap*.tw.
17 behavio*ral therap*.tw.
18 (cognitive adj2 (therap* or treatment* or control or approach* or training)).mp.
19 (behavio*ral adj2 (therap* or treatment* or control or approach* or training)).mp.
20 CBIT.tw.
21 Comprehensive behavio*ral intervention*.tw.
22 Behavio*r therap*/
23 Comprehensive behavio*ral intervention for tic*.tw.
24 Habit reversal therap*.tw.
25 HRT.tw.
26 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27 6 and 26

The PICOS framework (population, intervention, comparator, outcome, study design) (Amir-Behghadami & Janati, 2020) was employed to formulate the search strategy in line with the review questions, aligning with best practices for developing research inquiries focused on interventions.

1. Population
    i. Must meet diagnostic criteria for TS/TD.
    ii. Participants must be age 18 or older.
2. Intervention
    i. The research included will have used a psychological treatment intervention (any psychological or behavioural treatment including psychoeducation, with or without the use of medication) primarily targeting TS/TD. Studies which are solely pharmaceutical/medication based, with no element of psychological intervention, will not be included. Studies which use hypnotherapy alone,

outside a broader psychological/behavioural treatment context, will not be included.

3. Comparison
    i. Data will be collected comparing various outcome measures used to evaluate the effectiveness of treatment. Studies will be eligible regardless of whether a comparison condition is used.
4. Outcome
    i. Any quantitative or qualitative (e.g. allowing for the possibility of more open outcomes) assessments of treatment outcomes for the study sample and what domains they are appraising.
5. Study Design
    i. Studies were included if they used any interventional research design, including any group-based, single-case experimental treatment design or randomised control trial design.

2.3 Inclusion & Exclusion Criteria

Below are the criteria applied;

- *Inclusion Criteria*

a. Participants must have received a diagnosis of TS/TD from a Neurologist or Psychiatrist.
b. Participants must be aged 18 years or over. Studies that also have participants below the age of 18, must present separate results for adult and child populations, in order to be included.
c. Studies included must have implemented a psychological/behavioural/psychoeducation-based intervention primarily targeting TS/TD.
d. At least one quantitative or qualitative outcome measure must be used in the study.
e. Full text must be available in English.
f. No date restriction will be imposed on searches as this will be an original review.

- *Exclusion Criteria*

a. Studies which were solely pharmaceutical/medication based, or hypnotherapy-based, with no other element of psychological/behavioural/psychoeducation-based intervention, will be excluded.
b. Any studies where the primary intervention does not target TS/TD symptomology.
c. Mixed-age studies were excluded if they did not separate results for adults and children.

2.4 Study Selection

A detailed screening checklist was developed based on the criteria summarised above (appendix 1.3). The primary reviewer (author) screened titles and abstracts, and then went on to screen the full text of potentially eligible articles. Any studies that did not meet the criteria were identified, and the reason for exclusions noted. Papers that met all criteria but did not utilise any relevant outcome measures beyond those measuring tic intensity and severity, were excluded at the full text screening stage. Ten percent of the search results were screened independently by a second reviewer to check reliability (or a minimum of 100 results at title/abstract stage and a minimum of 20 at full-text stage), and the rest was carried out by one researcher independently.

2.5 Data Extraction and Synthesis

Data extraction was conducted utilising a structured form and Excel sheet specifically tailored for the purposes of this review, encompassing the following items: author, title, year published, country, journal, methodology, sample size, population, psychological intervention, measure used, rationale for measures, domains of measures, and quality appraisal outcome. The domains were identified by the primary reviewer based on published information about each measure, and then discussed with the supervisors to reach consensus. Due to time constraints, we did not contact the authors if information relevant to the review was not reported in the paper.

A narrative synthesis of all pertinent outcome measures was undertaken, analysing their frequency of utilisation, coverage across different domains, and customisation to the specific TS/TD population under review. Furthermore, justifications and rationales for the selection of these measures were recorded. Measures of quality of life, well-being, mental health, and functional outcomes were collected. ADHD-specific measures are also included in such evaluations due to the high comorbidity between TS/TD and ADHD, as ADHD symptoms can significantly impacting difficulties. Including ADHD measures allows for a comprehensive assessment of treatment efficacy, capturing changes in both tic and ADHD-related symptoms and their combined impact on well-being and functioning, ensuring a clear understanding of outcomes.

2.6 Assessment of Quality

By employing specialised matched appraisal tools, this review ensured a thorough and systematic assessment of the methodological quality and risk of bias across a range of study designs, enhancing the reliability and validity of the review's findings. For randomized controlled trials (RCTs), the Joanna Briggs Institute (JBI) RCT Critical Appraisal Checklist (Barker et al., 2023) was utilised to evaluate their quality and methodological rigour. In instances where the included studies were non-randomized group designs, such as quasi-experimental studies, the JBI Quasi-Experimental Study Checklist (Barker et al., 2024) was employed. We had planned to use the Risk of Bias in N-of-1 Trials (RoBiNT) tool for single case experimental papers, but none of the included papers used this design. A second independent rater evaluated the quality of 5 of the included papers. Overall agreement across all items was 92% (Cohen's kappa = 0.65, representing substantial agreement).

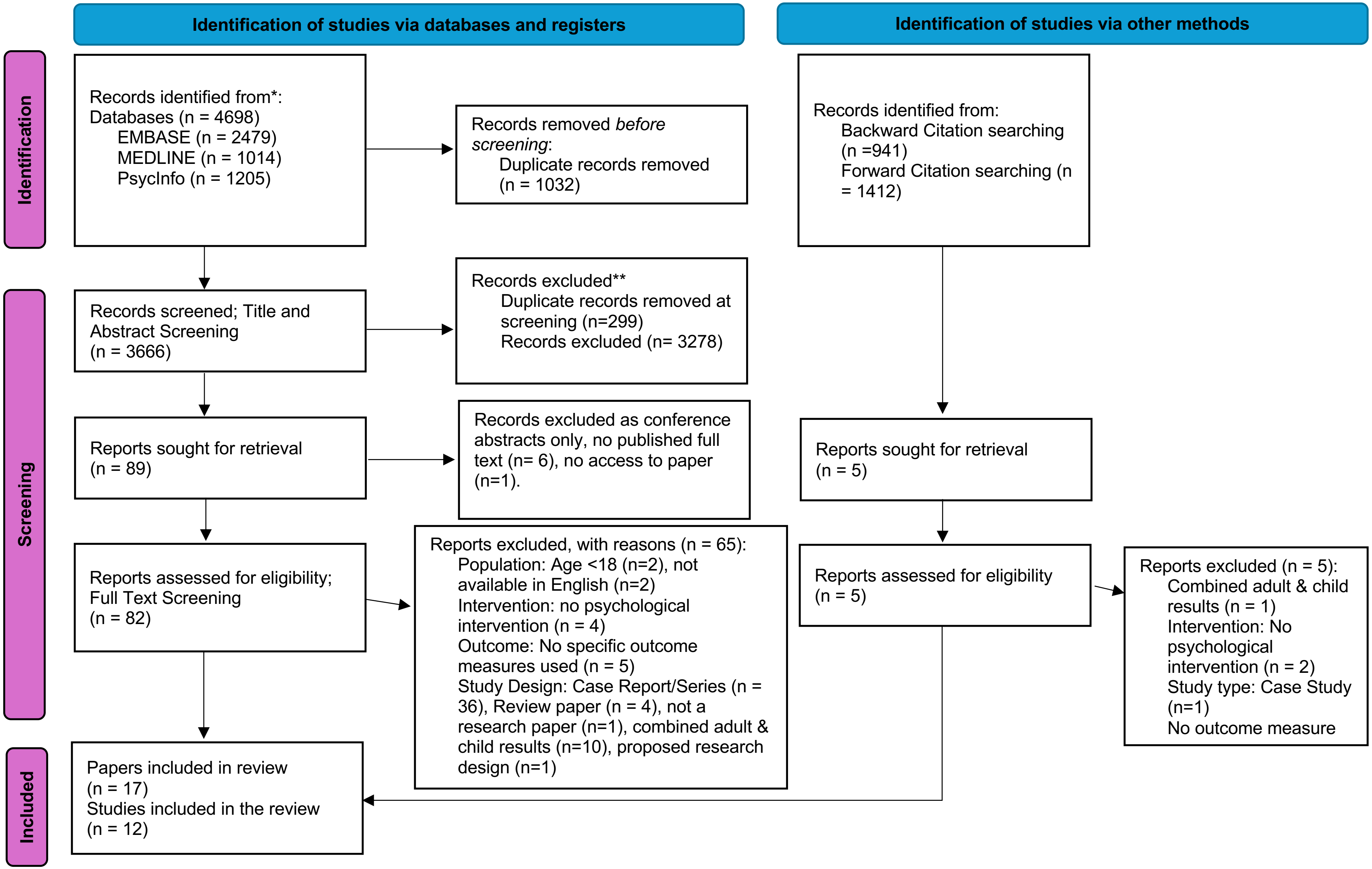
3. Results

3.1 Outcome of Selection Process

EndNote for Windows was employed to administer the outcomes of the database searches (n=4698). De-duplication was performed within EndNote, resulting in the removal of 1032. A total of 3666 papers underwent screening by title/abstract, adhering to the predefined inclusion/exclusion criteria, leading to the exclusion of 3278 papers as well as a further 299 duplicate records that were identified and removed at this stage. The second independent rater evaluated 350 of the papers by title/abstract. The agreement rate was 94% (Cohen's kappa = 0.67, representing substantial agreement). Five of these papers required further discussion and consensus was reached.

It follows therefore that 89 papers were sought for full-text review. Six of these were found to be conference proceedings and were therefore ineligible. Following the full-text review carried out on the remaining 82 papers, 66 of these were excluded in accordance with the predetermined exclusion criteria. Consequently, 17 papers remained for the evaluation of relevant outcome measures. A second independent reviewer screened 20 of the papers at the full-text stage, with no disagreements identified.

Figure 1: PRISMA Flow Diagram



3.2 Overview of Included Studies

This review identified 17 papers (Bekk et al., 2023; Capriotti et al., 2023; Deckersbach et al., 2014; Deckersbach et al., 2006; Essoe et al., 2021; Haas et al., 2022; Houghton et al., 2017; Lavoie et al., 2011; McGuire et al., 2020; Morand-Beaulieu et al., 2016; Morand-Beaulieu et al., 2015; O'Connor et al., 2001a; O'Connor et al., 2008a; Reese et al., 2021; Weingarden et al., 2018; Wilhelm et al., 2003; Wilhelm et al., 2012) that reported research studies of psychological and behavioural interventions with adult TS/TD populations (table 1.1). For the purpose of the synthesis, six papers were amalgamated (Deckersbach et al., 2014; Essoe et al., 2021; Houghton et al., 2017; McGuire et al., 2020; Weingarden et al., 2018; Wilhelm et al., 2012), aligning with Cochrane guidance (Tianjing Li, 2023) as these were all based on one original RCT study (Wilhelm et al., 2012) which yielded a series of related publications.

Therefore, 12 studies remained (Bekk et al., 2023; Capriotti et al., 2023; Deckersbach et al., 2006; Haas et al., 2022; Lavoie et al., 2011; Morand-Beaulieu et al., 2016; Morand-Beaulieu et al., 2015; O'Connor et al., 2001a; O'Connor et al., 2008a; Reese et al., 2021; Wilhelm et al., 2003; Wilhelm et al., 2012). Study designs included randomised controlled trials (Deckersbach et al., 2014; Deckersbach et al., 2006; Haas et al., 2022; Reese et al., 2021; Wilhelm et al., 2003; Wilhelm et al., 2012) and quasi-experimental studies (Bekk et al., 2023; Capriotti et al., 2023; Lavoie et al., 2011; Morand-Beaulieu et al., 2016; Morand-Beaulieu et al., 2015; O'Connor et al., 2001b; O'Connor et al., 2008b), encompassing an assessment of 700 participants in total. The fewest number of outcome measures used in a single study was two, while the greatest was 10; the mean number used across the 12 studies was 5.9.

Table 1.1: Overview of Included Studies

Article Reference	**Study type**	**Sample Size**	**Population**	**Brief Overview**	**Measures Used**	**Authors' rationale for selection of measures**
*O'Connor KP, Brault M, Robillard S, Loiselle J, Borgeat F, Stip E. Evaluation of a cognitive-behavioural program for the management of chronic tic and habit disorders. Behaviour Research and Therapy. 2001;39(6):667-81.	Uncontrolled pre-post design with follow up	47	adult	A manualised cognitive-behavioural program designed on habit reversal was implemented to manage chronic tic disorder. The treatment spanned 4 months, with follow-up assessments conducted over a two-year period.	SSI, LES, STAI, BDI, GHQ, EPI, STOP, & MPS.	Well- established measure, adequacy for the evaluated outcome
*Wilhelm S, Deckersbach T, Coffey BJ, Bohne A, Peterson AL, Baer L. Habit reversal versus supportive psychotherapy for tourette's disorder: A randomized controlled trial. American Journal of Psychiatry. 2003;160(6):1175-7.	RCT	29	adult	Participants were randomised into two groups: one receiving habit reversal therapy and the other undergoing supportive psychotherapy. The treatment consisted of 14 sessions, followed by a 10-month follow-up period.	YGTSS & CGI	Psychometric properties
*Deckersbach T, Rauch S, Buhlmann U, Wilhelm S. Habit reversal versus supportive psychotherapy in Tourette's disorder: A randomized controlled trial and predictors of treatment response. Behaviour	RCT	30	adult	The study compared the effectiveness of habit reversal therapy versus supportive psychotherapy (SP) in reducing tics, enhancing life satisfaction, and improving psychosocial functioning	^YGTSS, CGI-I, BDI, Y-BOCS, the ADHD symptom checklist, SDI & SOS-10.	Well- established measure, Psychometric properties,

