

# Initial treatment retention for habit reversal training in adults with Tourette syndrome

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## SUMMARY

### Objective

Tourette syndrome (TS) is a chronic neuropsychiatric disorder characterised by multiple motor and phonic tics. Habit Reversal Training (HRT) is increasingly recognised as an effective behavioural intervention in the treatment of tics, however little is known about the characteristics of adult patients who attend HRT sessions.

### Methods

In this study, the demographic and clinical characteristics of 57 adult patients with TS consecutively referred to HRT intervention were retrospectively reviewed. Correlation and regression analyses were used to examine associations between patients' characteristics and their HRT attendance.

### Results

Twelve out of 57 patients were excluded from the analysis because of inappropriate referral and/or insufficient data. One in three of the remaining patients (15/45) failed to attend HRT following referral by the treating consultant. There were no significant differences in the demographic or clinical characteristics between patients who attended HRT and patients who did not. A trend towards statistical significance ( $p = 0.08$ ) was found for decreased tic severity as predictor of poor attendance.

### Conclusions

Our findings suggest that initial treatment retention for HRT in TS can be suboptimal and reasons for poor attendance might be external to demographic or clinical factors. The statistical trend for decreased tic severity as predictor of poor attendance is of potential clinical relevance and needs replication. Further investigations on larger clinical samples will help to optimise care pathways and resource allocation strategies for patients with tics referred to behavioural interventions.

**Key words:** Tourette syndrome, tics, habit reversal training, behaviour, initial treatment retention attendance

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### Conflict of interest

The Authors declare no conflict of interest

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## Introduction

Tourette syndrome (TS) is a chronic neuropsychiatric disorder first described by George Gilles de la Tourette in 1885 and characterised by the concomitant presence of multiple motor tics and one or more phonic (vocal) tics<sup>1</sup>. TS has a worldwide prevalence of 1% in the school age population and typically begins in childhood with a mean onset of 7 years<sup>2</sup>. Tics are defined as a sudden, rapid, recurrent, non-rhythmic, stereotyped movements or vocalisations; their number, frequency, severity and complexity characteristically change over time. Motor and vocal tics are further classified as simple (i.e. involving a single muscle or group of muscles) and complex (i.e. involving co-ordinated movements mimicking normal motor acts). Tics are usually preceded by premonitory urges or

sensory tics, which are described as unpleasant sensations of mounting inner tension relieved on completion of the tic<sup>3-6</sup>. Behavioural co-morbidities, especially obsessive-compulsive disorder (OCD) and attention-deficit/hyperactivity disorder (ADHD), are commonly reported among patients with TS<sup>7-8</sup>.

Current treatment of TS aims to improve social functioning, self-esteem and health-related quality of life<sup>9</sup>. Pharmacological treatment of tics may be considered if daily functioning of the patient is affected. First-line medications are dopamine antagonists or alpha-2 agonists and current research indicates that tics are most effectively suppressed by antipsychotic medications, such as neuroleptics (e.g. haloperidol, pimozide) and atypicals (e.g. risperidone, aripiprazole)<sup>10</sup>. However a considerable proportion of patients refuse or discontinue medication because of unwanted side effects, whilst others fail to respond to conventional pharmacotherapy<sup>11</sup>. These drawbacks have led to renewed interest in behavioural interventions either alone or as an adjunct to pharmacological treatments<sup>12,13</sup>. Behavioural interventions attempt to identify and modify events associated with tic severity, exacerbation and maintenance. Controlled trials support the application of behavioural interventions to effectively reduce tic expression and improve health-related quality of life<sup>13,14</sup>.

Habit Reversal Training (HRT) is a behavioural intervention first developed for repetitive behaviours by Azrin and Nunn in 1973<sup>15</sup>. The primary components of HRT are awareness training and competing response. Awareness training encourages patients to increase their knowledge of their tic behaviour and premonitory urges, in order to facilitate better self-control<sup>16</sup>. Patients are taught a competing response often using antagonist muscles in order to control the target tic by performing an opposing movement<sup>16</sup>. The success of HRT has been exemplified in a number of individual case reports and original studies<sup>17,18</sup>, including a recent large scale randomised controlled trial involving both children<sup>4</sup> and adults<sup>19</sup>. Although there is empirical evidence to demonstrate the use of HRT in TS to effectively decrease tic severity, little is known regarding the characteristics of patients who attend HRT sessions. As highlighted by previous studies, poor attendance and compliance to HRT results in a lack of improvement in tic symptoms<sup>20,21</sup>. In the largest study to date, out of 61 children assigned to receive HRT almost 10% discontinued the intervention and did not complete the study<sup>4</sup>. An earlier randomised controlled trial reported an even higher drop-out rate of 18% in 4 out of 22 adults with TS receiving HRT<sup>14</sup>.

