



The Experiences of Diagnosis for Adults with Tourette Syndrome

Anekea Ross^{1,2}; Hugh Rickards^{2,3}

¹University of Warwick, ²University of Birmingham, ³Birmingham and Solihull Mental Health Foundation Trust

SUMMARY

The aim of this research was to explore the experiences of diagnosis for those with Tourette Syndrome (TS), specifically what having a diagnosis means and whether there are any advantages or disadvantages to this. Findings suggest that having TS is a multifaceted experience; participants felt that diagnosis was important and cited few disadvantages of diagnosis, however they described problems with the diagnostic procedure and some difficulties in living with the disorder.

BACKGROUND

TS is a clinical diagnosis, meaning that there is not a specific test for the disorder, it has been noted to be difficult to diagnose with research showing delays in the diagnosis of TS (Wand et al., 1992; Freeman et al., 2000; Shilon et al., 2008). Cultural factors may also play a role in the social perceptions of TS and differences were found between cultures regarding the impact of TS on quality of life (Mathews et al., 2001; Zinner et al., 2012).

Very little research has looked at the subjective experience of having TS and as far as the authors are aware there are no studies which have investigated the reasons for wanting or not wanting diagnosis in TS and whether having a diagnosis is a positive or negative experience for those with the disorder.

Looking at neurodevelopmental disorders (NDD) such as autism spectrum disorders, attention deficit hyperactivity disorder and motor disorders, it appears that there are a range of advantages and disadvantages related to obtaining a diagnosis of a NDD. Significant disadvantages relate to the lack of a cure and the stigma associated with the disorder and the significant advantages are related to help and support following diagnosis and greater understanding of the disorder.

DECLARATION OF INTERESTS

This research was completed by Anekea Ross as part of the MSc in Clinical Neuropsychiatry at the University of Birmingham and was supervised by Dr Hugh Rickards. A small grant for the purpose of travel expenses for participants was provided by Dr Rickards.

METHOD

Nine adult participants with TS were recruited through Tourettes Action.

Design: Semi-structured interviews were completed either face to face or via telephone and the resulting transcripts were analysed using thematic analysis.

Inclusion Criteria: Adults (over the age of 16) with a diagnosis of Tourette Syndrome were invited to take part. There was no upper age limit, and participants did not have to be newly diagnosed. Participants were required to be fluent in English Language as the interviews were conducted in English.

Exclusion Criteria: Those who had experienced brain injury or neurological disease or had a history of learning difficulties as these experiences may overlap with the experience of having Tourette Syndrome.

RESULTS

There were three main themes resulting from the data: *Diagnosis helps with coping*, *Dissatisfaction with the diagnostic process* and *Living with TS*.

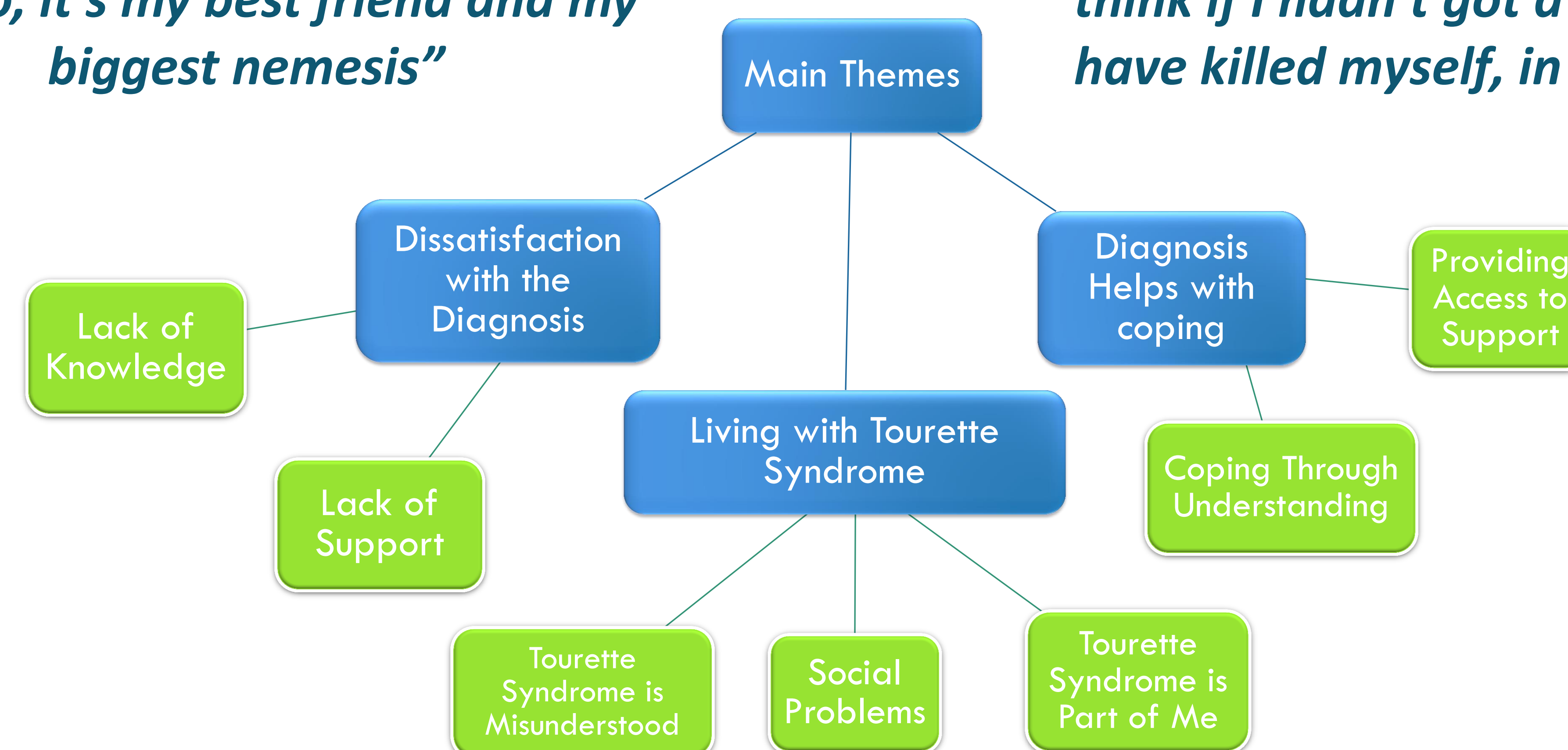
The majority of participants in this study felt that diagnosis helped with self-understanding and understanding for others, particularly with naming the disorder, and being able to explain the behaviour.