Research and Therapy. 2006;44(8):1079-90.				among outpatients with Tourette Syndrome (TS).		
*O'Connor KP, Lavoie ME, Stip E, Borgeat F, Laverdure A. Cognitive-behaviour therapy and skilled motor performance in adults with chronic tic disorder. Neuropsychological Rehabilitation. 2008;18(1):45-64.	Uncontrolled pre-post design with follow up	110	adults	The first aim of this study was to compare the executive function and motor skills of individuals with tic disorders (TD) to controls. The second aim was to examine the impact of cognitive behavioural therapy (CBT) on motor performance.	SSEI, STAI, BDI, GHQ – 12-item version, MOCI & STOP.	Psychometric properties, Adequacy for the evaluated outcome
*Lavoie ME, Imbriglio TV, Stip E, O'Connor KP. Neurocognitive changes following cognitive-behavioral treatment in Tourette Syndrome and chronic tic disorder. International Journal of Cognitive Therapy. 2011;4(1):34-50.	Uncontrolled pre-post design	24	adult	The aim of the research program was to compare motor Event-Related Potentials (ERPs) recorded before and after CBT in individuals with Tourette's syndrome.	TSGS, YGTSS, Y-BOCS, Padua Inventory, BAI, BDI, & The Personality Diagnostic Questionnaire-4th Edition.	Psychometric properties
*Wilhelm S, Peterson AL, Piacentini J, Woods DW, Deckersbach T, Sukhodolsky DG, et al. Randomized trial of behavior therapy for adults with tourette syndrome. Archives of General Psychiatry. 2012;69(8):795-803.	RCT - NCT00231985	122	adult	The research aimed to evaluate the effectiveness of a comprehensive behavioural intervention for tics in adults with Tourette syndrome.	^YGTSS, ^CGI-I scale, & ATQ.	Psychometric properties
Deckersbach T, Chou T, Britton JC, Carlson LE, Reese HE, Siev J, et al.	RCT	16	adult	The researchers employed functional magnetic resonance	^YGTSS, PUTS, Y-BOCS, BDI,	Well-established measure

Neural correlates of behavior therapy for Tourette's disorder. Psychiatry Research - Neuroimaging. 2014;224(3):269-74.				imaging (fMRI) to examine the neural changes linked to CBIT treatment.	BAI, the Sheehan Disability Scale & the Attention Deficit Hyperactivity Disorder (ADHD) Rating Scale (Barkley, 1990).	
*Morand-Beaulieu S, O'Connor KP, Sauve G, Blanchet PJ, Lavoie ME. Cognitive-behavioral therapy induces sensorimotor and specific electrocortical changes in chronic tic and Tourette's disorder. Neuropsychologia. 2015;Part B. 79:310-21.	Uncontrolled pre-post design	40	adult	To examine the effects of cognitive-behavioral therapy on electrocortical activation, we recorded event-related potentials (ERPs) and lateralized readiness potentials (LRPs) before and after CBT treatment for tic disorders.	BAI and BDI, TSGS, YGTSS, VOCI & BIS-11.	None given
*Morand-Beaulieu S, O'Connor KP, Richard M, Sauve G, Leclerc JB, Blanchet PJ, et al. The impact of a cognitive-behavioral therapy on event-related potentials in patients with tic disorders or body-focused repetitive behaviors. Frontiers in Psychiatry. 2016;7(MAY).	Uncontrolled pre-post design	80	adult	The researchers aimed to investigate the event potentials before and after CBT in individuals with tic disorders (TD).	TSGS, YGTSS, Padua inventory, BIS-10, BAI, & BDI.	Psychometric properties

Houghton DC, Capriotti MR, Scahill LD, Wilhelm S, Peterson AL, Walkup JT, et al. Investigating Habituation to Premonitory Urges in Behavior Therapy for Tic Disorders. Behavior Therapy. 2017;48(6):834-46.	RCT (NCT00218777 & NCT00231985)	122 (child 126 Adult 122)	adult & child	Researchers examined whether premonitory urges decreased in adolescents with PTDs (N = 126) and adults with PTDs (N = 122) who took part in concurrent randomised clinical trials comparing behaviour therapy to psychoeducation and supportive therapy (PST), each comprising 8 sessions over 10 weeks.	YGTSS, PUTS, CGI-I, Y-BOCS, BAI & BDI.	Psychometric properties
Weingarden H, Scahill L, Hoeppner S, Peterson AL, Woods DW, Walkup JT, et al. Self-esteem in adults with Tourette syndrome and chronic tic disorders: The roles of tic severity, treatment, and comorbidity. Comprehensive Psychiatry. 2018;84:95-100.	RCT (NCT00231985)	122	adult	The objective of this study was to understand the impact of tics compared to comorbid diagnoses on self-esteem.	YGTSS,CGI, SES, & BDI	Well-established measure, psychometric properties, Adequacy for the evaluated outcome
McGuire JF, Ricketts EJ, Scahill L, Wilhelm S, Woods DW, Piacentini J, et al. Effect of behavior therapy for Tourette's disorder on psychiatric symptoms and functioning in adults. Psychological medicine. 2020;50(12):2046-56.	RCT (NCT00231985)	122	adult	Researchers conducted comparisons on changes in tic severity, psychiatric symptoms, and functional outcomes utilising repeated measures and one-way analysis of variance after treatment.	^YGTSS, CGI-I,Y-BOCS, ADHD-RS-IV, BDI-II, BAI, STAXI-2, SDS, FAM-III, & SAS-SR.	Psychometric properties, well established, Adequacy for the evaluated outcome, Adaptable to be applicable to

						different populations
Essoe JK, Ricketts EJ, Ramsey KA, Piacentini J, Woods DW, Peterson AL, et al. Homework adherence predicts therapeutic improvement from behavior therapy in Tourette's disorder. Behav Res Ther. 2021;140:103844.	RCT (NCT00218777 & NCT00231985)	49 (49 adults, 70 child)	adult & child	The study investigated homework adherence by having therapists record homework adherence during each therapy session.	YGTSS, CGI-I, ADHD-RS, Y-BOCS, STAXI-2, & SDS.	Psychometric properties
*Reese HE, Brown WA, Summers BJ, Shin J, Wheeler G, Wilhelm S. Feasibility and acceptability of an online mindfulness-based group intervention for adults with tic disorders. Pilot and Feasibility Studies. 2021;7(1) (no pagination).	Pilot (NCT03525626)	5	adults	Researchers present findings on the feasibility, acceptability, safety, and symptomatic impact of a new online mindfulness-based group intervention for adults with Tourette syndrome or persistent tic disorder.	^YGTSS, FFMQ, & CGI-I.	Well-established measure, psychometric properties
*Haas M, Jakubovski E, Kunert K, Fremer C, Buddensiek N, Hackl S, et al. ONLINE-TICS: Internet-Delivered Behavioral Treatment for Patients with Chronic Tic Disorders. Journal of Clinical Medicine. 2022;11(1) (no pagination).	RCT – (NCT02605902)	161	adults	This study is a multicentre (n = 5), randomized, controlled, observer-blind trial comparing the efficacy of iCBIT Minddistrict® intervention with placebo and face-to-face (f2f) CBIT in the treatment of tics.	^YGTSS, MRVS, ATQ, GTS- QoL & GTS-QoL-VAS, PUTS-9, CGI-I, Y-BOCS, CAARS, BDI, BAI, WAI-SR.	none given
*Bekk M, Meland KJ, Moen E, Nostvik LI, Gausdal AL, Hummelen B. Group-based comprehensive	Uncontrolled pre-	26	adults	Researchers administered CBIT in group settings for adults with Tourette syndrome and chronic tic	YGTSS, CGI-I, & GTS- QoL.	Psychometric properties

behavioral intervention for tics (CBIT) for adults with Tourette syndrome or chronic tic disorders: A pilot study. Scandinavian journal of psychology. 2023;64(6):784-93.	post design			disorders, followed by a one-year follow-up period.		
*Capriotti MR, Wellen BC, Young BN, Himle MB, Conelea CA, Espil FM, et al. Evaluating the feasibility, acceptability, and preliminary effectiveness of tele-comprehensive behavior therapy for tics (teleCBIT) for Tourette syndrome in youth and adults. Journal of telemedicine and telecare. 2023:1357633X231189305.	Uncontrolled pre-post design	10 (19 child, 10 adults)	adult & child	This trial is a single-arm study aimed at assessing the feasibility, acceptability, and effectiveness of teleCBIT integrated into comprehensive medical tic specialty clinics.	^YGTSS, CGI, & ATQ.	Psychometric properties, Adaptable to be applicable to different populations

AQT = Adult Tic Questionnaire; Attention Deficit Hyperactivity Disorder Rating Scale; ADHD-RS-IV = Attention Deficit Hyperactivity Disorder Rating Scale-Fourth Edition; BIS-10 = Barratt Impulsiveness Scale; BIS-11 = Barratt Impulsiveness Scale; BAI = Beck Anxiety Inventory; BDI = Beck Depressive Inventory; CGI = Clinical Global Impression; CAARS = Conners' Adult ADHD Rating Scale; EPI = Eysenck Personality Inventory; FAM-III = Family Assessment Measure; FFMQ = Five Facet Mind-fulness Questionnaire; GHQ = General Health Questionnaire — 12-item version; GTS-QoL = Gilles de la Tourette Syndrome-Quality of Life Scale; LES = Life Experience Survey; MOCI = Maudsley Obsessional–Compulsive Inventory; MRVS = Modified Rush Video-Based Tic Rating Scale; MPS = Multi-dimensional Perfectionism Scale; PI = Padua Inventory; PDQ-4 = Personality Diagnostic Questionnaire-4th Edition; PUTS = Premonitory Urge for Tics Scale; SES = Rosenberg Self-Esteem Scale; GTS-QoL-VAS = Quality of Life - Visual Analogue Scale; SOS-10 = Schwartz Outcome Scale; SDI = Sheehan Disability Inventory; SAS-SR = Social Adjustment Scale Self-Report; SSI = Social Self-esteem Inventory; STAI = Spielberger State-trait Anxiety Inventory; STAXI-2 = State-Trait Anger Expression Inventory-Second Edition; STOP = Style of Planning Questionnaire; TSGS = Tourette Syndrome Global Scale; VOCI = Vancouver Obsessional Compulsive Inventory; YGTSS = Yale Global Tic Severity Scale; Y-BOCS = Yale-Brown Obsessive-Compulsive Scale.

*indicates the 12 unique studies included in the synthesis

^Indicates studies which have identified a primary outcome measure

3.3 Quality of Included Studies

The JBI Quasi-Experimental Study Checklist has nine items to assess the methodologic quality and risk of bias within studies (table 1.2 & appendix 1.4). The most common areas of clear strength were 'cause' and 'effect', multiple measures being used, outcomes being measured in a reliable way, and appropriate statistical analysis. A common area of weakness was lack of comparable groups within treatment conditions and lack of follow up. The JBI RCT Critical Appraisal Checklist has 13 items (table 1.3 & appendix 1.4). The most common areas of clear strength were treatment groups being treated identically, consistent use of outcome measures for groups, reliable outcome measures used, appropriate statistical analysis, and appropriate trials design. Studies were not excluded based on the quality appraisal, but key issues of quality are highlighted below in the synthesis.

Table 1.2 - Quality Appraisal Scores (JBI Quasi-Experimental Checklist)

Study	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**
O'Connor KP, Brault M, Robillard S, Loiselle J, Borgeat F, Stip E.*	Yes	*Yes*	*No*	Yes	Yes	Yes	Yes	Yes	Yes
O'Connor KP, Lavoie ME, Stip E, Borgeat F, Laverdure A.	Yes	Yes	Yes	Yes	Yes	No	Yes	yes	yes
Lavoie ME, Imbriglio TV, Stip E, O'Connor KP.	Yes	Yes	No	Yes	Yes	No	Yes	Yes	yes
Morand-Beaulieu S, O'Connor KP, Sauve G, Blanchet PJ, Lavoie ME.	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes
Morand-Beaulieu S, O'Connor KP, Richard M, Sauve G, Leclerc JB, Blanchet PJ, et al.	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Bekk M, Meland KJ, Moen E, Nostvik LI, Gausdal AL, Hummelen B.	Yes	No	NA	No	Yes	Yes	Yes	Yes	Yes
Capriotti MR, Wellen BC, Young BN, Himle MB, Conelea CA, Espil FM, et al.*	Yes	No	*NA*	No	Yes	Yes	Yes	Yes	Yes
Reese HE, Brown WA, Summers BJ, Shin J, Wheeler G, Wilhelm S. *	Yes	No	NA	No	Yes	No	Yes	Yes	Yes
NA = not applicable **Indicates the paper was co-reviewed* Items in italics indicates resolved disagreements at co review									

Table 1.3 - Quality Appraisal Score (JBI Randomized Controlled Trials Checklist)

Study	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**	**Q11**	**Q12**	**Q13**
Wilhelm S, Deckersbach T, Coffey BJ, Bohne A, Peterson AL, Baer L.*	?	No	?	*?*	No	No	Yes	Yes	?	Yes	Yes	Yes	Yes
Deckersbach T, Rauch S, Buhlmann U, Wilhelm S.	Yes	?	Yes	?	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Haas M, Jakubovski E, Kunert K, Fremer C, Buddensiek N, Hackl S, et al.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wilhelm S, Peterson AL, Piacentini J, Woods DW, Deckersbach T, Sukhodolsky DG, et al*	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	yes	Yes	Yes
Houghton DC, Capriotti MR, Scahill LD, Wilhelm S, Peterson AL, Walkup JT, et al.	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Weingarden H, Scahill L, Hoeppner S, Peterson AL, Woods DW, Walkup JT, et al.	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
McGuire JF, Ricketts EJ, Scahill L, Wilhelm S, Woods DW, Piacentini J, et al.	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Essoe JK, Ricketts EJ, Ramsey KA, Piacentini J, Woods DW, Peterson AL, et al	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Deckersbach T, Chou T, Britton JC, Carlson LE, Reese HE, Siev J, et al.	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

**Indicates the paper was co-reviewed*
? = Unclear
Items in italics indicates resolved disagreements at co review

3.4 What measures were used and what dimensions do they capture?

Collectively, a total of 34 outcome measures were employed across the 17 included papers (representing the 12 unique studies). These measures were broadly categorised into five domains (although recognising that there is some overlap between domains): severity/frequency of tics (6 measures), ADHD/Impulsiveness (5 measures), mental health (14 measures), QoL (5 measures), and functioning (4 measures) (table 1.3). Of these outcome measures, 16 were used in only one paper each, while 18 of the outcome measures were used across multiple papers. Outcome measures evaluating the quality of therapy were excluded from the synthesis as they are designed to assess the process of therapy delivery rather than directly measuring changes of tics presentation, functioning, QoL, or well-being of the individuals receiving the therapy.

Out of the 12 studies, 75% (n=9) assessed mental health as part of their outcomes, most often assessing for depression, anxiety, or general well-being. The most commonly utilised measure for assessing depression was the Beck Depression Inventory (BDI) (Beck, 1970), which was employed in 75% (n=9) of the studies. The BDI is designed to measure the severity of depressive symptoms experienced by individuals. While the BDI does not have distinct domains like some other assessment tools, it covers a range of cognitive, emotional, and behavioural symptoms commonly associated with depression (table 1.3). Of these 9 studies that assessed mental health domains, all were deemed to be of moderate to high quality (table 1.2 & 1.3).

