

# Experiences of a functional tics diagnosis received by adolescents and their caregivers: A qualitative study

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## Background

Functional tics (FTs) are thought of as a somatic expression of cumulative stress<sup>1-2</sup>. It is hypothesised that pandemic-related stress contributed to an increased prevalence in FTs<sup>3-4</sup>. The influence of social media in FT onset is debated<sup>5-6</sup>.

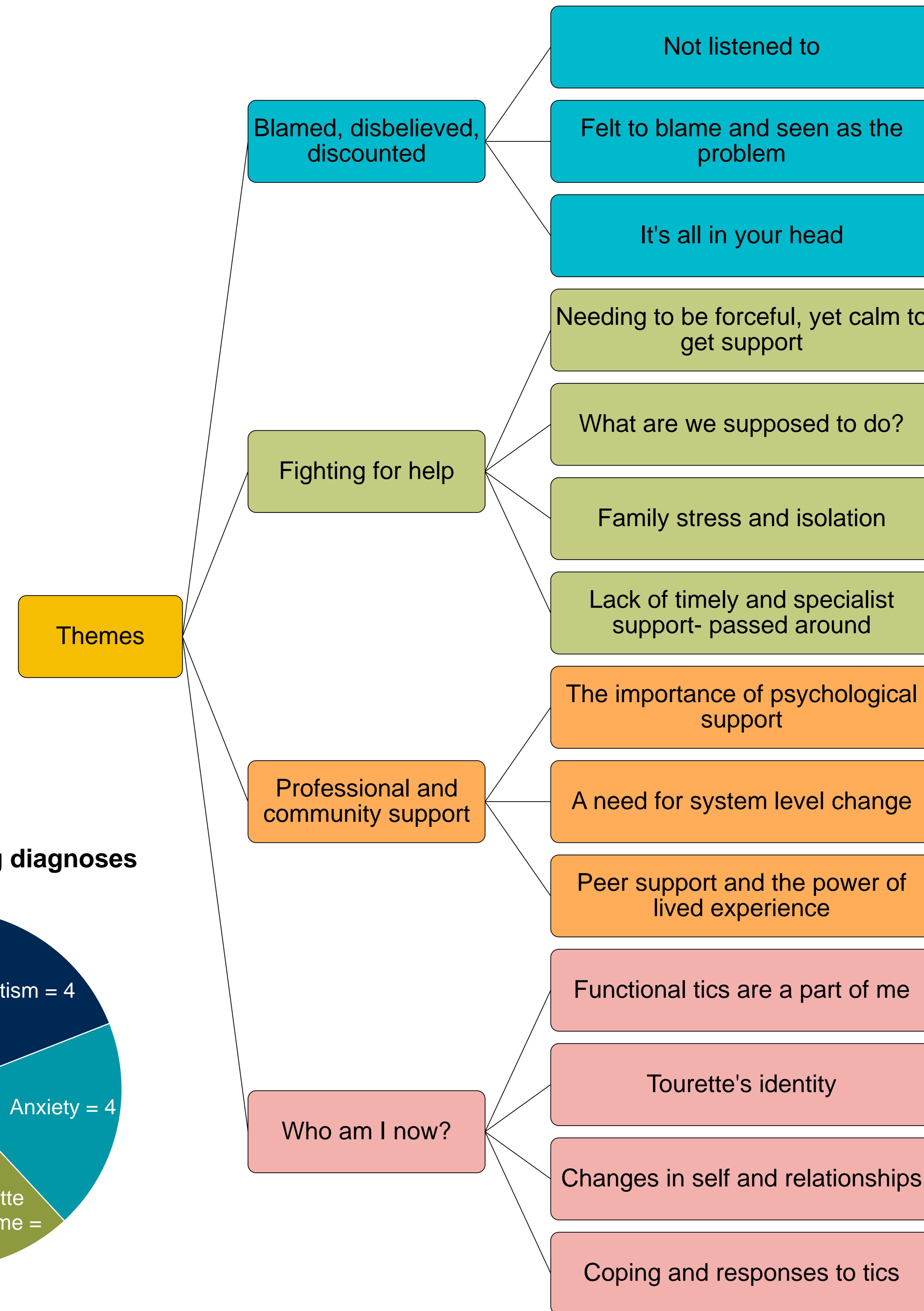
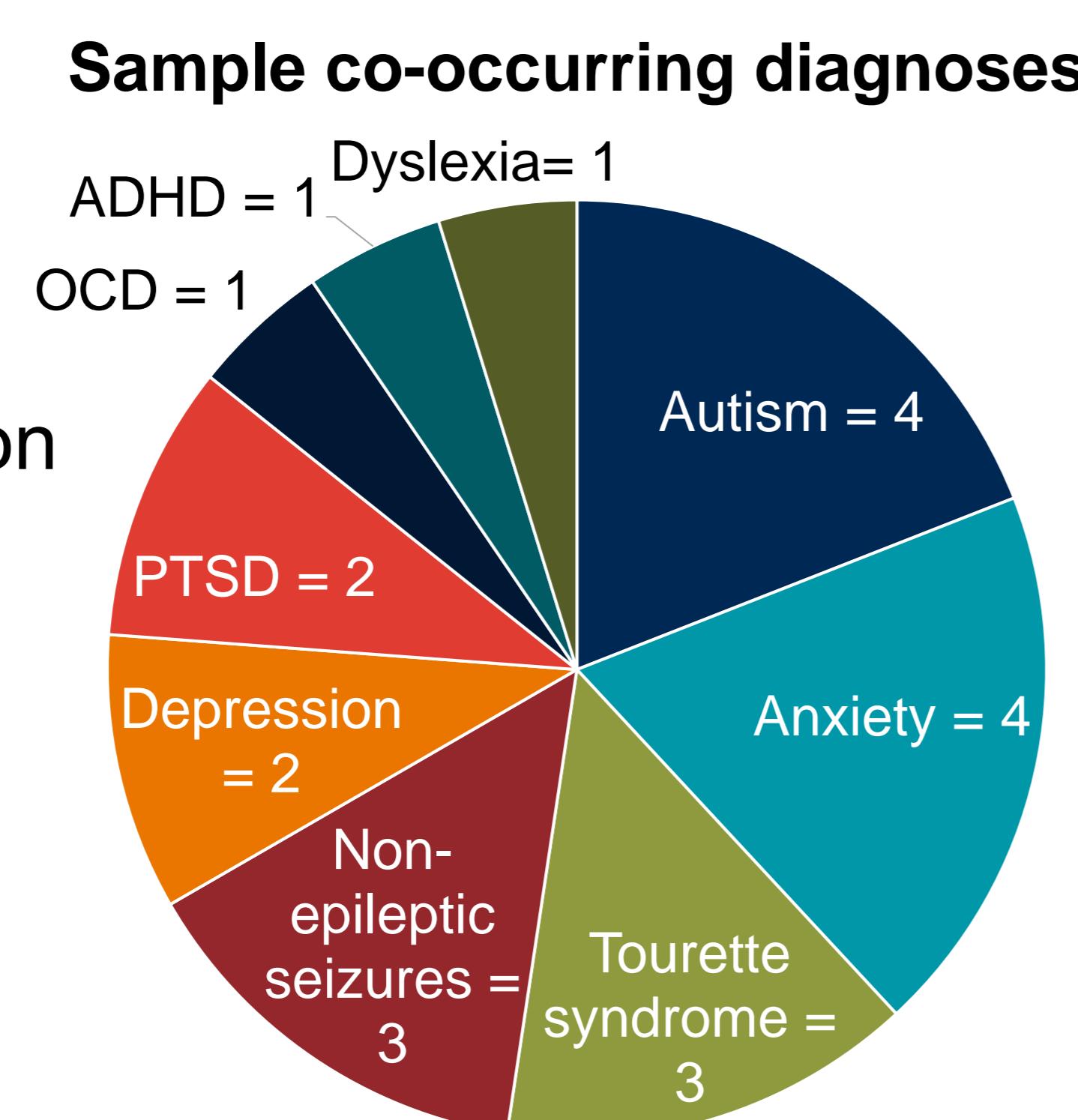
FTs are more prevalent in female adolescents who often present with co-occurring mental disorder and undiagnosed neurodevelopmental disorders<sup>7-8</sup>. The exact aetiology, prognosis and treatment of functional tics remains elusive.