The aim of this retrospective study was to determine the demographic and clinical characteristics of adult patients with TS who attend HRT intervention in order

to develop recommendations for treating clinicians on appropriate referrals. This is important as it could help prevent inappropriate use of resources and therapist appointment times, in addition to increased waiting time for more suitable patients.

## Methods

### Participants

The present study is a retrospective review of data collected from a cohort of adult patients attending the specialist TS clinic at the Department of Neuropsychiatry, BSMHFT and University of Birmingham, United Kingdom. We systematically collected clinical and demographic data from all consecutive patients with a DSM-validated diagnosis of TS who were referred to HRT intervention over a period of 18 months. Patients were excluded from this study if they were below 16 years of age, had limited understanding of English, reading level less than secondary school level, learning disabilities, or significant missing data in their medical records.

### Clinical measures

All patients underwent complete neuropsychiatric evaluation, which included the use of standardised psychometric instruments. The National Hospital Interview Schedule for Tourette syndrome (NHIS-TS), a detailed semi-structured interview schedule for patients with TS, was used to collect demographic and clinical details including family history of TS and co-morbid conditions<sup>22</sup>. Baseline tic severity of each patient was measured using the Yale Global Tic Severity Scale (YGTSS), a clinician-rated instrument designed for use in TS and other tic disorders. In the YGTSS, both motor and vocal tics are rated a score of 0-5 according to number, frequency, intensity, complexity, and interference. These scores are summed to give a score for motor and vocal tics out of 25 and a combined total tic score out of 50. A further 0-50 overall impairment score is added to yield the total YGTSS score, where higher scores indicate greater tic severity<sup>23</sup>. The Diagnostic Confidence Index (DCI) was used to strengthen the clinician's confidence in making a diagnosis of TS by assessing the presence of both simple and complex TS, including coprolalia, copropraxia, echopraxia, echolalia and palilalia. DCI scores range between 0-100, with higher scores indicating higher diagnostic confidence<sup>24</sup>.

Data regarding HRT attendance were collected through the appropriate HRT referral and appointment letters from relevant care-records. Attendance was defined as whether or not the patient made successful contact with the HRT therapist following their initial assessment by the referring clinician. Patients provided informed written consent prior to their participation to this study, for

which ethical approval was obtained from the South Birmingham Research Ethics Committee, Research and Development Department at BSMHFT and the University of Birmingham BMedSc Population Sciences and Humanities Internal Ethics Review Committee.

### Statistical analysis

Statistical analyses were performed using SPSS version 18.0 statistics software. Univariate analyses were carried out to examine whether or not each clinical/demographic characteristic was associated with attendance versus non-attendance. The chi-square test was applied to categorical data and the Mann-Whitney U test was performed on numerical data. The combined effect of potential predictors of the demographic and clinical characteristics on attendance at HRT sessions was examined using stepwise logistic regression.

## Results

Data were collected on 57 patients. Of these, 12 were excluded due to inappropriate referral or incomplete documentation. Statistical analyses were carried out on the remaining 45 patients; of these, 15 (33%) failed to attend at all. The clinical and demographic characteristics of our sample are shown in Table I.

The association between patients' demographic/clinical characteristics and attendance at the treatment sessions was analysed using Student t-test for normally distributed data (YGTSS and DCI; Shapiro-Wilk test of normality:  $p > 0.05$ ) and Mann-Whitney U test for age and duration, which did not show normal distribution (Shapiro-Wilk test of normality:  $p < 0.05$ ). Categorical data (gender, family history, medication, co-morbid ADHD, co-morbid OCD, presence of tic-related symptoms) were analysed using chi-square test. The results of these analyses are shown in Tab. II. There were no differences in either demographic or clinical characteristics between patients who attended the treatment sessions and patients who did not.