Quality of life (QoL) was assessed in 33.3% (n=4) of the studies, with the Gilles de la Tourette Syndrome-Quality of Life Scale (GTS-QoL/GTS-QoL-VAS) (Cavanna et al., 2008) being applied to two of the studies. The GTS-QoL measure is used to assess the impact of Tourette syndrome on an individual's quality of life across various domains; symptomatology, activities of daily living, coping, stigmatisation, school, work, leisure time, social support, and overall life satisfaction (table 1.4). Of the 4 studies that assessed QoL, all were deemed to be of high quality (table 1.2 & 1.3).

Features of ADHD/Impulsiveness were explored in 42% (n=5) of the studies, with the Attention Deficit Hyperactivity Disorder (ADHD) Rating Scale (Barkley, 2003) being the most commonly utilised measure, employed in three studies. This scale aids clinicians and researchers in quantifying ADHD symptoms across these domains (inattention, hyperactivity, and impulsiveness) to aid in diagnosis and treatment planning (table 1.4). Of the 5 studies that assessed impulsiveness and ADHD symptoms, all were deemed to be of moderate to high quality (see table 1.2 & 1.3).

Lastly, functional measures were used in 25% (n=3) of the studies, with the Sheehan Disability Inventory (SDI) (Leon et al., 1992) being the most frequently utilised, applied in three studies. The SDI self-report questionnaire is used to assess the extent of functional impairment across various domains, including work/school, social life/leisure activities, and family life/home responsibilities (table 1.4). Of the 3 studies that assessed functioning, all were deemed to be of moderate to high quality (table 1.2 & 1.3).

All studies employed either a tool (e.g. diary monitoring) or one measure to evaluate the frequency and severity of tics. In 10 out of the 12 studies (83%), the Yale Global Tic Severity Scale (YGTSS) (Leckman et al., 1989) was utilised which is considered the gold standard measure for assessment of severity of TS/TD (Haas et al., 2021). The Global Impression – Severity Score (CGI-S) and the Clinical Global Impression – Improvement Score (CGI-I) (Busner et al., 2007) were also utilised across eight studies. These measures involve a clinician rating improvement or worsening on an 8-point scale, with scores indicating levels such as "very much improved" and "much improved." It is worth highlighting that the two studies rated as having the highest risk of bias during the review, used a limited number of outcome measures (three or fewer) and notably, both studies employed the YGTSS and CGI scale.

Table 1.4 List of Measures

No.	Outcome Measure	No. of items	Items	Description	Domains
1	*Adult Tic Questionnaire (ATQ) (Leckman et al., 1989)	27	1. Frequency of tics 2. Severity of tics 3. Impact on daily functioning 4. Tic-related distress	The Adult Tic Questionnaire (ATQ) is a self-report assessment tool for evaluating the severity and frequency of tic symptoms in adults.	Tic Frequency/Severity
2	Attention Deficit Hyperactivity Disorder (ADHD) Rating Scale (DuPaul, 1990)	18	1. Inattention 2. Hyperactivity 3. Impulsivity	The scale aids clinicians and researchers in quantifying ADHD symptoms across domains to support diagnosis and treatment planning.	ADHD/Impulsiveness
3	Attention Deficit Hyperactivity Disorder Rating Scale-Fourth Edition (ADHD-RS-IV; (DuPaul, 2008)	18	1. Inattention 2. Hyperactivity-Impulsivity	The scale aids clinicians and researchers in quantifying ADHD symptoms across two domains.	ADHD/Impulsiveness
4	Barratt Impulsiveness Scale Version 10 (BIS-10)(Patton et al., 1995)	30	1. Attentional Impulsiveness 2. Motor Impulsiveness 3. Non-planning Impulsiveness	The BIS-10 measures impulsivity across various domains to aid assessment and treatment.	ADHD/Impulsiveness
5	Barratt Impulsiveness Scale Version 11 (BIS-11)(Patton et al., 1995)	30	1. Attentional Impulsiveness 2. Motor Impulsiveness 3. Non-planning Impulsiveness	Updated version of BIS-10. The Barratt BIS-11 measures impulsivity across various domains to aid assessment and treatment.	ADHD/Impulsiveness
6	Beck Anxiety Inventory (BAI)(Beck et al., 1988)	21	1. Cognitive 2. Emotional 3. Physiological 4. Somatic	These items are designed to measure the severity of anxiety symptoms that individuals have experienced over the past week.	Mental Health

7	Beck Depressive Inventory (BDI) (Beck et al., 1996)	21	1. Cognitive 2. Emotional 3. Somatic 4. Behavioural	The Beck Depression Inventory (BDI) was developed to evaluate the severity of symptoms experienced by individuals with depression. It covers a wide range of cognitive, emotional, and behavioural symptoms associated with depression.	Mental Health
8	Clinical Global Impression (CGI) (Guy, 1976)	2	1. Rating of Severity 2. Rating of Improvement	The Clinical Global Impression (CGI) is a widely used assessment tool in psychiatry and clinical trials. It is not designed to measure specific domains or symptoms but provides an overall assessment of a patient's illness severity, global improvement, and therapeutic response.	Tic Frequency/Severity
9	Conners' Adult ADHD Rating Scale (CAARS) (Conners et al., 1999)	66	1. Inattention/Memory Problems 2. Hyperactivity/Restlessness 3. Impulsivity/Emotional Lability 4. Problems with Self-Concept. 5. Inconsistent Performance 6. ADHD Index	The Conners' Adult ADHD Rating Scale (CAARS) assesses symptoms related to ADHD in adults.	ADHD/Impulsiveness
10	Eysenck Personality Inventory (EPI) (Eysenck & Eysenck, 1968)	57	1. Extraversion 2. Neuroticism	This inventory measures personality traits based on Eysenck's theory of personality, which primarily focuses on two main dimensions: extraversion-introversion and neuroticism-emotional stability.	Mental Health
11	Family Assessment Measure (FAM-III) (Skinner et al., 1983)	60	1. Communication 2. Roles 3. Affective Responsiveness	This tool is used for evaluating family functioning, including communication, roles, affective responsiveness, behaviour	Functioning

			4. Affective Involvement 5. Behaviour Control 6. Problem Solving 7. General Functioning	control, problem-solving, and general functioning.	
12	General Health Questionnaire (GHQ) — 12-item version (Goldberg et al., 1972)	12	No specific domains; assesses general mental health status.	This questionnaire is a brief self-administered screening tool used to identify experiences of psychological distress or mental health problems.	Mental Health
13	*Gilles de la Tourette Syndrome-Quality of Life Scale (GTS-QoL) (Cavanna et al., 2008)	27	1. Symptomatology 2. Activities of Daily Living 3. Coping 4. Stigmatisation 5. School 6. Work 7. Leisure Time 8. Social Support 9. Overall Life Satisfaction	This measure is utilised to evaluate the impact of Tourette syndrome on an individual's quality of life across various areas of their life’s.	Quality of Life
14	Life Experience Survey (LES) (Sarason et al., 1978)	52	1. Relationship changes 2. Occupational or educational transitions 3. Health-related events 4. Financial difficulties 5. Legal or criminal issues 6. Housing changes 7. Traumatic events 8. Social or community changes	This survey captures a wide range of potentially stressful life events that may impact an individual's well-being or psychological functioning.	Quality of Life

15	Maudsley Obsessional–Compulsive Inventory (MOCI) (Rachman, 1980)	30	1. Checking 2. Cleaning 3. Slowness 4. Doubting 5. Obsessing	The MOCI is a self-report questionnaire used to evaluate obsessive-compulsive symptoms and behaviours.	Mental Health
16	*Modified Rush Video-Based Tic Rating Scale (MRVS) (Goetz et al., 1987)	24	1. Motor Tics 2. Vocal Tics	The MRVS is a tool used to assess the severity of tic symptoms based on video recordings of tic behaviour.	Tic Frequency/Severity
17	Multi-dimensional Perfectionism Scale (MPS)(Frost et al., 1990)	45	1. Concern Over Mistakes 2. Doubts about Actions 3. Personal Standards 4. Parental Expectations 5. Parental Criticism 6. Organisation 7. Doubts about Actions 8. Socially Prescribed Perfectionism	The scale is used to assess different dimensions of perfectionism, including concern over mistakes, doubts about actions, personal standards, parental expectations, and organisation.	Mental Health
18	Padua Inventory (Sanavio, 1988)	60	1. Contamination 2. Checking 3. Mental Neutralisation 4. Urges to Check 5. Urges to Repeat 6. Urges to Contaminate 7. Symmetry 8. Hoarding	The Padua Inventory is a self-report questionnaire used to assess commonly experienced obsessive-compulsive symptoms and behaviours.	Mental Health

19	Personality Diagnostic Questionnaire-4th Edition (Hyler et al., 1990)	91	1. Affectivity 2. Cognition 3. Interpersonal Functioning 4. Impulse Control	This is a self-report questionnaire used to assess personality disorders based on DSM-IV criteria.	Mental Health
20	*Premonitory Urge for Tics Scale (PUTS) (Woods et al., 2005)	9	1. Intensity 2. Frequency 3. Duration 4. Specific Sensations 5. Interference	This scale is used to assess the intensity and frequency of premonitory urges experienced by individuals with tic disorders.	Tic Frequency/Severity
21	*Quality of Life-Visual Analogue Scale (GTS-QoL-VAS) (Cavanna et al., 2008)	1	No specific domains; assesses overall quality of life using a visual analogue scale.	The GTS-QoL-VAS provides a global assessment of an individual's quality of life-related to Gilles de la Tourette syndrome and does not have specific domains.	Quality of Life
22	Rosenberg Self-Esteem Scale (SES) (Rosenberg, 1965)	10	No specific domains; assesses overall self-esteem.	The SES assesses overall self-esteem without specific domains. It consists of a series of statements related to self-worth, self-acceptance, and self-confidence, and respondents rate their level of agreement or disagreement with each statement.	Mental Health
23	Schwartz Outcome Scale (SOS-10) (Blais et al., 1999)	10	1. Satisfaction with Life 2. Perceived Control over Life 3. Self-Efficacy 4. Social Support 5. Self-Esteem 6. Emotional Stability 7. Mental Well-being 8. Physical Well-being	This measure is used to assess various outcomes related to quality of life and to assist in evaluating the effectiveness of treatments.	Quality of Life

			9. Financial Well-being 10. Quality of Work Life		
24	Sheehan Disability Inventory (Leon et al., 1992)	3	1. Work/School 2. Social Life/Leisure Activities 3. Family Life/Home Responsibilities	A self-report questionnaire is utilised to evaluate the level of functional impairment in various areas, such as work/school, social life/leisure activities, and family life/home responsibilities.	Functioning
25	Social Adjustment Scale Self-Report (SAS-SR) (Weissman, 1999)	54	1. Work 2. Social and Leisure Activities 3. Extended Family Relationships 4. Role as Spouse 5. Parental Role	A self-report questionnaire used to assess social adjustment across various domains, including work, social and leisure activities, extended family relationships, role as spouse, and parental role.	Functioning
26	Social Self-esteem Inventory (SSI) (Lawson et al., 1979)	27	1. Social support 2. Social acceptance 3. Social satisfaction 4. Social loneliness 5. Social confidence 6. Social competence	SSI is a questionnaire used to assess various areas of social self-esteem.	Quality of Life
27	Speilberger State-trait Anxiety Inventory (STAI) (Speilberger et al., 1983)	40	1. Trait Anxiety 2. State Anxiety	This self-report questionnaire evaluates both state (emotional response to stimuli) and trait (part of someone's personality) anxiety.	Mental Health
28	State-Trait Anger Expression Inventory-Second Edition (STAXI-2) (Spielberger, 2010)	57	1. Trait Anger 2. State Anger 3. Anger Expression 4. Anger Control	This measure is used to assess various aspects of anger expression and control.	Mental Health

29	Style of Planning Questionnaire (STOP) (O'Connor et al., 2015)	30	No specific domains; assesses individual's planning style.	The STOP assesses an individual's planning style, but it does not have distinct domains. Instead, it provides a comprehensive assessment of an individual's planning tendencies.	Functioning
30	*Tourette Syndrome Global Scale (TSGS) (Harcherik et al., 1984)	7	1. Motor Tics 2. Vocal Tics 3. Tic Severity 4. Impairment 5. Overall Global Severity	The TSGS assesses the severity and impact of Tourette syndrome symptoms across multiple domains.	Tic Frequency/Severity
31	Vancouver Obsessional Compulsive Inventory (VOCI) (Thordarson et al., 2004)	55	1. Contamination 2. Checking 3. Mental Neutralisation 4. Urges to Check 5. Urges to Repeat 6. Urges to Contaminate 7. Symmetry 8. Hoarding	The VOCI is a self-report questionnaire used to assess obsessive-compulsive symptoms, avoidance behaviours and personality traits.	Mental Health
32	*Yale Global Tic Severity Scale (YGTSS) (Leckman et al., 1989)	17	1. Tic Severity 2. Impairment	The YGTSS scale is used to assess tic severity and impairment in individuals with tic disorders, evaluating the complexities of both motor and phonic tics.	Tic Frequency/Severity
33	Yale-Brown Obsessive-Compulsive Scale (Y-BOCS)(Goodman et al., 1989)	10	1. Obsessions 2. Compulsions	The Y-BOCS scale assesses the severity of obsessive-compulsive symptoms.	Mental Health

34	Five Facet Mind-fulness Questionnaire (FFMQ)(Baer et al., 2006)	39	1. Observing 2. Describing 3. Acting with Awareness 4. Non-judging of Inner Experience 5. Non-reactivity to Inner Experience	The FFMQ is a widely used self-report measure designed to assess various aspects of mindfulness.	Mental Health
*Measure has been specifically developed for TS/TD population					

4.5 What reasons were given by authors for the selection of measures used?

Predominantly, the reasons cited for selecting specific instruments were their robust psychometric properties, as noted in 9 of the 17 papers (53%), and their status as well-established measures, mentioned in four papers (23.5%). Less frequently stated rationales noted were the instrument's suitability for capturing the desired outcome, as observed in 2 (12%) papers, and its adaptability across diverse populations, only noted in 2 (12%) of papers also. Only two papers (Haas et al., 2022; Morand-Beaulieu et al., 2015) did not provide any rationale for their choice of measures, though both studies overall received high ratings on their quality review.

4. Discussion

4.1 Overview of the Findings

This review identified 17 papers, reporting 12 unique studies of psychological and behavioural interventions with adult TS/TD populations. All studies employed pre and post measures to evaluate changes within participant groups. The findings of this systematic review highlight the diverse and multifaceted approaches the majority of researchers have taken to measure QoL, functional, and mental health outcomes. Our analysis has revealed trends and commonalities in the selection and application of outcome measures. With the exception of one paper, all others reported employing a specific tool to evaluate outcome measures associated with QoL, general functioning, or mental health. This reflects the importance of recognising the complex interplay of various factors—such as mental health and quality of life—in adults with tics, focusing solely on reducing tic frequency or severity is insufficient for understanding their overall experience.

