

Adapting psychoeducation to accommodate neurodiversity among young people with Tourette syndrome.

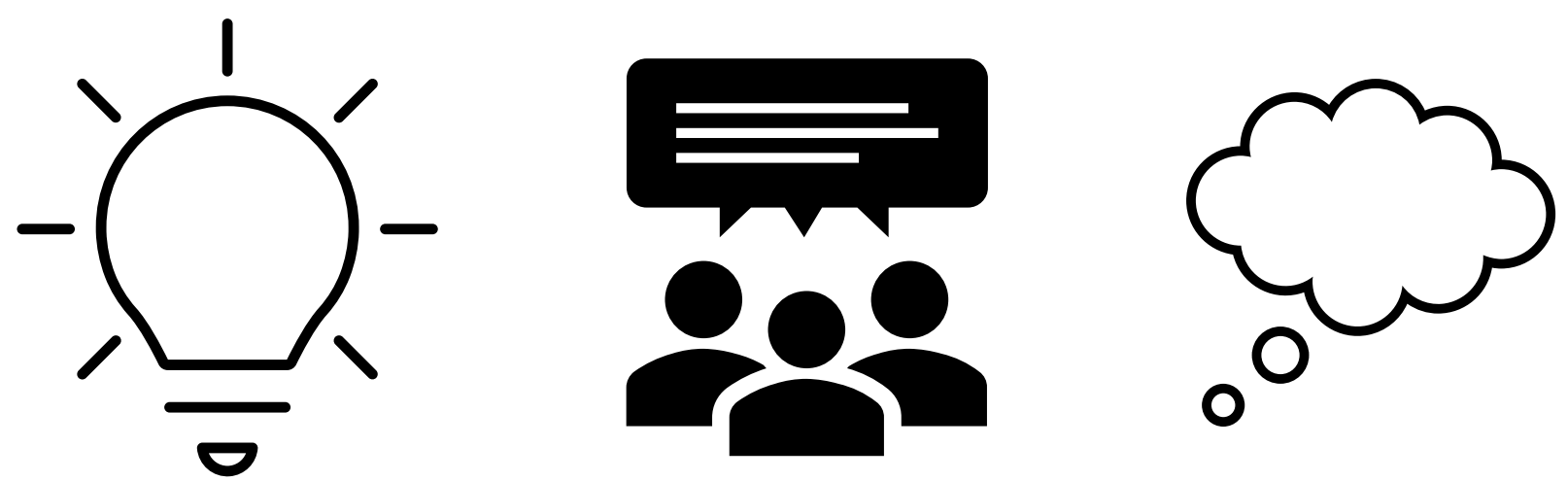
Isabel M. G. Archer,¹ Madiha Shoaib,¹ Anthony W. Harrison,¹ Jane Gilmour,^{1,2} Maria Hadji-Michael,¹ Ross Nedoma,¹ Sara Shavel-Jessop,^{1, 2} Tara Murphy,¹

¹ Tic Service, Great Ormond Street Hospital for Children ² University College London



Background

- ❖ Psychoeducation is recommended as the first line of intervention for Tourette syndrome (TS; Andrén et al., 2022) irrespective of symptom severity.
- ❖ TS commonly co-occurs with other neurodevelopmental conditions, including autism and attention-deficit hyperactivity disorder (ADHD; Yang et al., 2021). This presentation is associated with increased functional impairment (Bolen et al., 2022) so services must consider the needs of these young people.
- ❖ Existing literature describes specialised adaptations of routine psychological intervention such as Habit Reversal Therapy and Exposure Response Prevention for young people who have ADHD (Sanderson et al., 2022) but to date minimal guidance on how to adapt psychoeducation for TS when other conditions are present.
- ❖ **Aim:** We gathered feedback from young people with tics and co-occurring conditions about their experience of a ‘service as usual’ psychoeducation group with the aim to improve the service experience.



Methods

Design: We conducted a qualitative investigation on a ‘service as usual’ psychoeducation group for young people who have TS and one or more co-occurring neurodevelopmental condition and had participated in the group within the last twelve months. Eligibility criteria required that participants were aged between 11 and 17 years and had a confirmed diagnosis of either autism and/or ADHD in addition to TS.

