



Experiences of self-identification, diagnosis and support for adults seeking a late diagnosis of tic disorders in the United Kingdom

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Introduction

Tic disorders are often considered a disorder of childhood, that diminishes over time during adolescence and into adulthood. (Malli, Forrester-Jones, & Triantafyllopoulou, 2019).

However a growing body of research and lived experience accounts suggests that tics can persist longer (usually in a milder form) and that a recurrence of symptomology after asymptomatic periods is common. (Black, Kim, Yang & Greene, 2021; Chouinard & Ford, 2000; Schaefer, Chow, Louis & Robakis, 2017)

UK adults with tic symptomology were asked:

About their experiences and opinions regarding their tic symptom presentation

The process and reasoning for attaining a diagnosis and/or self-identifying with a tic disorder

What post-identification support and validation they received

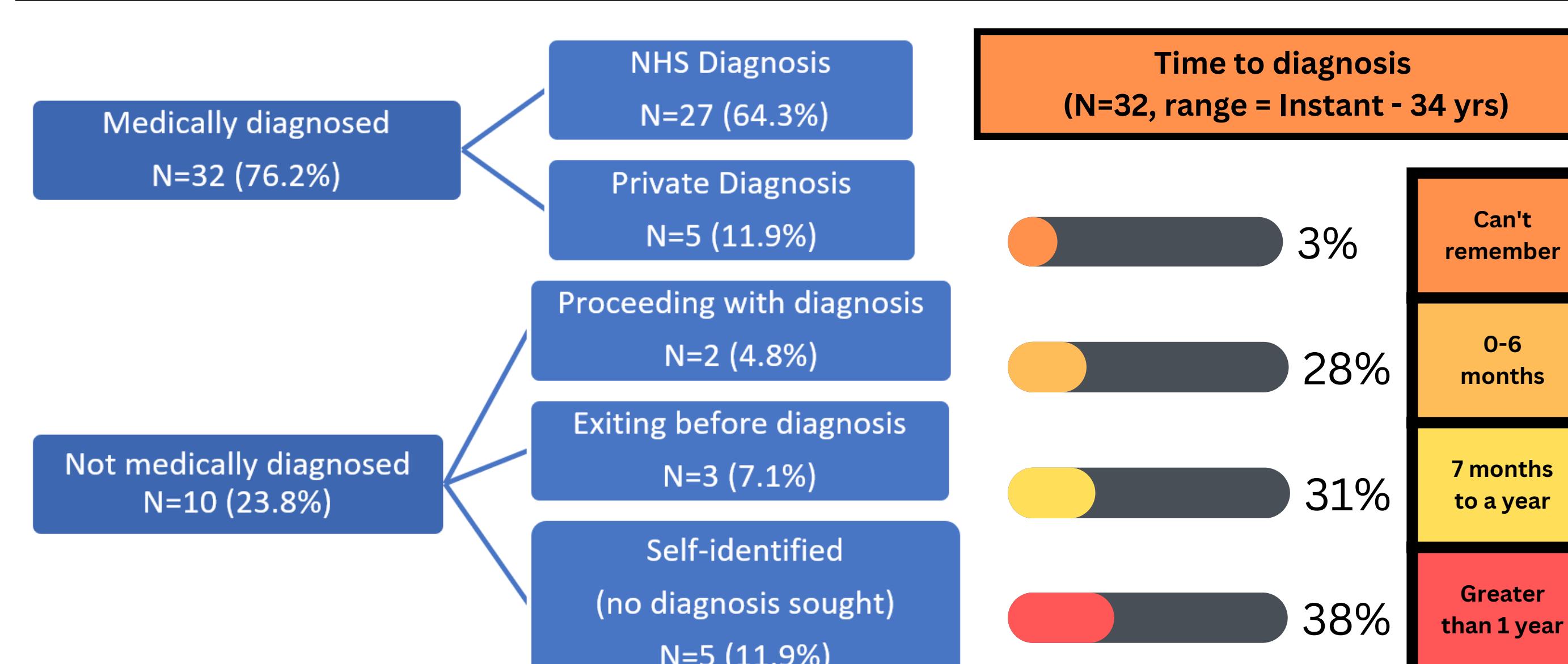
Sociodemographic characteristics

The mean age of the final sample		N = 42						
Male	13	Female	22	Non-Binary	5	Gender-Fluid	1	Trans
was 36.12 years (standard deviation (SD) = 13.39, range 18-68)								

Location		Education	
England	Scotland	76%	completed education beyond secondary school
Wales		Ethnicity	
White (N) = 41	Mixed (N) = 1		

General tic and diagnostic status

	Total	Of those who specified an age of onset:
Reported onset	N=42	N=37
Adult-onset	13 (31%)	mean = 35.5, standard deviation (SD) = 12.2, range = 18-62
Childhood-onset	29 (69%)	mean = 9.6, standard deviation (SD) = 4.1, range = 4-17



Participants completed a **three-part online survey** of multiple choice and open-ended questions

1 Captured sociodemographic characteristics

Explored the participants tics (history, severity, acceptance and action, interference with daily life and cooccurrence with other conditions).