4.2 Quality of Life Measures

The Gilles de la Tourette Syndrome-Quality of Life Scale (GTS-QoL) was created in response to an increasing awareness of the importance of patient perceptions in evaluating treatment outcomes and recognising the critical role of health-related QoL as a measure of treatment effectiveness (Devinsky, 1995). Studies have further noted that though generic instruments allow for comparison across different populations, they are less feasible for neuropsychiatric conditions such as TS/TD (Cavanna et al., 2008). Researchers developing the GTS-QoL focused on domains that are meaningful to individuals with TS/TD. These included items that effectively distinguish between patient groups of varying disease severity and health impairment. Concerns around the sensitivity of the QoL measure used within TS/TD populations have been previously highlighted. However, the GTS-QoL was designed to minimise ceiling and floor effects, ensuring sensitivity and holding an internal consistency of $\alpha = 0.8$ (Cavanna et al., 2008).

Our review identified relatively few studies employing QoL measures within an adult population. However, the categories within QoL are not absolute; some measures may include elements of QoL domains while primarily assessing other aspects, such as functioning. For example, the Life Experience Survey (LES) (Sarason et al., 1978) which evaluates functioning; though, understandably, incorporates QoL elements. Despite the advantages of using QoL measures specific to TS/TD, their infrequent use with adults raises questions. Further investigation may be required to understand the reasons behind this limited utilisation. Exploring our findings, researchers often appear to prioritise clinical symptoms over QoL, leading to less emphasis on broader impacts of TS/TD. QoL is also complex; it encompasses multiple dimensions, making it difficult to measure and interpret, particularly in populations with diverse symptoms and comorbidities like TS/TD. Researchers might believe they have captured sufficient factors by using other measures; however this is unclear, and no rationales were provided for this.

4.3 Mental Health Measures

Measures designed to evaluate mental health outcomes, particularly depression and anxiety, were incorporated across nine studies. Individuals with TS/TD often experience significant psychological distress due to the chronic and unpredictable nature of their symptoms, which can contribute to feelings of sadness, hopelessness, and worthlessness which align with characteristic of depression. The most commonly used tool to evaluate depression was the Beck Depressive Inventory (BDI), which has established good validity and reliability in assessing depressive symptoms. The BDI has been found to have good internal consistency (ranging between α = 0.86 to 0.93) (Zgaljardic, 2011). Second to the BDI, the Beck Anxiety Inventory (BAI) was utilised to assesses frequency of anxiety symptoms and has been found to have good internal consistency also (α = 0.91) (Starosta et al., 2017).

This widespread use of tools such as the BDI and BAI, demonstrates acknowledgement of previous research highlighting psychiatric comorbidities within TS/TD populations, with 85% of individuals with TS/TD also contend with another psychiatric disorder (Hirschtritt et al., 2015). This pertains to the range measures used throughout this review's papers, exploring other areas such as OCD, perfectionism and personality traits as comorbidities to TS/TD populations. Out of the 34 measures, four were explicitly dedicated to detecting symptoms associated with obsessive-compulsive disorder and were utilised in eight of the reviewed studies. The Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) (Goodman et al., 1989) was most commonly used in four studies and is considered the gold standard for assessing tics and comorbid OCD symptoms (Szejko et al., 2022). Researchers have highlighted the importance of developing a valid, consistent, and easy-to-administer severity scale that captures the full spectrum of pathological behaviours in TS/TD, including complex repetitive behaviours, impulsive actions, attention deficit-hyperactivity disorder, and obsessive-compulsive disorder–related symptoms (Martino et al., 2017). However, a consistent measure or approach that encompasses all these dimensions has yet to be identified and adapted for use in adult research.

4.4 Functional Measures

Functional measures in research and clinical work are essential for gaining a comprehensive understanding of impact, evaluating treatment efficacy, providing patient-centred care, identifying needs, and conducting useful follow-up studies. Previous systematic reviews have highlighted numerous studies examining functioning; however, these predominantly focus on child and adolescent populations, where family functioning plays a critical role in overall assessments of quality of life (Evans et al., 2016). In this review exploring adult populations, directly measuring functional impacts appears uncommon with only 25% of the studies specifically utilising a measure to assess function. This change in approach between child versus adult population may reflect the result of the Tourette Syndrome Impact Survey which indicated that adults experience less interference with work productivity than the academic interference reported by children, which may be attributed to developmental changes such as the development of coping skills and increased autonomy (Evans et al., 2016). These factors likely contribute positively to an individual, effecting the level of impact TD/TS have on daily life. Similarly, researchers may conclude that the close overlap between functioning and QoL domains—such as occupation, social satisfaction, and home life—might already be captured within the measures they are currently using.

4.5 ADHD/Impulsivity Measures

Including ADHD measures in the review enhanced its comprehensiveness by addressing the significant overlap between Tourette syndrome and ADHD. It allowed for a more accurate reflection of treatment outcomes, capturing improvements in both tic and ADHD symptoms and their combined impact on quality of life, mental health, and functioning. This ensured the review reflects the full scope of challenges and benefits associated with treatment in this population. Among TS/TD patients, ADHD is the most frequent comorbidity, affecting up to 60% of individuals (Ganos & Martino, 2015). Difficulties with concentration, forgetfulness and inability to complete tasks contribute to key elements of QoL. Research employing the GTS-QoL indicated that cognitive factors may have a more pronounced impact on QoL perception in adulthood compared to childhood (Evans et al., 2016). Given this context, it is understandable that several studies utilise ADHD measures alongside other wellbeing measures.

Researchers have found that the severity of ADHD symptoms may be a stronger indicator of QoL in individuals with TS than the severity of tics alone. Adults with tic disorders and ADHD symptoms have been found to be strongly associated with poor health-related QoL, even when severity of depression, anxiety, and obsessive-compulsive comorbidities are accounted for (Isaacs et al., 2021). Therefore, it is essential to utilise measures to distinguish between tic disorders on their own and tic disorders accompanied by significant ADHD symptoms, both in terms of diagnosis and treatment outcomes. However, researchers have shown that having ADHD alongside TD/TS does not impede the effectiveness of cognitive behavioural-based treatments; therefore, they conclude a specialist treatment pathway is not required (Mazur-Lainé et al., 2024).

4.6 Limitations of Reviewed Studies

The review looked at a range of studies which explored various aims of the psychological interventions, various treatment interventions and outcome measures which can result in significant heterogeneity, making it challenging to directly combine and compare results. It is essential to acknowledge that the quality of the reviewed research varied, although most studies received favourable ratings. Conclusions of a systematic review are only as reliable as the quality of the studies it includes. Poorly conducted studies can bias the results of the review. The papers that were rated poorly may have influenced the overall results and subsequent conclusions. Furthermore, a number of studies had small samples, impacting generalisability, and only a few studies included follow-up assessment post-treatment evaluating long-term efficacy, adverse outcomes, or maintenance of therapeutic gains.

In addition, the reliance on only a few well-regarded measures in some studies, may limit the comprehensiveness of their evaluations, potentially impacting the overall quality and reliability of their findings. Seven studies identified the Yale Global Tic Severity Scale (YGTSS) as their primary outcome measure, while all other measures were considered secondary. The implication for research is that the focus on YGTSS as the primary outcome measure may lead to a narrow interpretation of treatment effectiveness, potentially overlooking other important factors as discussed above. A key limitation is that the primary outcomes emphasise quantitative measures rather than quality of life for individuals with tics, as improvements in symptom severity may not necessarily translate to meaningful enhancements in daily functioning or well-being.

4.7 Limitations of this Review

Methodological concerns within the review will result in limitations. For example, aligning with the review questions means that, to some extent, the review itself was constrained by the predefined scope. Furthermore, despite efforts to minimize bias, the subjective decisions made during the review process, such as inclusion/exclusion criteria, data interpretation and measure categorisation, can still introduce reviewer bias. Biases are also introduced with exclusion criteria, such as being limited to only English-language papers. There was limited resource available to employ a second reviewer; therefore only a percentage of papers were co-rated during screening and quality assessment. Furthermore, some grey literature (e.g. potential non-published papers) may have been missed due to time constraints in seeking author replies, which can lead to publication bias as often non-significant results are less likely to be published.

The review was unable to identify sufficient data regarding the rationales for selecting specific measures, as many studies did not explicitly explain their rationale or provide in-depth information. This could be due to various factors such as the lack of standardised measures, specific contextual needs, and practical constraints. However, this hinders the review's ability to interpret measure selection.

4.7 Future Research Implications

The review has demonstrated that while there is a consistent use of standardised measures in line with previous research into their validity with TS/TD populations, there is little consistency in outcome measures used across studies of psychological/behavioural treatments. Research focused on treatment outcomes in tic disorders should aim to provide a comprehensive understanding of the QoL impacts, support consistency in clinical practice, and address the broader effects of tic disorders. By incorporating diverse methodologies and perspectives, such research can ultimately enhance the care and well-being of individuals with tic disorders. This is also reflected in the range of condition-specific versus general measures in studies of interventions for TS/TD which has important implications, with each approach offering distinct advantages and limitations. Condition-specific measures, such as the GTS-QoL, are tailored to the unique features of the condition, allowing for a more nuanced understanding of its impact on quality of life, symptom severity, or functioning. These tools are often more sensitive to detecting changes or treatment effects directly relevant to TS/TD. However, their focus on a specific condition can limit comparability across different populations and conditions, and their development and validation can be resource-intensive. In contrast, general measures provide the advantage of facilitating comparisons across diverse populations and conditions, offering broader applicability. They are often well-validated and widely used, enhancing the interpretability and credibility of findings. However, they may lack the sensitivity needed to capture subtle or condition-specific changes, and some dimensions may be less relevant to individuals with TS/TD, potentially diluting the focus of the assessment.

In addition, assessing the psychometric properties of the measures was beyond the scope of this review. Future research could address this gap by thoroughly evaluating the validity and reliability of these tools within this population, a task that extends well beyond the limitations of our current protocol.

5. Conclusion

Consistency in measurement tools is crucial for comparability across studies, which enhances the robustness of research outcomes and facilitates a better understanding of the impacts of interventions on various aspects of people's lives. Currently, there is a wide variation in the measures used for assessing psychological outcomes in adult patients with TS/TD. Only a small minority of these studies have developed tools specifically for the TS/TD population. There are a number of advantages to utilising the same generic outcome measure across studies such as enhancing the comparability of results across studies, facilitating meta-analyses, and ultimately contributing to a more cohesive body of evidence.

Though to further strengthen the conclusions, it is important to advocate for the inclusion of measures beyond those focusing solely on TS/TD symptomatology, expanding the scope of outcome evaluations. However, despite the vast array of measures available to assess treatment efficacy and follow-up, there are no consistent options that comprehensively cover all relevant categories for the TS/TD population. Therefore, standardising outcome measures in TS/TD research remains a critical need to improve the quality and applicability of clinical findings.

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Chapter 2: Major Research Project

EXPLORING ADULTS’ EXPERIENCES OF PSYCHOLOGICAL TREATMENT FOR TIC AND TOURETTE’S SYNDROME: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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Plain Language Summary

Title: Exploring Adults Experiences of Psychological Treatment for Tic and Tourette's Syndrome: An Interpretative Phenomenological Analysis

Background: Tourette's Syndrome (TS) and tic disorder (TD) are characterised by the presence of movement and vocal tics, that often appear at first in childhood. Tics are sudden and fast movements or sounds a person makes. Comprehensive Behavioural Intervention for Tics (CBIT) is a good treatment option for children and adults (Pringsheim et al., 2019). In contrast to previous research, this study gives a unique perspective of adults' experiences of CBIT utilising a qualitative approach, with the aim of positively impacting guidance for improving patient experiences and care.

Aims and Questions: The study aimed to explore the experiences of adult participants with TS/TD moving through a CBIT pathway. The study addressed four key questions;

i. How do adults make sense of their experiences of the CBIT pathway?
ii. How do expectations shape an individual's experience of the CBIT?
iii. How do adults with TS/TD perceive their sense of self after experiencing the CBIT pathway?
iv. What are the keys parts of CBIT that effect change for individuals?

Methods:

Participants: We recruited five individuals diagnosed with TS/TD. Participants were recruited through the CBIT treatment pathway at NHS Greater Glasgow and Clyde Neuropsychology service.

Consent: Patients were asked to indicate their interest by contacting the research team. The Principal Investigator provided further information, and written consent was sought.

Design of study: A qualitative approach taken in the form of interpretative phenomenological analysis (IPA). IPA looks at someone's experiences of something (Smith & Fieldsend, 2021).

Data collection: A semi-structured, one-to-one interview was carried out. Interviews lasted around 50 minutes.

Main Findings and Conclusion: Four experiential themes were derived from the interviews. The first theme captured the diagnosis experiences of individuals with tics, focusing on issues such as diagnostic ambiguity, treatment availability, and stigma. The second theme addressed strategies for managing tics within CBIT, identifying both helpful and unhelpful processes. The third theme emphasised the significance of quality of life (QoL) before and after treatment. Finally, the fourth theme highlighted the role of the therapeutic alliance. This study has underlined the importance of further research into adult services for TS/TD, focusing on diagnostic processes, referral pathways, treatment access, and the role of the therapeutic relationship in CBIT.

Clinical Recommendations: Our findings emphasise the ongoing concerns about validation and stigma linked to a TS/TD diagnosis. The healthcare system plays a key role in addressing these issues, but the lack of clear guidelines for assessing and treating TS/TD makes it harder to provide the best care. Clinicians should be well-informed about different treatment options and adaptable in adjusting care to each person. Finally, a better understanding of how TS/TD affects QoL will help guide treatment priorities and resource allocation for adults.

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Abstract

This study provides a unique perspective of adults' experiences of Comprehensive Behavioural Intervention for Tics (CBIT) utilising a qualitative approach, with the purpose of positively impacting guidance for improving patient experiences. The study aimed to explore the experiences of adults with Tourette’s Syndrome (TS) and tic disorder (TD) while progressing through CBIT.

Interpretative phenomenological analysis (IPA) was employed. Five individuals were recruited. All participants had completed the CBIT pathway. Semi-structured, one-to-one interviews were conducted.

Four group experiential themes (GETs) were derived. The first theme captured the diagnosis experiences, focusing on issues such as diagnostic ambiguity, treatment availability, and stigma. The second theme addressed strategies for managing tics. The third theme emphasised the significance of quality of life. Finally, the fourth theme highlighted the role of the therapeutic alliance.

The study has underlined the importance of further research into adult services for TS/TD, focusing on diagnostic processes, referral pathways, and treatment access. Our findings emphasise the ongoing concerns about validation and stigma linked to a TS/TD diagnosis. The healthcare system plays a key role in addressing these issues, but the lack of clear guidelines for assessing and treating TS/TD exacerbates barriers to providing optimal care.