All variables were entered into a binary logistic regression model to determine the predictive value of patient demographic/clinical characteristics with respect to attendance at HRT sessions. The results of the logistic regression analyses are presented in Table III. Again, no demographic or clinical characteristic was a significant predictor of attendance at HRT sessions ( $p > 0.05$  for all variables), however we found a trend towards statistical significance ( $p = 0.08$ ) for decreased tic severity as predictor of poor attendance.

## Discussion

The present study aimed to determine the demographic and clinical characteristics of adult patients with TS

**TABLE I.** Demographic and clinical characteristics of the patients with Tourette syndrome referred to Habit Reversal Training ( $n = 45$ ).

Age, years (mean (SD))	29 (11)
<b>Gender (n (%))</b>	
Male	31 (69)
Female	14 (31)
Duration of tics, years (mean (SD))	21 (11)
<b>On medication (n (%))</b>	
Yes	31 (69)
No	14 (31)
<b>Presence of tic-related symptoms (n (%))</b>	
Yes	21 (47)
No	24 (53)
<b>Family history of tics (n (%))</b>	
Yes	21 (47)
No	23 (53)
<b>Presence of co-morbid ADHD (n (%))</b>	
Yes	14 (31)
No	31 (69)
<b>Presence of co-morbid OCD (n (%))</b>	
Yes	16 (36)
No	29 (67)
YGTSS score (mean (SD))	49 (14)
DCI score (mean (SD))	66 (11)

Abbreviations. ADHD: Attention-deficit/hyperactivity disorder; OCD: Obsessive-compulsive disorder; YGTSS: Yale Global Tic Severity Scale; DCI: Diagnostic Confidence Index

who attend HRT intervention. In our clinical sample one in three patients (15/45) failed to attend HRT following referral by the treating consultant, suggesting that initial treatment retention to HRT in TS can be suboptimal. This finding is consistent with the results of a previous randomised controlled trial, which reported a treatment drop-out rate of 18% in 22 adults with TS receiving HRT<sup>14</sup>. The present study also reflects the general knowledge that non-attendance is a common problem in mental health services and high rates of non-attendance are found for different psychological treatments<sup>25-28</sup>.

With regards to possible variables that could predict poor attendance, the results of our study did not show any of the demographic or clinical characteristics examined to be a statistically significant predictor for attendance at HRT sessions. The trend towards statistical significance for decreased tic severity (as measured by YGTSS scores) as predictor of poor attendance is of potential clinical relevance, given the suboptimal treat-

**TABLE II.** Comparison of demographic and clinical characteristics between patients who attended and patients who did not attend Habit Reversal Training.

	Attend (N = 30)	Not attend (N = 15)	Test	P-value
Age, years (mean (SD))	26 (9)	26 (8)	Z = 0.48	0.63
Gender (n (%))			$\chi^2 = 0.52$	0.99
Male	21 (68)	10 (32)		
Female	9 (64)	5 (36)		
Duration of tics, years (mean (SD))	20 (10)	20 (13)	Z = 0.47	0.64
Family history of tics (n (%))			$\chi^2 = 0.40$	0.75
Yes	15 (71)	6 (29)		
No	15 (63)	9 (38)		
Presence of tic-related symptoms (n (%))			$\chi^2 = 0.40$	0.75
Yes	15 (71)	6 (29)		
No	15 (63)	9 (38)		
Medication (n (%))			$\chi^2 = 0.52$	0.99
Yes	21 (68)	10 (32)		
No	9 (64)	5 (36)		
Presence of co-morbid ADHD (n (%))			$\chi^2 = 1.30$	0.32
Yes	11 (79)	3 (21)		
No	19 (61)	12 (39)		
Presence of co-morbid OCD (n (%))			$\chi^2 = 0.19$	0.75
Yes	10 (63)	6 (38)		
No	20 (69)	9 (31)		
YGTSS score (mean (SD))	50.37 (15.01)	44.80 (13.42)	t = 1.21	0.23
DCI score (mean (SD))	66.10 (12.70)	65.80 (8.10)	t = 0.08	0.93

Abbreviations. ADHD: Attention-deficit/hyperactivity disorder; OCD: Obsessive-compulsive disorder; YGTSS: Yale Global Tic Severity Scale; DCI, Diagnostic Confidence Index

**TABLE III.** Results of the logistic regression analysis of the demographic and clinical characteristics as potential predictors of attendance to Habit Reversal Training.

