



The Social Care Needs of Adults with Tourette's Syndrome

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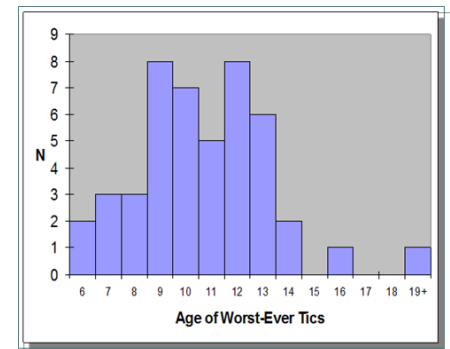
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Tourette's syndrome

- ▶ Tourette's Syndrome (TS) is a neurodevelopmental disorder characterised by tics (American Psychiatric Association, 2013).
- ▶ Multiple motor and at least one vocal tic must be present for at least a year, during which time the severity of the tics fluctuate.
- ▶ 0.77% of school aged population and male predominance over females (Knight et al., 2012)
- ▶ 80% of people with Tourette's have other comorbidities (OCD, ADHD etc)
- ▶ Tics often reduce and in some people disappear by adulthood.



But what if the tics continue into adulthood?

- ▶ Adults who have Tourette's syndrome usually exhibit the most florid clinical presentation and experience many difficulties in their everyday life.

Difficulties:

- ▶ Mobility difficulties and practical needs
- ▶ Financial Difficulties (Miller et al., 2014).
- ▶ Social relationships (Conelea et al., 2013).



Aims of the Study

- Firstly, to identify the difficulties adults with Tourette's may experience in their everyday lives due to their condition and how these difficulties may affect their Quality of Life.
- Secondly, to find out the extent to which adults with TS are accessing and receiving social care and benefits. We also sought to explore the views of individuals with TS in relation to their use of social services, identifying the types of care they would value.
- Thirdly, we aimed to understand how receiving social care does/or might affect their personhood and embodiment.



Mixed Method Design

Online survey

- ▶ Sociodemographic Information
- ▶ Employment and Income etc
- ▶ Yale Global Tic Severity Scale- Self-Report Version (YGTSS-SR)
- ▶ Perceived Quality of Life (QoL) (Patrick et al. 1988, 2000)
- ▶ Discrimination Scale

One to one in Depth Interviews

- ▶ **Interpretative Phenomenological Analysis** (Smith, Flowers & Larkin, 2009). how the condition had impacted their social identity and sense of self.

Online Survey

- ▶ A total of 68 participants comprised the final sample (31 male and 35 female).
- ▶ We found that only 54.4% of our sample were employed compared to 75.7% of the general population in March 2018.
- ▶ 41.2% of the sample were receiving disability benefits or social care.

Online Survey

- ▶ Our findings show that the overall Quality of life of adults with TS is poor.
- ▶ We found no correlation between the severity of the tics and the perceived Quality of life in adults with TS ($r = -0.169$, $p = 0.186$).
- ▶ There was no correlation between the tic severity and the tic-related impairment ($r = .120$, $p = .353$).
- ▶ However, impairment caused by tics was inversely associated to the quality of life of adults with TS.
- ▶ Furthermore, the QoL in adults with TS was not conditioned by sociodemographic variables such as gender and age, but was significantly dependant on being employed or not and the extent to which the participants had experienced discrimination.

Online Survey

- ▶ Recipients of disability benefits and/or social care reported higher rates of impaired functioning in relation to their counterparts that that do not receive social care and/or disability benefits.
- ▶ They also reported a lower Quality of life in relation to adults with Tourette's that were not receiving social care and/ or disability benefits. This might suggest that adults with Tourette's experience a negative impact on their lives as a result of a lack of adequate support.

One-to-one Interviews

- ▶ Sixteen adults with Tourette's took part in the one-to-one interviews (12 males and 4 females).
- ▶ Five of the participants were receiving disability benefits and/or social care.
- ▶ 3 main themes:
 - ▶ The practical Needs of adults with Tourette's syndrome
 - ▶ The shame and Desperation of asking for help
 - ▶ The social exclusion of Tourette's syndrome



The practical needs of adults with Tourette's syndrome.

“So like if I'm preparing a meal with knives and my arms are like lunging out or throwing things. I put down that knife and I have to ask [name] to come, my wife to come and do it for me.” (Participant 1)

“But there are parts of like the physical sides of Tourette's which can be quite dangerous for the person to not have someone there to help them at times. So, you have these tics that are almost looking like seizures and people could like break limbs and bones and things like that. I have had to have [my wife] sit on me before or to restrain me from kind of like the tick attack” (Participant 3)

The practical needs of adults with Tourette's syndrome

“Reviews and assessments are stressful and you usually get a different person each time who hasn't read your file and especially as I have no speech and have to type everything it takes ages ..and they do not understand that the tics come and go. Sometimes they stop for a long time..what then?”

The shame and desperation of asking for help

“And then there is a part of ourselves that feels less of a person because of asking for the help.. That stigma created by the Daily Mailm the Mirror and the Sun and all these Red Benner Newspapers” (Participant 2).

“my family and my sister, we've always like, we've always tried to work really hard...we just kind of...I don't know...it was just like this thing that we didn't actually want to be seen as like finance sort of thing (Participant 8)

“ keep my affairs very private and it's because of the stigma attached to benefits. It's something that I just don't like to discuss or get into with people. So that's another thing that keeps me sort of separated from people. Because I don't want people to judge me or you know...and then if they know that I'm on ESA...it's like well why, what's wrong with you?” (Participant 5)

The shame and desperation of asking for help

“As I want to do things on my own and go out on my own, but I am also so glad of it as without it things would be much worse. It helps me cope with this crazy situation, because it is crazy and difficult. Before receiving social care I felt that if I accepted it I would be giving in, well giving in in hoping things could improve.” (Participant 9)

“I think as well it depends on if people haven't got a good support network around themselves. You know they haven't got the friends and the relationships there to support them” (Participant 14).

The social exclusion of adults with Tourette's syndrome

"I was kept in the...I was hidden in the cupboards and the rooms. I was never taken out into public. I was even kept away from my own family except from my grandparents" (Participant 7)

"Imagine in pubs and working in a bar and stressful nights and stuff like that and you start ticking and people start asking questions, poking fun of you drunk, so, you know...And you try and speak to your employer about it...'I need to stop right now, I need to pull myself away or go home or something because it's gonna make me worse'. It's just a big blow down, it really is. And they don't understand that, and they don't care either and they don't believe they have to care" (Participant 14)



The social exclusion of adults with Tourette's syndrome

- ▶ *“A lot of information they [relevant organisations] were providing was mainly geared towards children with Tourette's syndrome and parents that have children that have Tourette's. And there was not much for adults, so I have to say...I had to figure out a lot of things all by myself”*



CONCLUSION

- ▶ Adults with Tourette's syndrome may experience difficulties in everyday chores, have mobility difficulties and experience pain that makes it difficult for them to live independently. However, they may be hesitant to access support because of the stigma attached to receiving it, including disability benefits and/ or social care.
- ▶ The study also indicated that the sense of impaired functioning in adults with Tourette's might be determined by more than the core symptomology of Tourette's- thus the tics. Social care practitioners should be aware of the psychosocial challenges related to living with Tourette's syndrome.
- ▶ The study suggests that adults with Tourette's syndrome may experience feelings of isolation, and stigma due to their condition.

CONCLUSION