Keywords: Tourette’s Syndrome, Tic Disorder, Interpretative Phenomenological Analysis, and Adult.

1. Introduction

1.1 Background

Tourette's syndrome (TS) and chronic tic disorder (TD) are characterised by the occurrence of chronic motor tics and vocal (phonic) tics, with onset during the developmental period (ages 4 to 12 years) and adolescence. Motor and vocal tics are defined as sudden, rapid, non-rhythmic, and recurrent movements or vocalisations, respectively. To be diagnosed with TS, both motor and phonic tics must have been present for at least one year, with the presence of both motor tic(s) and phonic tic(s) that may or may not manifest concurrently or continuously during the symptomatic course (World Health Organisation, 2019). In contrast, chronic tic disorder is characterised by the presence of either phonic (vocal) or motor (movement) tics over a period of at least one year (World Health Organisation, 2019). TS and TDs are believed to share a common neurobiological origin (Pringsheim et al., 2019). The basal ganglia holds a key role in receiving the impulses for future movement from the cerebral cortex. In TS and TDs, clusters of neurons in the ventral striatum of the basal ganglia can become uncharacteristically active, leading to the inhibition of neurons in the globus pallidus and substantia nigra, which normally act to suppress unwanted movements (Robakis, 2017).

Epidemiological studies have reliably shown that the prevalence for TS in children ranges from 0.4% to 1.5% across cultures, while the prevalence of TDs ranges from 0.9% to 2.8% (Knight et al., 2012). However, there are distinctly fewer population-based estimations of the prevalence of TS/TD in adults; one population-based study found a prevalence of diagnosed TS of approximately 1 per 1,000 (Yang et al., 2016), though a more recent meta-analysis suggested that the prevalence is around 118 cases of TS per million adults (Levine et al., 2019). Research has suggested that living with TS can lead to functional impairment, disability, and psychological distress across the lifespan (Cavanna et al., 2013).

There is a strong evidence base for using Comprehensive Behavioural Intervention for Tics (CBIT) in child, adolescent, and adult populations (McGuire et al., 2014; Piacentini et al., 2010; Pringsheim et al., 2019). CBIT involves in-depth psychoeducation, relaxation training, competing response training, and function-based interventions (Kim et al., 2021). A randomised controlled trial in adults demonstrated clinically significant improvement for those who received CBIT compared to those who received psychoeducation and supportive therapy (Wilhelm et al., 2012). Furthermore, one study has established that behavioural interventions are equivalent to pharmacotherapy in reducing tics however, did not find any improvements in comorbid conditions presentations (e.g. OCD) (Rizzo et al., 2018). Treatment choices for TS/TD have significantly evolved in the last ten years, with variations to established therapies enabling behavioural interventions to be more accessible through virtual CBIT platforms, condensing the number of CBIT sessions, and providing behavioural therapy in a group setting (Frey & Malaty, 2022). Positive treatment expectancy has also been identified as a mediating factor for treatment response, through quantitative research finding that positive expectations for change in CBIT among participants was associated with greater tic reductions over time (Sukhodolsky et al., 2017). However, to our knowledge, this mediator for effective treatment has not been explored in depth from an adult participant perspective.

There is an emergent body of qualitative literature exploring lived experiences of people with TDs and TS. A meta-synthesis of all age ranges highlighted that qualitative research has touched on negative treatment experiences as a theme among individuals with TS. However, these negative treatment experiences referred to diagnosis and pharmaceutical interventions rather than psychological (Smith et al., 2015). Recently, a small body of literature investigating adults' experiences of TS has found that the experience is often multidimensional and highlighted themes of self-identity threat, social withdrawal, and self-stigma (Malli et al., 2019). The role of social support online has also been explored and has found that online communities have positive impact on psychological wellbeing providing both informative and emotional support (Perkins et al., 2020). Pain management has also been identified as a critical area for care as repetitive movements that cause pain can lead to impairments in daily functioning (Taylor et al., 2022).

No study, to our knowledge, focuses on specific experiences through CBIT, its pathway or adult clients’ experiences of psychological interventions for TS. In the last decade, there has been a dominant focus on quantitative outcomes following treatment; however, there is emerging literature more recently on adults’ experiences from a qualitative perspective that can have clinical implications for effective treatment pathways. In contrast to previous research, this study offers a unique perspective on adults' experiences with CBIT by employing a qualitative approach. This methodology enables exploration of elements such as the mediating factors for change and participants' sense of self following treatment. The findings aim to contribute to improved patient experiences and care provision by enhancing guidance in this area.

1.2 Aim of current study

The study aimed to explore the process by which adult participants with TS/TD make sense of their own experiences moving through a CBIT pathway.

1.3 Research Questions

The literature review of research undertaken guided us in highlighting key questions for this study to address:

i. How do adults with TS/TDs make sense of their experiences of the CBIT pathway?
ii. How do expectations shape an individual’s experience of the CBIT?
iii. How do individuals perceive their sense of self after the experience of the CBIT pathway?
iv. What are the keys parts of CBIT that effect change for individuals?

2. Method

2.1 Theoretical framework

The researchers adopted an ontologically relativist stance, focusing on how an individual's experience shapes their perception of reality. Epistemologically, we undertook a constructionist approach, aiming to derive truth and meaning through engagement with participants and their experiences (Creswell & Poth, 2016).

2.2 Design

A qualitative approach was employed in the form of interpretative phenomenological analysis (IPA). IPA is a detailed examination of humans' lived experiences, which, as far as possible, enables that experience to be expressed in its own terms rather than according to predefined category systems (Smith & Fieldsend, 2021). IPA underpinning theory hinges on understanding the perspective upon our involvements in the world, personal to us although connected by relationships, and subsequently how these are interpreted (Smith & Fieldsend, 2021). By choosing IPA, we committed ourselves to exploring, describing, and interpreting the means by which the participants make sense of their experiences. We were especially interested in what happens when treatment impacts everyday life and takes on a particular significance for people. IPA aims to target the reflections people have on these experiences. This is one of the fundamental advantages of IPA as it provides a rich, in-depth approach and first-person account detailing the process of meaning-making for the subject phenomena. Categories to describe, structure, and explain the phenomena are derived inductively by initially analysing transcripts to study the detailed experience of each participant, then searching for common themes and/or points of similarity and divergence between cases.

2.3 Participants

Recruitment took place between June and August 2024. Participants were recruited using convenience sampling. Participants were recruited through the CBIT pathway at the Institute of Neuroscience NHS Greater Glasgow and Clyde Neuropsychology service which covers a portion of the west of Scotland population. Patients referred to the CBIT pathway must have their referral to Neuropsychology initiated by a Consultant Neurologist. Tics are complex neurological and behavioural phenomena that can sometimes overlap with or mimic other neurological or psychological conditions. A Consultant Neurologist is best qualified to assess and confirm the diagnosis of tics, ensuring that patients referred to CBIT are suitable for this specialised intervention. This step helps avoid misdiagnosis and ensures that the intervention provided is appropriate and effective for the patient's needs. We aimed to recruit approximately eight individuals. This choice was embedded in the principles of IPA, in which it is desirable to have a small, homogeneous sample (Smith & Fieldsend, 2021). However, IPA additionally emphasised that there is no 'right sample size' and researchers should feel that they have accomplished integration in their analysis while preserving nuances presented to them. Researchers have proposed the concept of information power, where the larger the information power the sample holds, the lower the number of participants required. With this in mind, our narrow study aim supports a smaller sample size to avoid information redundancy (Malterud et al., 2016).

2.4 Inclusion Criteria

- All participants needed to have commenced treatment when they were 18 or above, with no upper age limit.
- There were no limitations based on gender.
- All participants must have either completed the CBIT pathway or attended at least three sessions before discontinuing within the last two years. This criterion aims to provide insights into why some individuals complete the pathway while others do not. Understanding this range of experiences is crucial for addressing our research questions.
- Due to the linguistic nature of IPA studies, solely fluent English speakers were included in this study as translating may unfairly represent the participants' views and experiences. There is also the potential of experiencing difficulties understanding the questions being asked, which could have impacted the study

results. There are criteria that must be met for all patients to be accepted for the CBIT pathway for NHS Greater Glasgow and Clyde Neuropsychology service (appendix 2.17). As this is where our participants were recruited, our sample aligned with these.
- Individuals capable of providing informed and voluntary consent were included.

2.5 Recruitment Procedure

Ethical approval was obtained from the NHS Research Ethics Committee (appendix 2.2) and correspondence recorded (appendix 2.4). Management approval was obtained from the NHS Greater Glasgow and Clyde research and innovation department (appendix 2.3). The clinical team identified all patients who met the eligibility criteria. Some patients were asked at the end of treatment if they were interested in hearing about research (this question is asked routinely in the service); anyone who had recorded in the medical notes as stating they do not wish to be contacted were excluded from the recruitment process. A study invitation (appendix 2.8), information sheet and reply-slip (appendix 2.9), privacy notice (appendix 2.10) and pre-paid reply envelope was sent by post by the clinical team.

Patients who wished to participate, returned their reply slip indicating their interest to the clinical team which was subsequently passed on to the research team. The Principal Investigator contacted them to provide any further information required and, if they were still interested, arranged a suitable time and date to attend the interview. Interviews could take place either at the Institute of Neuroscience at the Queen Elizabeth University Hospital or remotely, as telephone and video options were also offered. Written consent was taken before the interview commenced. If written consent could not be achieved prior to the interview (i.e., if the interview was conducted remotely), consent was recorded via a MS Form online (appendix 2.11). Post-interview information was sent out to participants when the interview has been completed (appendix 2.15). Participant feedback was requested on the initial write-up of the results (not the full raw transcript) via email (appendix 2.18)

2.6 Sample

Due to the specialist nature of the small service, limited information about participants is provided to protect confidentiality. Out of approximately 40 individuals that were approached to take part in the study, five expressed interest, and five were recruited. All participants rated themselves with moderate to severe symptoms. Some participants also experienced comorbidities often found in TS/TD populations such as obsessive-compulsive disorder, anxiety, and attention deficit hyperactivity disorder. Table 2.1 provides pseudonyms and demographics.

Table 2.1: Characteristics of the sample

Participant Number	**Pseudonym**	**Gender**	**Age Range**
1	Jess	Female	20-25
2	Abbey	Female	20-25
3	Cassie	Female	20-25
4	Joe	Male	20-25
5	Lyn	Female	40-45

2.7 Procedure

The Principal Investigator conducted a single semi-structured, one-on-one interview with each participant, lasting approximately 50 minutes (ranging from 48 to 54 minutes). These interviews were designed to elicit participants' experiences, thoughts, and feelings, providing them with the opportunity to speak freely and reflectively. The semi-structured interviews consisted of open-ended questions about the individual's experiences before, during, and post CBIT (appendix 2.13). The interview schedule was not pilot tested prior to implementation. The interviews were guided by the participants’ narratives and remained flexible. Open-ended and spontaneous follow-up questions were used to encourage participants to elaborate on their experiences. Three interviews were carried out via telephone call and two interviews were conducted on a MS teams video call. The interview audio was digitally recorded and transcribed verbatim using Microsoft Word on a password-protected laptop for analysis. Participants were given a pseudonym, and any references to specific locations or other aspects that may compromise their anonymity were removed from interview transcripts. All interviews took place in the months of July and August 2024.

As the study required a time commitment, a small gratuity for participation was appropriate. Participants received a ten-pound voucher in acknowledgement and appreciation of their efforts.

2.8 Analysis

The interview transcripts were carefully analysed using a seven-stage methodological approach for IPA (Smith & Fieldsend, 2021). This involved immersing in the data by thoroughly reading the detailed transcriptions and listening to the interviews again, taking notes on intonation, stress, and other speech features. Initial thoughts, observations, and reflections related to the narrative were then added to the transcripts through a process known as exploratory noting. To manage the large volume of data while preserving its complexity, experiential statements were constructed (appendix 2.16). The experiential statements were meticulously aligned to directly reflect the participants' experiences. Subsequently, the experiential statements from each participant were organised and interconnected. Themes were then derived, consolidated, and organised from the ordered experiential statements (appendix 2.16). This process was repeated for each transcript before amalgamating all the data to develop overarching experiential themes across all interviews.

The researcher compared the overall themes and identified the convergence and divergence of experiences. To ensure rigour, the researcher maintained a reflective log and received regular collaboration and supervision at different stages of analysis. One transcript was reviewed in detail by a supervisor to provide a second perspective on the coding process. To enhance credibility, all participants were also invited to provide reflections on the draft write-up, and their feedback influenced the final presentation of the results. Two participants provided feedback (appendix 2.18).

2.9 Research Reflexivity

In the IPA approach, the researcher plays a central role, making it essential to consider how their experiences, beliefs, and assumptions could influence the analytic process (Smith & Fieldsend, 2021). A female doctoral trainee in clinical psychology conducted the interviews. She had previous experience treating young people with TD/TS and acknowledges an interest in neuropsychological treatments. Approximately five years ago, she worked with the neuropsychology team in an assistant role though was not involved with CBIT pathway. She has no personal experiences of TS or TDs. The researcher maintained a reflective log to identify potential sources of bias and document emotional responses evoked by interview content. This practice supports the skill of 'bracketing,' which involves recognising and setting aside personal perspectives and expectations throughout the research process (Smith & Fieldsend, 2021). Additionally, research supervision was employed to aid coherence in the interpretation. The paper has been written in accordance with the Consolidated Criteria for Reporting Qualitative research (COREQ) Checklist (Tong et al., 2007).

3. Results

Four group experiential themes (GETs) were derived from the data collected. Participants' quotations have been used to illustrate GETs and group-level subthemes (table 2.2). Sections of the quotations have been removed as they were either irrelevant or may hold identifiable information and are marked as […]. The group subthemes represent both convergent and divergent experiences and are discussed in detail below.

Table 2.2: Group Experimental Themes and Sub-themes

Group Experiential Themes	**Group level sub-themes**
A. Feeling Seen: The Importance of Validation for Individuals with TS/TD	A1. Navigating uncertainty and ambiguity in diagnosis A2. Concerns regarding availability of treatment A3. How others perceive TS/TD diagnosis

B. Personal Strategies for Managing Tics	B1. Useful strategies to manage symptomology B2. Changing their relationship with tics B3. Unhelpful elements and side effects of CBIT
C. Exploring the Complexities of Quality of Life	C1. The importance of considering the impact on QoL
D. Building Trust: The Lived Experience of Therapeutic Alliance	D1. Feeling heard by your therapist

A. Feeling Seen: The Importance of Validation for individuals with TD/TS

All participants reported challenges in obtaining a clear diagnosis and accessing appropriate treatment, which in turn shaped their expectations and outlook. They were also acutely aware of the negative perceptions surrounding a TD/TS diagnosis and how these experiences had impacted their daily lives. The persistent stigma associated with TD/TS also affected their lifestyle and well-being.