Variable	Attend Odds ratio (95% CI)	P-value
Age	1.03 (0.87 to 1.22)	0.721
Male sex	1.61 (0.30 to 8.68)	0.577
Duration of tics	0.94 (0.80 to 1.11)	0.474
Medication	0.65 (0.10 to 4.32)	0.655
Family history of tics	0.84 (0.16 to 4.61)	0.845
Presence of tic-related symptoms	1.12 (0.23 to 5.41)	0.887
Co-morbid ADHD	3.00 (0.50 to 17.97)	0.230
Co-morbid OCD	0.57 (0.13 to 2.62)	0.472
YGTSS score	1.07 (0.99 to 1.16)	0.080
DCI score	0.96 (0.89 to 1.04)	0.309
Likelihood ratio test $\chi^2$ (df)	13.418 (7), p > 0.05	

Abbreviations. ADHD: Attention-deficit/hyperactivity disorder; OCD: Obsessive-compulsive disorder; YGTSS: Yale Global Tic Severity Scale; DCI: Diagnostic Confidence Index

ment retention. The results of the binary logistic regression analyses suggesting that patients with increased tic severity are more likely to attend HRT sessions following initial referral by the treating consultant can have different explanations. One possible explanation is that patients with a lower tic severity may not feel that their TS affects their quality of life severely enough to justify the amount of time and effort required to attend HRT sessions and engage in the behavioural treatment. At our specialist TS clinic, the basic principles of HRT were routinely introduced and explained by the treating consultant to all consecutive patients with TS without learning and/or linguistic difficulties. Referral to HRT session was solely based on the interest shown by the patient towards commencing the treatment. This may have resulted in a skewed sample of patients, not representative of the whole population of TS patients. The average age of our sample was 29 years and 31 (69%) patients were male. Previous literature has shown that non-attendance at outpatient clinics is significantly associated with being younger and male<sup>29</sup>, therefore a difference between those who attend or not may have been missed due to the low number of female patients. The present study should be considered with respect to limitations. All patients were recruited at a specialist clinic for TS, where more complex clinical presentations are usually referred. This could have introduced referral bias. Given the relatively small sample size, an existing association between the demographic/clinical characteristics and attendance could have been missed. Our study would have been strengthened by collecting data over a longer period of time in order to allow a greater number of patients to be included. Finally, there is a possibility that some potentially relevant variables (e.g. travelling distance to attend the HRT sessions, track record of failure to attend routine appointments) were missed/not included in the present analysis.

Findings from the present study suggest avenues for future research. Firstly, the identified trend towards statistical significance for milder tic severity as predictor of poor attendance prompts further investigation using larger clinical samples. Secondly, data were only collected regarding demographic and clinical characteristics of patients referred to HRT sessions. Previous litera-

ture examining attendance at behavioural interventions has highlighted other factors that may be important predictors of patient attendance at appointments. The findings of the study by Startup et al.<sup>27</sup> suggest that the relationship between patient and therapist is related to engagement with and retention in psychological treatment, reporting drop-outs as less engaged with their therapists: perhaps this could also apply to the relationship with the referring clinician. Furthermore, non-attendance at psychiatric clinics is more likely in patients who have missed previous appointments and those with a long waiting time between referral and appointment<sup>30</sup>. Other patient characteristics that are thought to be associated with poor initial treatment retention include socio-economic class, marital status, family support and employment<sup>31-33</sup>. These factors may be of importance in predicting which patients with TS are more likely to attend HRT sessions and engage in behavioural treatment interventions.

## Conclusions

Non-attendance is an important issue in psychiatry, particularly in the delivery of behavioural interventions, due to the potential waste of health-care resources and therapy appointment times, which might lead to increased waiting times for more suitable patients. Our findings suggest that initial treatment retention to HRT in TS can be suboptimal, with one in three patients (15/45) failing to attend initial appointments following referral by the treating consultant. The trend towards statistical significance for decreased tic severity as predictor of poor attendance is of potential clinical relevance and needs further investigation on larger samples. Future research should also focus on other factors, which may be of importance in predicting the characteristics of patients more likely to attend HRT sessions. With this knowledge, recommendations can be developed for treating clinicians on the delivery of appropriate care pathways in the treatment of TS.

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