

I TIC, THEREFORE I AM

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A qualitative analysis of adults with Tourette syndromes' experiences of leisure occupations

Leisure is an occupational performance component defined as a non-obligatory, individualistic activity of one's own volition, separate from tasks of work or self-care and is widely considered a fundamental human need¹



INTRODUCTION

Occupational therapists (OT) provide interventions to enhance wellbeing by considering the relationship between the self, the occupation, and the environment. Tourette syndrome (TS) in adulthood is associated with reduced quality of life, higher rates of mental health needs, self-stigma, and pain, which are all risk factors for occupational deprivation. Limited research suggests that despite its benefits, individuals with TS may disengage from previously enjoyed occupations due to their primary and secondary symptomology^{2,3,4}

OBJECTIVE

- To ascertain the perceived impact of engaging in leisure activities on wellbeing through lived experiences of adults with TS
- To determine the perceived impact participation in leisure occupations has on adults' TS characteristics
- To identify potential facilitators and barriers to participation in leisure occupations in adults with TS
- To inform social and therapeutic approaches to enable participation in lesiure for adults with TS

METHODOLOGY

The researcher conducted a systematic literature search including allied healthcare databases, using CINAHL and AMED, identifying and critiquing relevant articles to inform the literature review.

Qualitative data was obtained through online individual semi-structured interviews with five adults diagnosed with TS. Two hundred and seventy minutes of transcripts were analysed utilising Thematic Analysis. Key themes were outlined and discussed if mentioned by more than four out of five participants.

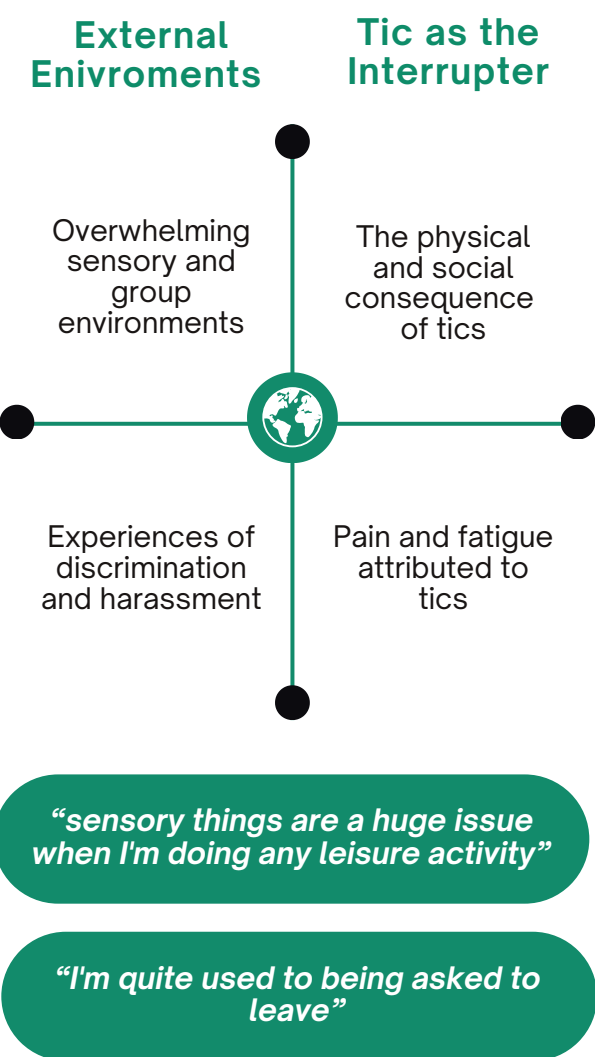
PARTICIPANT DEMOGRAPHICS

Gender	Age	Co-occurring diagnosis
M	25	Chronic Fatigue (ADHD diagnosis ongoing)
F	34	ADHD / OCD
F	35	OCD (ADHD and ASD diagnosis ongoing)
M	29	ASD / OCD
F	23	OCD Anxiety (ADHD diagnosis ongoing)