A1. Navigating uncertainty and ambiguity in diagnosis

All participants discussed their uncertainty regarding their diagnoses, describing their journeys toward a clear outcome as challenging and, at times, unresolved. All participants experienced similar pathways from diagnosis to treatment, which guided appropriate interventions and supports tailored to their individual formulations. However, their differing experiences of diagnosis and the subsequent impact on treatment were expressed throughout the interviews. Abbey noted that receiving a diagnosis has been a persistent issue.

> *“Part of the difficulty of it, is I would say that its very unclear, but I would say overall just having sort of recurrent tics, you know, I suppose it's just been referred to as a tics.”* (pg.2)

Jess also experienced uncertainty due to inconsistent communication from their clinician.

> *"My neurologist said that I likely have Tourette syndrome, but he doesn't want to make an official diagnosis. But put me through anyway, so I'm kind of in limbo at the moment. So, it's kind of like, I've confirmed to have tics, specified tic disorder, yet to be confirmed, but he thinks it's Tourette Syndrome."* (pg.2)

Jess's use of the word "limbo" indicates that's she remains in a state of ambiguity.

Lyn mentioned that she initially believed she had one specific diagnosis, but the clinicians' use of inconsistent and interchangeable language led to confusion. This underscores the importance of using consistent clinical terminology to ensure patients understand their diagnosis.

> *"I'm not quite sure because at just the start of the journey, I did the initial assessment and they said that because I had so many tics that it would be Tourette's. Umm, but when I'm going to my behavioural therapy sessions, they're more talking about tics rather than, today I believe it's Tourette's….You know, it sounds really daft, but it's not something I've asked because to be fair, it doesn't really matter to me what the title is. Just knowing how to help it…"* (pg.2)

Lyn expressed their lack of certainty, emphasizing that while achieving a definitive diagnosis may not always be possible, the most important priority for them is accessing treatment.

A2. Concerns regarding available treatment

Throughout the interviews, it became evident that participants had a requirement for improved treatment availability, rooted in their past experiences. They expressed significant concerns about the lack of viable treatment options and emphasised that being offered treatment was crucial. Abbey spoke about the relief knowing there was treatment that she could access and how this validates her diagnosis.

> *"I think it felt good to finally have someone take it seriously because I think for years I've been kind of told that they couldn't do anything about it, which is quite obviously a difficult thing to hear over and over again. So, I suppose it was kind of a relief, I would say, yeah, the relief. To be seen as something that can be treated or a legitimate condition."* (pg. 5)

Abbey elaborated on how the availability of treatment is crucial for shaping both others' and her own perceptions of TD/TS.

> *"…it was massively helpful to have someone treat it at all. Because when something, when you're treated for something. It, sadly, makes it legitimate to people, so I think the biggest part of that. I viewed it as just not being a problem, which I think has calmed me a lot, it's not an issue. It's just something that people have and you have to deal with it. So, it's actually, I think, changed it kind of, changed my entire outlook on it…"* (pg.19)

Cassie voiced her openness to try any treatments offered even when other people's perceptions of the treatment are sometimes negative.

> *"I was happy to try anything, to be honest, my GP put me on medication to try for the tics before and I really don't get on with that …I was a bit apprehensive at first because I had done some research myself when I'd heard - CBIT therapy, and I haven't heard very good*

> *things, you know, looking online. I'll go anyway and see if it works for me. Definitely, worth the shot."* (pg. 4)

Similarly, Jess, was open to treatment and keen to engage due to the impact of her symptoms.

> *"I think having some sort of intervention was really useful and even if you know, in the long run, there is no long-term benefit, I think it's very beneficial at least to see what was out there and at least try something and at least something was being attempted [….] because sometimes, you know, the healthcare industry, I think especially with Tourette's syndrome, there really isn't a lot there."* (pg.22)

Joe also voiced a lack of options offered previously.

> *"… I was fine with it {being referred to CBIT}, to be honest. In my experience. I've had a lot of doctors who have never really been able to offer any support…"* (pg.4)

A3. How others perceive their diagnosis

All participants reported negative experiences with how others perceived their diagnosis and symptoms, including incidents of stigma. Abbey noted how the diagnosis itself, isn't well known.

> *"'Tic' doesn't mean anything. In fact, when I say that people usually think of the bug. So, it's a very useless diagnosis when it comes to describing it to anyone that is not in the medical industry..."* (pg.18)

The phrasing, "people usually think of the bug" highlights the potential lack of societal knowledge regarding TS/TD, with the word "tic" not being commonly associated with a health condition. Furthermore, the use of terms like "useless" conveys the sense of meaninglessness Abbey may feel, tied to the language used for her diagnosis.

Cassie shared an experience when she was out in the community.

> *"Before {CBIT}, I did have the sort of, almost embarrassment, going out in public and start ticking, and people look at you and I had to couple bad experiences last summer, people kind of pointing, staring, which is just horrible experience"* (pg. 15)

Joe shared how his family had responded to the diagnosis. The way others have perceived and reacted to Joe's diagnosis appears to have influenced how he perceives it himself.

> *"I don't speak to anyone about Tourette's, except my mom… the family just doesn't believe in it. And I struggle to show anyone because to me it's a sign of weakness."* (pg. 15)

Similarly, Lyn voiced how others impact her views of herself. Lyn discussed how it had changed her career progression and how she developed self-stigma, believing other people would not take her seriously for promotion.

> *"…people telling me that I would need to get rid of my twitch because it was unprofessional…you'll have to get rid of that so that you can progress and so on, and in my head that's why I started suppressing them because it was, I saw as unprofessional. I saw how people thought it was."* (pg. 13)

B. Personal Strategies for Managing Tics

Strategies and approaches to managing tic symptoms were important to all participants. This included not only teaching practical skills but also helping them adjust to their diagnosis.

B1. Useful strategies to manage symptomology

All participants recognised CBIT as providing strategies to manage their symptoms.

Jess describes the processes she went through in therapy.

> *"…the alternative behaviour wasn't satisfying the urge, and so then we were able to come up with a different way of doing it […]. Another part was working on specific triggers as well as determining what they are and coming up with solutions to avoid or lessen the triggers as much as possible, to lessen the amount of tics happening […] we were working on stress management, emotion works, breathing techniques, relaxation techniques and I had trouble with kind of knowing my emotions, it's difficult to know how to correlate my emotions to tics and if it was impacting them. So, she {the psychologist} was able to then tell me, give me a strict structure when to write it down and then write down my emotion so I could have better practice to recognise it."* (pg. 11)

Abbey also spoke about her experiences in therapy and the role of having a therapist being involved in the process.

> *"I would say it started out a lot with describing the physical sensation of the tic itself, like what it feels like and where it comes from and then in a less direct way. It was over quite a long period of time, so I can't remember all the details, but it would be a lot of talking about*

> *where my sources of stress and anxiety were, and so I would be asked to describe a lot of my thought processes… at certain points we would all to do physical exercises, but I do use them today as well to, reduce it, so different relaxations or body relaxations or physical methods. If I was ticking a lot, I would do certain methods that were shared with me, to reduce the impulse to move, which were quite helpful. So, it spanned from movement, to describing the tic and then describing anxieties and sources of anxieties."* (pg. 11)

> *"…I think sometimes, having someone sort of, not correct, but like reframe different words that I would use, or say something, kind of stands out."* (pg.13)

Cassie voiced a similar experience around describing sensations and using the time in therapy to practice skills.

> *"Talking and figuring things out. You're trying the different movements and things as well, and useful to try and then programme them in your mind, because I think when your tics are bad or whenever, you're not doing so good, it can get quite overwhelming. So, practicing them beforehand, it would kind of say, Ok, I can come back to this when I need it, but you're pre-programming into yourself."* (pg.9)

Lyn explained when developing breathing techniques, she started noticing changes in her body.

> *"… just breathing through my mouth and having that flow up and up and down. Not meditation, but just sitting and letting all my tics go and breathing through it and she {the psychologist} would observe to see where what was happening…"* (pg.11)

> *"… it was really good. I felt as if. It sounds really silly, but I was clearer. I always felt kinda very blocked up inside. That's it. It's all clearer doing that."* (pg.11)

B2. Changing the relationship with their tics

Cassie shared how she went through a process of changing the perception of her tics and how she now interacts with them.

> *"…instead of having the fear, it's more of a curiosity now. Like, I can't do that because you get stares and looks and things and that's not gonna happen, but kind of me being more curious myself instead of treating myself how other people would look at me […] What is my body trying to tell you? What's the need and if it is a really funny little bit of pressure on your shoulders, right, and that's it, odd, but it works and it's great…"* (pg. 11)

These questions exploring her tics seem to mirror the discussions that have taken place in therapy, which have altered her internal dialogue with her tics. Cassie elaborates on how her relationship with her tics is now a friendship.

> *"… becoming friends with the tics, as soon as I had heard that - I was like, you know what, you're right. There isn't actually any reason for me to be so kind of scared or fighting off something like this because it's not that big of a thing, we'll break it down. I think when your kind of having good days, it isn't too big of a thing… I think, I'm not scared of this."* (pg.3)

> *"…I know that I will at some point, I'll try not revert back to that kind of being scared and kind of tiptoeing around […], but just getting stuck in and thinking what is this tic looking for and maybe using all*

> *the different things that I've learned. And trying to keep that positive relationship."* (pg. 21)

Similarly, Abbey recalled that the psychologist offered a space to reflect on her relationship with the diagnosis and symptoms whilst providing guidance on how to adapt to it.

> *"I kind of changed my entire outlook on it, I think my psychologist was a big centre of it, and they mentioned that a lot, just accepting it and treating it as something to reduce and learn how to live the best with. I think that has been really useful, because that's not typically what you know they offer, it's always to solve something or get rid of something or that kind of thing. So, just treating it as like a process of understanding it, managing it, and then that makes it less of a negative thing and more of just a neutral. I would say that neutralising it is a big deal because once it becomes neutral, then you can just manage it."* Pg.17

Abbey's use of the phrase "get rid of something" reflects a traditional healthcare perspective, whereas there is now a shift towards living well with a health condition.

B3. Unhelpful elements and side effects of CBIT

All participants mentioned areas that could be improved in relation to their treatment journey or side effects directly related to their treatment.

Abbey shared that she didn't always fully understand the direction of the treatment and at times sessions lacked guidance.

> *"I think sometimes not feeling very guided through {treatment}, so having to show up every time to do something that's quite, I would*

> *say distressing. But feeling like you have too, come up with it yourself every time. So, I think that feels quite stressful sometimes or I feel like I said, sharing something that is quite difficult to share and then kind of not doing anything with it and not knowing quite why you had that conversation feels quite odd and so I would say maybe just the process is not being led through something and having to lead it yourself."* (pg. 14)

Joe highlighted that CBIT is not going to align with everyone's needs and presentation.

> *"I think the sessions worked very well, they just didn't work for me. The reason being my biggest trouble with Tourette's isn't being socially unacceptable because, like I say, I always hide it, so that's not a problem to me at all and that's what CBIT is at the end of the day, trying to get around to improve people's quality of life."* (pg.8)

Jess reported how exhausting the treatment process was, and the level of motivation required to persist.

> *"Although this was good, I also think it is for anyone who wants to do it, think it {CBIT} is exhausting though, and it depends on your abilities and different disciplines as well. It is a lot of work like, as I said, I really want to do it, but I also have noticed that it might have had. It might, could have, a negative impact as well. Because it is exhausting to do, and exhaustion, of course makes my tics worse and so it's difficult to find a balance to make sure I don't burn out…"* (pg. 21)

Abbey also highlighted side effects of attending treatment.

> *"I would actually feel quite sick for the rest of the day {post CBIT treatment}. I'm quite dizzy and discombobulated, and it takes me a day to recover just from speaking about something."* (pg.9)

C. Navigating the Complexities of Quality of Life

All participants discussed, to varying extents, the impact that TS/TDs had on their lives, including aspects such as daily activities, social interactions and relationships, occupation, and physical health.

C1. The importance of considering the impact on QoL

Jess described how much her tics were a barrier to treatment due to it effecting her ability to travel or potentially attend appointments.

> *"…with my tics it's really hard to travel and I don't have a blue badge at the moment. With my mobility being limited because of my tics it was a hassle {to travel to the appointment} and it was making me worse to travel two hours…"* (pg.9)

Jess also shared how her daily functioning has been affected, limiting her abilities at home to the extent that she now requires additional support.

> *"My tics are so bad that, you know I need OT {Occupational therapist} to come in today and put like stuff into my shower and my toilet and stuff, sometimes I have difficulty getting up because of my tics, if I don't have use of my arms…"* (pg.23)

Multiple participants expressed that their tics made it difficult for them to socialise and communicate with others. Joe described the following.

> *"I do suppress massively and it's led me into trouble with relationships and friendships […], people don't understand what I'm going through half the time."* (pg.24)

Likewise, Lyn explained how her confidence in her communication had impacted her working relationships.

> *"It's quite isolating, people would come into work, new people and I would automatically see people making friends and having a joke […] and being very relaxed and I always think. How can they do that? How can they and just be so sure about talking to people or having that relaxed conversation? […] That's what I used to be like maybe. In my early 30s, but maybe for the last, I don't know. Ten years. It's not been like."* (pg.17)

Lyn also expressed how it has impacted her work.

> *"It has stopped me from going for interviews, for work, progressing at work."* (pg. 12)

Abbey raised how the physical pain caused by tics can be challenging.

> *"I think it's hard to convey how it kind of affects you, like physically it can affect you quite a bit. There's quite a lot of pain in my shoulder, and I was starting to lose the ability to do things or like drop things all the time and those things got worse and worse…"* (pg.4)

D. Building Trust: The lived Experience of the Therapeutic Alliance

Participants praised the quality of their therapists, noting the knowledge and skills they used to build a helpful therapeutic relationship.

D1. Feeling heard by your therapist

Joe stated that the CBIT practices didn't necessarily resonate with him at this time in his journey and didn't have a significant positive impact on his TS/TDs symptomology. However, he found value in the therapeutic alliance.

> *"I was very grateful to have that support, because I'm a long way from home and I don't really have anyone to speak to about my Tourette's besides my mum. It was actually probably something I needed at the time to be able just to speak about the condition […] maybe that's not the direct benefit it was supposed to have, but it was still a benefit."* (pg.10)

When asked what element of the intervention was important to them, Joe responded.

> *"I think the doctor I had was brilliant. And I genuinely felt like she cared, that is something that is rare..."* (pg. 21)

Lyn also expressed a similar sentiment around the importance of being heard during therapy.

