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. 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)

Method

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

1. Captured sociodemographic characteristics

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

3. Built upon findings from previous research and lived experience to ensure a robust analysis.

Sociodemographic characteristics

The mean age of the final sample was 36.12 years (standard deviation (SD) = 13.39, range 18-68)

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

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)

Results and Conclusion

The majority did not receive post-diagnostic support. Those who self-identified quoted fear of dismissal, long waiting lists and lack of understanding from the healthcare professions as reasons for not seeking a late diagnosis.

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

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

References


General tic and diagnostic status

<table>
<thead>
<tr>
<th>Total</th>
<th>N =42</th>
<th>Time to diagnosis (N=32, range = Instant - 34 yrs)</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Can’t remember</td>
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<td></td>
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<td>0-6 months</td>
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<td>1 month to a year</td>
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<td>Greater than 1 year</td>
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</tbody>
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| Total Motor Frequency | 0.539 (significance <0.001) | Total Motor Intensity | 0.485 (significance 0.001) | Total Motor Severity | 0.559 (significance <0.001) |

The qualitative data from open-ended questions were analysed using thematic analysis (Braun & Clarke, 2006)