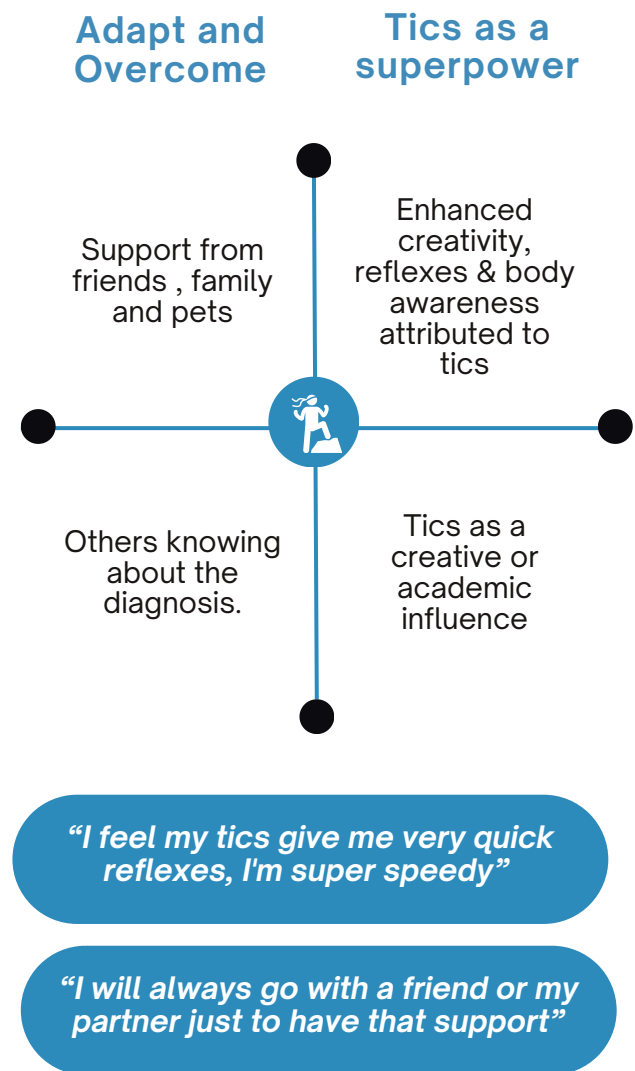
BENEFITS TO PARTICIPATION



BARRIERS TO PARTICIPATION



FACILITATORS TO PARTICIPATION



RESULTS

All participants in the study reported benefits from engagement in leisure, including a reprieve from tics without the negative or 'rebound' effect they associated with suppression. This led many to incorporate their leisure interests into their professional or educational pursuits, examples include a musician and yoga teacher. Leisure participation was seen as a source of pride and accomplishment, and an outlet for excess restless energy associated with co-occurring ADHD and anxiety. However, barriers to engagement in leisure were also identified, including the internal experience of tics, related pain and fatigue from tic suppression, and the external physical, social, and sensory environment. A key finding was that a supportive community, and others being aware of the TS diagnosis, along with the strengths attributed to the condition itself, played a crucial role in enabling participation in leisure activities.

CONCLUSION

These outcomes underscore the complex interaction between the self (person with TS), environment (social, physical, sensory), and occupation (leisure activities), which may inform universal design and intervention approaches to reduce barriers to engagement. The results indicate the value social prescribing may offer as an alternative targeted approach to enable a reprieve from tics and commonly co-occurring symptomology.

POTENTIAL FOR PRACTICE

- Assess and adapt the sensory environment in leisure settings using universal design principles
- Provide compensatory tools to reduce sensory overwhelm during leisure tasks
- Provide carer/family member goes free scheme support in leisure settings
- Small group or 1:1 sessions
- Provide TS education to session facilitators
- Explore educational or professional options which align with tic reducing leisure occupations
- Consider social prescribing to increase wellbeing
- Continue to raise public awareness and understanding of tics and TS to reduce social stigma
- Promote participation and engagement via a strength-based narrative

RELATED LITERATURE

1.Suto, M. 1998. Leisure in Occupational Therapy. Canadian Journal of Occupational Therapy. 65(5), pp.271-278. Doi: 10.1177/000841749806500504.
2.Brown, W.C. 2016. Influence of Musical Engagement on Symptoms of Tourette's Disorder. PhD Thesis, University of South Florida.
3.Conelea, C.A. et al. 2013. The impact of Tourette syndrome in adults: results from the Tourette syndrome impact survey.Community Mental Health Journal 49, pp. 110-120
4.Conelea, C.A, Busch, A.M., Catanzaro, M.A., and Budman, C.L. 2014. Tic-related activity restriction as a predictor of emotional functioning and quality of life. Comprehensive Psychiatry 55(1), pp.123-129.