> *"… the therapist was very welcoming, and I felt as if she really listened. I felt heard..."* (pg.10)

Abbey also expressed similar appreciation

> *"I think it felt good to finally have someone take it seriously…"* (pg.5)

Jess shared how she felt the psychologist was able to accommodate her which aided her engagement in the treatment.

> *"…my psychologist was very, very good at, at accommodating me because as I said with my ADHD, I think it did have an impact on some of the things that I was asked to do were difficult, and also my understanding of the questions, and the questions that she would ask me, I had to ask for clarification a lot because I didn't fully understand. So, she was able to do it, in a clear and better manner […] she was good at compromising and accommodating based on my needs to make it easier"* (pg.12)

4. Discussion

This study aimed to explore adults' experiences with CBIT. Specifically, it sought to understand their treatment journey and how they interpret their experiences. Four key themes were derived from the participant interviews exploring the challenges of coping with a TS/TD diagnosis, the strengths and limitations of psychological interventions, the broader impacts of TS/TD on their lives, and the crucial role of therapeutic skills when working with individuals. The identified themes address our research questions by exploring how adults with TS/TD interpret their experiences with the CBIT pathway, how their expectations shape these experiences, how they perceive their sense of self, and which key aspects of CBIT drive meaningful change.

4.1 *Feeling Seen: The Importance of Validation for Individuals with TS/TD*

One of the key areas we aimed to explore was how participants made sense of their experiences, with a recurring theme being the uncertainty, ambiguity, and lack of clarity surrounding their diagnosis. This uncertainty was not only emotionally challenging but also had a significant impact on their understanding of treatment and their overall experience. It also shaped their expectations of treatment, influenced their sense of self, and affected how they perceived others viewed them. Without a clear and timely diagnosis, participants often felt invalidated, which delayed access to appropriate interventions and supports. One participant described this process as a journey to "legitimise" their condition, highlighting the need to validate and understand their struggles both personally and socially. This journey encapsulated their past experiences, the challenges of seeking recognition, and their path through treatment. The sentiment of seeking legitimacy and clarity was echoed by all participants, underscoring the critical role of a diagnosis in providing direction, validating their experiences, and fostering a more effective and personalised treatment pathway. A previous meta-synthesis has identified themes regarding diagnosis similar to those in our research, including negative experiences related to diagnosis and treatment, difficulties in diagnosing TS, issues with communicating a TS diagnosis, and concerns about the impact on others and peer acceptance (Smith et al., 2015).

Additionally, qualitative research has also highlighted comparable themes, with participants' narratives clearly indicating the presence of TS/TD related stigma within healthcare systems leading to suboptimal care. Other researchers found that participants described how general practitioners often failed to recognise the key signs of TS or held outdated and inaccurate beliefs about the condition, resulting in complicated referrals and delayed diagnoses (Malli & Forrester-Jones, 2022). Consistent with our findings, these studies also noted discrepancies in clinical responses to TS/TD due to the absence of specific guidelines for adults in the UK (e.g. NICE guidelines), constraining practitioners to rely on their own judgments. European guidance has highlighted that there are difficulties in of assessing TS/TDs due to the wide range of tics, co-existing heterogeneous symptoms, and additional other complexities arising requiring an extensive neurological evaluation (Szejko et al., 2022). In our study, this lack of knowledge appears to have potentially delayed treatment and created additional challenges for patients.

Research on stigma in TS/TD populations has found that negative experiences often lead individuals to adapt by attempting to control, suppress or hide their tics. While this strategy can help them avoid stigmatisation, and promote social acceptance and integration, the literature suggests that it may also perpetuate societal stigma and misconceptions about the nature of TS, including confusion around control and illness (Smith et al., 2015). Many of our participants highlighted their discomfort with suppression but felt it was the only option prior to CBIT.

4.2 Personal strategies to Manage Tics

Strategies for managing tics, such as relaxation and breathing exercises, developing alternative behaviours, and understanding the tics and their triggers—like anxiety and distress—were crucial strategies to managing tics and appear to algin with participants expectations. Consistent with other researchers' findings (Smith et al., 2016), our participants noted the importance of the therapist's role in guiding the therapy, maintaining its structure, and helping reframe perceptions of self. The physical aspects of the treatment were also valued across participants, who highlighted the importance of memorising and practising specific movements and breathing techniques. This included incorporating elements of understanding how anxiety and stress manifest in the body. The participants' experiences reflect the primarily behavioural-based intervention of CBIT and three core components of CBIT: habit reversal therapy, functional assessment/intervention and relaxation training (Peterson et al., 2022). Our participants emphasised relaxation training as a helpful skill. In relaxation training, patients acquire specific skills, such as diaphragmatic breathing and progressive muscle relaxation, to manage stress—a common trigger for increased tic expression (Ramsey & McGuire, 2024). Research has explored the independent efficacy of relaxation training alone, but found that it was insufficient to reduce tics severity significantly; however, this was conducted on a child population and did not measure impact on QoL or wellbeing measures (Peterson et al., 2022).

An area that was evident in our themes but has received less research is the change in participants' relationship with their tics. Drawing on principles from acceptance and commitment therapy, predominantly regarding living well with chronic health conditions, participants described how their perspective on their tics shifted through treatment. This change helped them redefine their sense of self and led to a more positive outlook, which they identified as a particularly helpful aspect of their treatment. Other researchers exploring TS experiences have identified themes related to participants' views of their TS identity, noting that their participants often described themselves as ‘not living with’ the condition, but rather ‘”trying to live through it”’(Malli et al., 2019). This perspective somewhat mirrors some of the perceptions our participants had before undergoing treatment.

Pharmacotherapy for TS/TD is often avoided due to its associated side effects (Wilhelm et al., 2012), but it's essential that patients are aware of side effects from talking therapies as well. In our research, one participant mentioned feeling disoriented, describing feeling "dizzy" and "discombobulated" after sessions. Participants also discussed the significant amount of energy required for therapy, with "exhaustion" being a common experience. Additionally, one of our participants raised a key point that CBIT may not be suitable for all presentations of TS/TD. Clinicians need to conduct thorough assessments and consider different treatment modalities based on the individual needs of each patient. In cases were CBIT isn't applicable for certain presentations, alternative approaches, such as Cognitive Psychophysiological treatment (CoPs), could be considered (Leclerc et al., 2024)

4.3 Exploring the complexities of quality of life

This theme encapsulates the impacts of a TS/TD diagnosis on a range of different areas in life which can significantly impact wellbeing and function. All participants discussed elements where their QoL had been altered due to their tics, highlighting difficulties such as attending treatment, traveling, pain, mobility, building social relationships and progressing in their occupations, with some participants noting improvement in these areas post treatment.

These difficulties have not gone unreported previously. An impact study highlighted adults with TS/TD described greater psychological difficulties, greater disability, and lower QoL than their normed counterparts (Conelea et al., 2013). Studies have found that adults with TDs often report a consistent decline in overall QoL due to the persistence of tic symptoms, even when their severity diminishes (Evans et al., 2016). Additionally, the impact of co-morbid depression and anxiety on QoL appears to become more apparent with age (Evans et al., 2016). Research has shown that participants in moderate to severe groups can experience heightened anxiety in social situations, depression due to a lack of employment opportunities, and discomfort or pain from physical movements (Eapen et al., 2016). Our participants identified all these areas as challenges. They noted that living with TS/TDs can feel "isolating" as there is often a lack of understanding from others. In a clinical cohort of adult TS patients, 29% reported problems with family relationships, 27% had difficulties making friends, 20% experienced challenges in their social life, and 15% felt self-conscious (Elstner et al., 2001). Challenges in performing daily activities, including self-care and accessing treatment, similarly to what our participants reported have been documented within the TS populations previously (Parisi, 2010).

4.4 Building Trust: The Lived Experience of Therapeutic Alliance

There is limited research investigating the role of the therapeutic relationship as a mediating factor in CBIT for adults with TS/TD. However, it has been well established that a strong therapeutic alliance is generally associated with better outcomes, though the extent to which this relationship directly drives therapeutic change remains unclear (Baier et al., 2020). Researchers investigating young people's experiences with TDs found similar results to ours regarding therapeutic alliance, highlighting that participants valued a collaborative therapeutic environment where they could explore their sense of self. The interpersonal qualities and values of therapists, such as being reassuring, accepting, non-judgmental, relaxed, empathetic, and trustworthy, were particularly appreciated (Smith et al., 2016). These qualities, which also occurred in our research, led participants to feel genuinely cared for, listened to, and taken seriously, reinforcing the importance of a supportive therapeutic relationship. We also note that one study, using outcome measures, found that the therapeutic alliance did not have a significant impact on treatment outcomes for adults who underwent CBIT (Haas et al., 2022).

4.5 Clinical Implications

Our findings further highlight the well-established concerns around validation and stigma associated with a TS/TD diagnosis. The healthcare system plays a crucial role in addressing these issues. Still, the lack of standardised guidelines for the assessment and treatment of TS/TD exacerbates barriers to providing optimal care for this population (Malli & Forrester-Jones, 2022). There is a clear need for clinicians and researchers to expand the understanding of TS/TD, creating well-defined diagnostic and treatment pathways in the UK.

Clinicians should strive to be knowledgeable regarding various therapeutic modalities and flexible in tailoring treatment to the individual. Acceptance-based components were particularly important to participants, aligning with previous findings (Smith et al., 2016). Additionally, exploration of how individuals' relationships with their condition evolve and how clinicians can support this adjustment is essential. There were also side effects associated with CBIT that clinicians and patients should be aware of to make informed decisions about their care. Furthermore, a deeper understanding of the specific QoL domains affected will help guide clinical priorities and resource allocation in adult care. This knowledge could also provide patients with valuable information about the expected long-term outcomes of their condition.

5. Strengths & Limitations

Our research approach has enabled us to capture the nuances and complexities of how participants perceive and interpret their experiences in treatment. It has also facilitated a person-centred approach, emphasising the voices and perspectives of participants and prioritising their interpretations and meanings over predefined theories. The methodological approach generated rich data, with saturation evident as similar themes were identified consistently across participants (Smith et al., 2009). The homogeneity of the sample, resulted from the sampling methods used, may limit the diversity of perspectives or experiences in the study. For example, our sample was sourced from a single service where participants with moderate to severe symptoms are offered treatment, while those with milder conditions are less likely to be referred and thus were not included in our sample. However, while convenience sampling reduces the generalisability of the results, this homogeneity is appropriate for IPA (Smith et al., 2022). We note that all participants completed the intervention, which may have influenced the results. Due to all participants finishing their treatment, their shared experience of completing it might have introduced a specific narrative or bias. This could limit the diversity of perspectives and potentially lead to an overrepresentation of positive or cohesive experiences. Acknowledging this is essential for maintaining transparency about factors that may have shaped the findings and interpretations.

Including patients and public in an IPA studies can profoundly enhance the study's sensitivity, inclusivity, and authenticity. Their input not only ensures the methods are tailored to the population but also refines the findings to reflect lived realities more accurately, ultimately leading to an enhanced understanding of their experiences and needs. Unfortunately, we were unable to fully implement our planned PPI input, which we acknowledge as a limitation of the research.

Furthermore, similarly to previous research in this field, the literature highlights methodological limitations of conducting remote interviews, such as challenges in building rapport and difficulty reading participants' non-verbal cues. However, remote interviews offer advantages by being less intrusive, providing greater privacy, and enhancing the relationship, which may lead to good-quality data. They also improve accessibility, making it easier for participants to contribute to research (Malli et al., 2019).

6. Future Research

This study underscores the need for further research into adult services for TS/TDs, focusing on several critical areas, these include; the diagnostic process, referral pathways, access to treatment, understanding of side effects of psychological therapy, and the impact of TS/TD on one's sense of self and relationships with tics. Additionally, examining the role of the therapeutic relationship in CBIT is essential as further research will aid in identifying gaps and challenges in current practices, improve treatment protocols, enhance patient outcomes, and ultimately lead to more effective support for individuals navigating these conditions in adulthood.

7. Conclusion

This study set out to explore the experiences of adults undergoing CBIT treatment for TS/TD, with a focus on understanding their treatment journey and how they interpret their experiences. The derived themes provided valuable insights into how adults with TS/TD interpret their experiences with the CBIT pathway, how their expectations shape these experiences, their perceptions of self, and the key aspects of CBIT that drive meaningful change. This study highlights the importance of further research into adult services for TS/TD, focusing on diagnostic processes, referral pathways, treatment access, and the role of the therapeutic relationship in CBIT which will lead to better patient outcomes and more effective care.