This incorporated a variety of measurement scales:

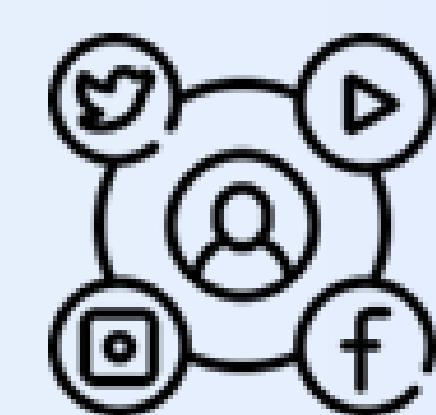
- Adult Tic Questionnaire (ATQ)
- Acceptance and Action Tic Specific Questionnaire (AAQ-T), and
- Daily Interference Scale

Focused on questions regarding the participants diagnostic or self-identifying journey and post-identification support and impact.

Adapted from questionnaires originally designed to assess the process of seeking a diagnosis of Autism in the UK (Crane, Chester, Goddard, Henry & Hill, 2016).

Quantitative data analysis of multiple-choice questions was conducted in SPSS. Relationships between ATQ, AAQ-T, age, onset and Daily Interference were analysed using Pearson Correlation Coefficient and T-test with statistical significance set at $p = < 0.05$. The qualitative data from open-ended questions were analysed using thematic analysis (Braun & Clarke, 2006)

Recruitment was achieved by social media and UK organisation (Tourettes Action, Tourette Scotland) promotion.



Participants needed to be over 18 and resident in UK when they sought diagnosis or self-identified.

Results and Conclusion

Adult participants:

- Reported a variety of motor and vocal tics
- Had at least one cooccurring condition (88%)

Higher levels on AAQ-T were:

- associated with ATQ total frequency, intensity and severity of motor tics but not vocal tics
- highly correlated to age/daily interference

Reasoning for seeking or continuing to pursue a diagnosis included:

- Getting a better understanding of oneself
- Medical intervention
- Validation

Those who self-identified quoted fear of dismissal, long waiting lists and lack of understanding from the healthcare professions as reasons for self-identifying.

Nearly all adults surveyed were extremely dissatisfied with the diagnostic process, information provided and availability of post-diagnostic support.

The majority did not receive post-diagnostic support. Those supported were offered medication or signposted to other medical services, charity organisations or therapy.

The findings highlight the need for professionals and clinicians to understand how to support adults seeking a late diagnosis.

Significant Pearson's Correlations

	AAQ-T
Age	-0.376 (significance 0.014)
Daily Interference	0.696 (significance <0.01)
Total Motor Frequency	0.539 (significance <0.001)
Total Motor Intensity	0.488 (significance 0.001)
Total Motor Severity	0.559 (significance <0.001)

References

Black, K. J., Kim, S., Yang, N. Y., & Greene, D. J. (2021). Course of Tic Disorders Over the Lifespan. *Current Developmental Disorders Reports*. <https://doi.org/10.1007/s40474-021-00231-3>

Braun, V. (2006). Using thematic analysis in psychology. *Q Res Psychol*, 3:77-101. doi: 10.1191/1478088706qp063oa

Chouinard S, & Ford B (2000). Adult onset tic disorders. *Journal of Neurology, Neurosurgery & Psychiatry*, 68:738-743

Crane, J. W., Chester, J., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of adult diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism: the international journal of research and practice*, 20(2), 153-163. <https://doi.org/10.1177/1362361315573636>

Malli, M. A., Forrester-Jones, R., & Triantafyllopoulou, P. (2019). "Tourette's is a Lonely Place": An Interpretive Phenomenological Analysis of the Personal Experience and Identity of Adults with Tourette's Syndrome. *Journal of Developmental and Physical Disabilities*, 31(6), 819-845. <https://doi.org/10.1007/s10882-019-09676-2>

Schaefer, S. M., Chow, C. A., Louis, E. D., & Robakis, D. (2017). Tic exacerbation in adults with tourette syndrome: A case series. *Tremor and Other Hyperkinetic Movements*, 7. <https://doi.org/10.7916/D8FF3Z1Q>

The primary author's institution ethics board approved the study - UH protocol number LMS/PGR/UH/04921



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