The use of psychoeducation in FT management has been advised<sup>9</sup>. Younger age at diagnosis, receipt of cognitive behavioural therapy for anxiety or depression and antidepressant medication have been associated with lower FT severity at 6 month follow up<sup>10</sup>.

Further research is required to understand how families experience seeking a FT diagnosis and their experiences of post-diagnostic support, to improve clinical services

## Methods

- 7 White British females with FTs aged between 12-18 years
- 7 mothers and 1 father
- Recruited through Tourette's Action
- Individual semi structured interviews
- Experiences of obtaining a FT diagnosis, the impact of FTs and experiences of post-diagnostic support.
- Analysis using reflexive thematic analysis<sup>11</sup>.



## Findings

Families experienced a challenging and isolating journey to a FT diagnosis. They fought for help in the context of feeling invalidated by professionals. Experiences of stigma were seemingly perpetuated by FTs being viewed as psychological in nature.

*"It was really frustrating that we felt that nobody was taking it seriously. She also felt frustrated because I think she felt not believed." (Parent)*

Services were described as not set up to cater for the holistic needs of adolescents as evidenced by lack of knowledge on FTs, dualism and diagnostic overshadowing. Many fell in the gap between physical and psychological services, though there was variation in post-diagnostic support.

*"I think sometimes people forget that I'm autistic on top of the tics. And forget that the trauma [resulting in FTs] was caused by me being autistic" (Adolescent)*

Psychological support facilitated a holistic understanding of adolescents' needs, management of psychological needs causing and maintaining FTs as well as strategies to manage FTs. Coupled with community support, this aided adjustment to FTs.

*"We understood that we were somehow making it worse by our anxiety and by our trying to protect her" (Parent)*

## What this study adds

Lack of FT awareness impacts service provision, duration of symptoms and availability and suitability of support.

Further research should develop an understanding of FTs, to improve awareness and to meet the needs of affected families.