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Appendices

Appendix 1: Systematic Review

Appendix 1.1- PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg.11
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg.12
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg.15
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg.15
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg.17
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg.16
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Pg.16
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg.18
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg.18
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Pg.18
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Pg.18
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg.19
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Pg.18

Section and Topic	Item #	Checklist item	Location where item is reported
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Pg.18
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pg.18
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg.18
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Pg.NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Pg.NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Pg.19
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Pg.19
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Pg.21
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Pg.21
Study characteristics	17	Cite each included study and present its characteristics.	Pg.22
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Pg.30
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Pg.23
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Pg.30
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Pg.30
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Pg.30
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Pg.29
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Pg.29
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pg.42
	23b	Discuss any limitations of the evidence included in the review.	Pg.46
	23c	Discuss any limitations of the review processes used.	Pg.46

Section and Topic	Item #	Checklist item	Location where item is reported
	23d	Discuss implications of the results for practice, policy, and future research.	Pg.47
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg.16
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg.16
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg.16
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	NA
Competing interests	26	Declare any competing interests of review authors.	NA
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	See appendix

Appendix 1.2 - Search Strategy

2. Medline (Ovid)

Date of Search: 25.03.24

1 Tourette syndrome.tw.
2 tic disorder.tw.
3 (tic* or tourette* or TS or GTS).tw.
4 gilles de la Tourette syndrome.tw.
5 tic*.tw.
6 1 or 2 or 3 or 4 or 5
7 psycholog* intervention*.tw.
8 psychotherap*.tw.
9 Psychotherapy/
10 Psychotherapy, Group/
11 cognitive therap*.tw.
12 Cognitive behavio*ral therapy/
13 Psychotherapy/
14 psycho* treatment.tw.
15 psycho* education.tw.
16 cognitive behavio*ral therap*.tw.
17 behavio*ral therap*.tw.
18 (cognitive adj2 (therap* or treatment* or control or approach* or training)).mp.
19 (behavio*ral adj2 (therap* or treatment* or control or approach* or training)).mp.
20 CBIT.tw.
21 Comprehensive behavio*ral intervention*.tw.
22 Behavio*r therap*/
23 Comprehensive behavio*ral intervention for tic*.tw.
24 Habit reversal therap*.tw.
25 HRT.tw.
26 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27 6 and 26

3. EMBASE (Ovid)

Date of Search: 25.03.24

1 Tourette syndrome.tw. or Gilles de la Tourette syndrome/
2 Tic disorder.tw.
3 Tic.tw.
4 (tic* or tourette* or TS or GTS).tw.
5 1 or 2 or 3 or 4
6 Psycholog* intervention*.tw.
7 Psychosocial intervention/
8 Psychotherap*.tw.
9 Psychotherapy/
10 Body psychotherapy/

11 Interpersonal psychotherapy/
12 Short term psychotherapy/
13 Psychodynamic psychotherapy/
14 Cognitive therap*.tw.
15 Psycho* treatment.tw.
16 Cognitive therapy/
17 Psycho* education.tw.
18 Psychoeducation/
19 Cognitive behavio*ral therap*.tw.
20 Behavio*ral therap*.tw.
21 CBT.tw.
22 (cognitive adj2 (therap* or treatment* or control or approach* or training)).mp.
23 (behavio*ral adj2 (therap* or treatment* or control or approach* or training)).mp.
24 Comprehensive behavio*ral intervention.tw.
25 Behavior therapy/
26 Comprehensive behavio*ral intervention.tw.
27 CBIT.tw.
28 Comprehensive behavio*ral intervention for tic*.tw.
29 Habit reversal therap*.tw.
30 HRT.tw.
31 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
32 5 and 31

4. PsychInfo (EbscoHost)

Date of Search: 25.03.24

S29 S7 AND S28

S28 S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27

S27 TI "HRT" OR AB "HRT"

S26 HRT

S25 TI "Habit reversal therap*" OR AB "Habit reversal therap*"

S24 Habit reversal therap*

S23 Comprehensive behavio*ral intervention for tic*

S22 TI "Comprehensive behavio*ral intervention for tic*" OR AB "Comprehensive behavio*ral intervention for tic*"

S21 TI "Comprehensive behavio*ral intervention*" OR AB "Comprehensive behavio*ral intervention*"

S20 Comprehensive behavio*ral intervention*

S19 TI "CBIT" OR AB "CBIT"

S18 CBIT

S17 TI "behavio*ral therap*" OR AB "behavio*ral therap*"

S16 "behavio*ral therapy"

S15 TI "cognitive therap*" OR AB "cognitive therap*"

S14 cognitive therap*

S13 TI "psycho* education" OR AB "psycho* education"

S12 psycho* education

S11 TI "psychotherap*" OR AB "psychotherap*"

S10 psychotherap*

S9 TI "psycholog* intervention" OR AB "psycholog* intervention"

S8 psycholog* intervention

S7 S1 OR S2 OR S3 OR S4 OR S5 OR S6

S6 TI "GTS" OR AB "GTS"

S5 TI "TS" OR AB "TS"

S4 TI "Tourette*" OR AB "Tourette*"

S3 TI "tic*" OR AB "tic*"

S2 TI "tic disorder" OR AB "tic disorder"

S1 DE "Tic Disorders" OR DE "Tics" OR DE "Tourette Syndrome"

Appendix 1.3 – Paper Screening and Selection Tool

Reviewer Name:
Date:
Author Name:
Year:
Title:
Journal:

Patient Population

Include	Exclude
Participants have a diagnosis of tic/Tourette’s syndrome. Must be 18 or older	Participants under the age of 18

Interventions

Include	Exclude
used a psychological treatment intervention (any psychological or behavioural treatment including psychoeducation, with or without the use of medication) primarily targeting TS.	Studies which are solely pharmaceutical/medication based, with no element of psychological intervention, will not be included. Studies which solely utilise hypnotherapy will be exclude also.

Comparators

Include	Exclude
Data will be collected comparing various outcome measures used to evaluate the effectiveness of treatment. Studies will be eligible regardless of whether a comparison condition is used.	

Outcomes

Include	Exclude
Quantitative or qualitative (e.g. allowing for the possibility of more open outcomes) assessments of treatment outcomes for the study sample and what domains they are appraising.	Papers that do not report any outcomes measuring psychological wellbeing or mental health factors.

Study Design

Include	Exclude
Studies will be included if they used any interventional research design, including any group-based, single-case experimental treatment design or randomised control trial design.	Case studies Case series

Overall Decision

INCLUDED **EXCLUDED**

Reason if excluded:

Appendix 1.4 –Quality Appraisal Tools

a. JBI Critical Appraisal Checklist for Quasi-Experimental Studies

Copyright removed

b. JBI Critical Appraisal Checklist for Randomised Control Trials

Copyright removed

Appendix 2: Major Research Project

Appendix 2.1 – Consolidated Criteria for Reporting Qualitative research (COREQ) Checklist

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Please indicate in which section each item has been reported in your manuscript. If you do not feel an item applies to your manuscript, please enter N/A.

For further information about the COREQ guidelines, please see Tong *et al.*, 2017: https://doi.org/10.1093/intqhc/mzm042

No.	Item	Description	Section #
Domain 1: Research team and reflexivity			
Personal characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	66
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	67
3.	Occupation	What was their occupation at the time of the study?	67
4.	Gender	Was the researcher male or female?	67
5.	Experience and training	What experience or training did the researcher have?	67
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	65
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *E.g. Personal goals, reasons for doing the research*	65
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *E.g. Bias, assumptions, reasons and interests in the research topic*	67
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	67
Participant selection			
10.	Sampling	How were participants selected? *E.g. purposive, convenience, consecutive, snowball*	65
11.	Method of approach	How were participants approached? *E.g. face-to-face, telephone, mail, email*	65
12.	Sample size	How many participants were in the study?	65
13.	Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	65
Setting			
14.	Setting of data collection	Where was the data collected? *E.g. home, clinic, workplace*	66
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	65

16.	Description of sample	What are the important characteristics of the sample? *E.g. demographic data, date*	66
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	65
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	65
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	66
20.	Field notes	Were field notes made during and/or after the interview or focus group?	66
21.	Duration	What was the duration of the interviews or focus group?	66
22.	Data saturation	Was data saturation discussed?	87
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	64
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	67
25.	Description of the coding tree	Did authors provide a description of the coding tree?	NA
26.	Derivation of themes	Were themes identified in advance or derived from the data?	67
27.	Software	What software, if applicable, was used to manage the data?	67
28.	Participant checking	Did participants provide feedback on the findings?	67
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *E.g. Participant number*	68
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	68
31.	Clarity of major themes	Were major themes clearly presented in the findings?	68
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	82

Appendix 2.2 – Research Ethics Committee Approval Letter

Research Ethics Committee Approval Letter removed due to confidentiality issues.

Appendix 2.3 – NHS Greater Glasgow & Clyde, Research & Innovation Approval Letter

NHS Greater Glasgow & Clyde, Resarch & Innovation Approval Letter removed due to confidentiality issues,

Appendix 2.4 – Research Ethics Committee Correspondence Regarding Study Amendments

Research Ethics Committee Correspondence Regarding Study Amendments removed due to confidentiality issues.

Appendix 2.5 – NHS to NHS letter of Access

NHS
Greater Glasgow
and Clyde

Coordinator/Administrator: Euan Rennie
Telephone Number:
E-Mail: euan.rennie@ggc.scot.nhs.uk

Research & Innovation
Ward 11 - Dykebar Hospital
Grahamston Road
Paisley PA2 7DE

Miss Emma Camsey
Ayrshire Central Hospital
NHS Lanarkshire

Dear Miss Camsey

NHS to NHS - Letter of Access for Research

This letter should be presented to each participating organisation before you commence your research at that site.

In accepting this letter, each participating organisation confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. This right of access commences on **29/05/2024** and ends on **26/09/2024** unless terminated earlier in accordance with the clauses below.

As an existing NHS employee you do not require an additional honorary research contract with the participating organisations. The organisations is satisfied that the research activities that you will undertake in the organisations are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in the organisations. Evidence of checks should be available on request to NHS Greater Glasgow and Clyde.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving the organisation permission to conduct the project.

You are considered to be a legal visitor to NHS Greater Glasgow and Clyde premises. You are not entitled to any form of payment or access to other benefits provided by NHS Greater Glasgow and Clyde to employees and this letter does not give rise to any other relationship between you NHS Greater Glasgow and Clyde, in particular that of an employee.

While undertaking research through NHS Greater Glasgow and Clyde, you will remain accountable to your employer but you are required to follow the reasonable instructions of your nominated manager in in each organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by

[Insert organisation] or this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **NHS Greater Glasgow and Clyde** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **NHS Greater Glasgow and Clyde** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on NHS Greater Glasgow and Clyde premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and NHS Greater Glasgow and Clyde prior to commencing your research role at each site.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 2018. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The organisation will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation accept no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in each participating organisation.

Yours sincerely

Euan Rennie
Senior Research Administrator

Cc: **HR/line manager (person who signed off the NHS to NHS proforma)**

Appendix 2.6 – Organisation Information Document

The Final approved Organisation Information Document (OID) can be accessed at the following link;

https://osf.io/3z4hm

Appendix 2.7 – Major Research Project Proposal

The Final Approved MRP Proposal can be accessed at the following link;

https://osf.io/kn6g4?view_only=d2c66ac832f5486cb25f14411dbb0266

Appendix 2.8 – Invitation Letter to Participant

The Letter to Participant can be accessed at the following link:

https://osf.io/fe947?view_only=d2c66ac832f5486cb25f14411dbb0266

Appendix 2.9 – Participant Information Sheet

The Participant Information Sheet for participants can be accessed at the following link:

https://osf.io/f2x6q?view_only=d2c66ac832f5486cb25f14411dbb0266

Appendix 2.10 – Privacy Notice

The Privacy Notice can be accessed at the following link:

https://osf.io/htnsw?view_only=d2c66ac832f5486cb25f14411dbb0266

Appendix 2.11 – Participant Consent Form

The Participant Consent Form can be accessed at the following link:

https://osf.io/y6ezj?view_only=d2c66ac832f5486cb25f14411dbb0266

Appendix 2.12 – Interview Confirmation

The Interview Confirmation can be accessed at the following link:

https://osf.io/3m95j?view_only=d2c66ac832f5486cb25f14411dbb0266

Appendix 2.13 – Semi-structured Interview Schedule

The Semi-structured Interview Schedule can be accessed at the following link:

https://osf.io/hejzn?view_only=d2c66ac832f5486cb25f14411dbb0266

Appendix 2.14 – Participant Information Proforma

The Participant Information Proforma can be accessed at the following link:

https://osf.io/7ap2e?view_only=d2c66ac832f5486cb25f14411dbb0266

Appendix 2.15 – Post Interview Information

The Post Interview Information can be accessed at the following link:

https://osf.io/8ktvz?view_only=d2c66ac832f5486cb25f14411dbb0266

Appendix 2.16 – Examples of IPA Analytical Process

Experiential Statements	**Transcript**	**Exploratory Notes**
Individual needs Treatment – helpful and unhelpful Self-awareness	00:24:03 Participant Yes, some of the regularity, yes. So, I had three that I worked on and then each we would talk about it, you know if we had progress, two of which there was two of which there. It run down in, the small one. That was intrusiveness and then the moderate kind of intrusiveness. They think, they used to be every day. I had the urge less. And also one of them was a tongue clicking one, which actually is a combined tic with whistling. And because that one was being worked upon my whistling. Also going down, so we had so that was great and so. And then there was one that wasn't really working. So then we were just trying to see if like is it because of how intrusive it is? Is it becoming too taxing for me to do? And then we were able to discuss that. Maybe it's because the specific movement wasn't working.	‘three to work on’ goal orientated, clear expectation for the weeks homework ‘Intrusiveness’ language consistently used throughout (impactful in day) Description of treatment progressions Ups and down/worked and didn’t work -needed adaption ‘we’ collaborative stance Number of questions and curiosity to tics
Guidance from therapist ‘we’	00:25:09 Like the, you know the alternative behaviour wasn't satisfying the urge, and so then we were able to come up with a different way of doing it and then, yes, so we we did that and then we didn't just do triggers. It was another part was working on specific triggers as well determining what they are and coming up	Behaviourist approach to treatment CBIT basis

Treatment process Skills development Adaptation	with solutions to avoid or lessen the triggers as much as possible to lessen the amount of tics happening. I was pretty self-aware and kind of already grounded in this work before we did it, so we didn't do as much work on this, but it was one of my biggest ones was intense emotions like stress, except and overwhelming tiredness, so things like alcohol and cold also affect me. Those are easily avoidable, but this was more we were working on like stress management, emotion works, breathing techniques, relaxation techniques and I had trouble with kind of knowing my emotions, it's difficult to know how to correlate my emotions to tics and if it was impacting them. So she was able to then tell me to like, you know, give me a strict structure when to write it down and then write down my emotion so I could have better practice to recognise it. And so we're still kind of working on that. So whether or not that's having an impact is still to be seen.	Solution focused, problem solving. Driven to reduce tics frequency by addressing triggers Understanding of self “pretty self-aware” Bringing own strength to the process Whilst acknowledging areas of work Emotions regulations works identifying triggers Related to the tools practiced in therapy Supported with guidance for therapist and adapted to align with individual needs

Appendix 2.17 - NHS Greater Glasgow & Clyde - Institute of Neuroscience Neuropsychology Service Referral Criteria for CBIT Pathway

Guidance on referral criteria and contra indicators are based on local guidelines and evidence base.

- Must be over age of 16 and not in full time education
- Referral into Neuropsychology must be made by Consultant Neurologist
- Must live in the Greater Glasgow & Clyde area or be under the care of an NHS Greater Glasgow and Clyde Neurologist
- Tics must be causing impact on psychosocial wellbeing or resulting in physical injury (distress thermometer score of 5 or more)
- Must not have complex comorbid mental health problems e.g OCD, ADHD, severe and enduring MH problems e.g. schizophrenia
- Happy to try a behavioural approach with an understanding of what this involves highlighting that this does not include medication
- There are some contra-indicators to therapeutic gains that may need to be discussed at vetting to determine appropriateness:
- Poor tic awareness
- Lack of premonitory urge
- More severe/multiple tics
- Substantial co-morbidities
- History of poor engagement with neurology or mental health services in the past
- Poor treatment motivation
- Cognitive impairment
- Long time between diagnosis and treatment

Appendix 2.18 – Participant feedback on initial results

To protect anonymity, communication of feedback has either been summarised or direct quotes provided if appropriate.

Participant	Feedback	Action
i.	“I'm very pleased and on board with the report overall.” Removal of one quote was requested, with clear and understandable rationale.	Discussed at research team meeting – All present agreed with participant. Quote was removed.
ii.	“I have read through these results, and I am happy with the findings. It’s so interesting to hear others experiences!”	No actions required