Participants: Two male participants (aged 14 years) took part in the online focus group. Both had TS and autism, with one participant having ADHD in addition. No other conditions were identified following a full assessment.

Qualitative Interview: Targeted questions explored participants’ beliefs regarding the structure and content of the program, methods of delivering the program, group format, use of icebreakers, in-session exercises, use of videoconference cameras, and the chat function. Finally, open discussion questions explored participants’ recommendations to adapt and improve the program. Results were analysed qualitatively, based on the approach described by Braun & Clarke (2006), to explore the feedback provided by focus group participants.

Results

Participants’ views were prompted using polls (10 = the most positive response).

How well did you understand the information on the slides?

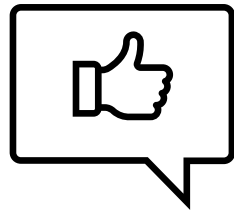
How much did you like having the camera on?

9 out of 10

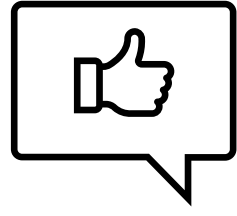
9 out of 10

2 out of 10

10 out of 10



Yes, the group offers us...



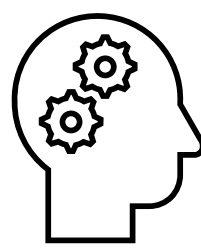
Information about tics: ‘they help you and like teach you stuff that you don’t know’ ‘I thought the group was helpful and educational’ ‘You will learn more about your condition’

Peer connection: ‘it was good to see like other people in the same group learning that like, not that we all have the same stuff but like the same condition’

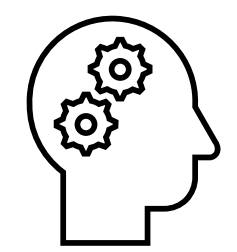
Validation: ‘it is good to know that a famous person has something like that I have as well’

Supportive environment (adults): ‘I don’t know how to explain but like having my mum near me is like good’ ‘They don’t like make fun of you for what you have...they help you’

User friendly designs: ‘I think the pictures help’



But...



We want more breaks and games: ‘you can give them brain breaks or something’

Everyone needs to remember the challenges of being bullied: ‘with autism and ADHD, people know...and like people still get bullied’ ‘like a few weeks after the start of year eight I was getting bullied for having Tourette’s’

We want bigger text and clear visuals: ‘the text is a bit too small’ ‘I think like the writing, I mean like, maybe a little bit bigger’

We don’t use the resources (our parents do): ‘I didn’t really use the websites’ ‘I don’t think I saw it...my mum like saw it ...she was like telling people [about it]’

We may have different preferences about group delivery: ‘I would prefer to do it face to face like physical.... I feel like you can explain more and stuff’ ‘I like having the camera on like I don’t mind it’ ‘sometimes I don’t really like the camera on...my hair might not look good...’

Conclusions

Our results highlight the importance of adapting group-based TS psychoeducation to accommodate the needs of neurodiverse young people.

Findings from this exploratory focus group were consistent with research suggesting neurodiverse young people **value peer support** (Crompton et al., 2023), validation of their experiences (Chown et al., 2023), and communication of information in a manner that is sensitive to their needs (Wong et al., 2015).

Consistent with research demonstrating reduced processing speed in autistic people (Hedvall et al., 2013), young people raised the importance of **visual communication and the pace of delivery**.

In accordance with views expressed by the participants, and previous research exploring adaptations for patients with both TS and ADHD (Sanderson et al., 2022), consider **shortened sessions, regular breaks, and interactive games**.

Our findings reflect diversity in the preferences of neurodiverse young people, with respect to online versus face-to-face delivery (Zahir et al., 2024; Jaswal et al., 2019), highlighting the need to **avoid assumptions related to neurodiversity**. Future research should explore adaptations of TS psychoeducation programs for neurodiverse individuals.

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