Although most participants felt that diagnosis was important, dissatisfaction with the diagnostic process was common and many experienced poor communication from clinical staff during diagnosis. Participants felt there was a general lack of knowledge surrounding TS outside of specialist TS services.

Several participants felt TS was stigmatised in the media and expressed concerns about the future and prognosis with the disorder. Participants in this study disclosed mixed feelings regarding ownership of TS. Some were proud of the disorder and were actively involved in educating others and running support groups whereas others held strong resentment towards the TS and attempted to hide their tics.

“I've got the condition and I am proud of the position it leaves me. But, so, it's my best friend and my biggest nemesis”

“[The diagnosis] totally changed my life, for the positive. 100%. I think if I hadn't got a diagnosis, I'd have killed myself, in the end.”



DISCUSSION

In line with previous research looking at NDDs, (Huws & Jones, 2008; Young et al., 2008; Punshon et al., 2009) participants in this study highlighted access to support and resources as a key benefits of the diagnosis, particularly being able to meet others with the disorder which participants felt was important in providing a sense of belonging and understanding.

There are many strengths of this research such as providing new information to this field of research. Nonetheless, the data consists of retrospective accounts with an average of a seven year gap between diagnosis and taking part. It would be interesting to obtain the perspectives of individuals within a timeframe closer to the diagnosis. This could be done by recruiting newly diagnosed participants from a TS clinic. Additionally, the perspectives of those diagnosed in childhood would be of interest in order to ascertain whether the age at diagnosis has an effect on the perception of the disorder.

CONCLUSION

The findings suggest that a diagnosis of TS is useful for those with the disorder but indicate a gap in services for those with TS post diagnosis. Results indicate that increased knowledge of TS for clinicians and improved support post-diagnosis will be useful in continuing to help those with TS to cope with the disorder.

REFERENCES

- Freeman, R.D., Fast, D.K., Burd, L., Kerbeshian, J., Robertson, M.M., Sandor, P., (2000). An International perspective on Tourette Syndrome: selected findings from 3500 individuals in 22 countries. *Developmental Medicine & Child Neurology*, 42: 436-447
- Huws, J.C., & Jones, R.S.P., (2008). Diagnosis, disclosure and having autism: An interpretive phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual & Developmental Disability*, 33(2), 99-107.
- Mathews, C.A., Amighetti, L.D.H., Lowe, T.L., Van de Wetering, B.J.M., et al., (2001). Cultural influences on diagnosis and perception of Tourette Syndrome in Costa Rica. *J. Am. Acad. Child Adolesc Psychiatry*, 40(4), 456 – 463
- Punshon, C., Skirrow, P., & Murphy, G., (2009). The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, 13(3) 265-283.
- Shilon, Y., Pollack, Y., Benarroch, F., Gross-Tsur, V., (2008). Factors influencing diagnosis delay in children with Tourette syndrome. *European Journal of Paediatric Neurology*, 12, 398- 400.
- Wand, R., Shady, G., Broder, R., Furer, P., Staley, D., (1992). Tourette Syndrome: Issues in Diagnosis. *Neuroscience and Biobehavioral Reviews*, 16, 449 – 451.
- Young, S., Bramham, J., Gray, K., & Rose, E., (2008). The experience of receiving a diagnosis and treatment of ADHD in Adulthood: A qualitative study of clinically referred patients using interpretive phenomenological analysis. *Journal of Attention Disorders*, 11(4), 493-503
- Zinner, S.H., Conelea, C.A., Glew, G.M., Woods, D.W., Budman, C.L., (2012). Peer victimisation in Tourette syndrome and other chronic tic disorders. *Child Psychiatry Hum Dev*. 43(1) 124-36.