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The social care needs of adults with Tourette's Syndrome

RESEARCH FINDINGS

Many adults with Tourette's Syndrome (TS) have everyday needs that are not being met. Due to the debilitating effects of the tics they may require help with simple everyday chores

The fluctuating nature of the tics led some participants to worry whether adult social care (ASC) assessments were adequate to capture the debilitating nature of having TS. This requires knowledge about TS, which they felt individuals working in ASC do not always have

Because of stigma attached to receiving social care many adults with TS relied on friends and family for financial and emotional support

The severity of the tics may not be the only determinant of the quality of life of adults with TS, which appears to be conditioned on being employed or not and the extent to which the participants had experienced discrimination

Social care workers need to have specialist knowledge in relation to TS, its psychosocial consequences and understanding of its nature so they can respond holistically to people's needs

BACKGROUND

There is a lack of research about the adult social care needs of adults with Tourette's Syndrome (TS).

Adults with TS may experience mobility difficulties, unemployment and/or social isolation, and may therefore require social care.

There is also little evidence of the impact of social care on people with TS when this support is provided and when it is not.

This study aimed to address this gap in the evidence by understanding the difficulties adults with TS experience (e.g. personal support needs, employment, relationships) and their access to adult social care. It also aimed to explore whether they felt they needed or wanted to receive social care.

Methods

The research team conducted online questionnaires in which 68 individuals with TS took part:

- 31 male and 35 female
- only 54.4% of the sample were employed compared to 75.7% of the general population in March 2018
- 41.2% of the sample were receiving disability benefits or adult social care
- 88.2% disclosed that the tics had caused physical pain or damage to them.

Participants were a self-selected sample of adults with TS who were invited to take part in the study via websites and social media platforms, including Tourette's Action, Tourette Focus-UK/Europe and ADHD Wise UK.

This was followed by one-to-one in-depth interviews with 16 of those individuals:

- 12 males and 4 females
- 5 were receiving disability benefits and/or social care

TOURETTE'S SYNDROME

Tourette's Syndrome (TS) is a hereditary neurodevelopmental disorder characterised by tics – sudden uncontrolled movements and/or sounds.

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, to be diagnosed with TS.

TS has a prevalence of 0.77% in school-aged children, with prevalence higher in boys than girls.

80% of people with Tourette's have other comorbidities (for example, obsessive compulsive disorder, attention deficient hyperactivity disorder).

Tics often reduce and in some people disappear by adulthood.

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ONLINE SURVEY

Through an online survey the research team assessed the impact of Tourette's Syndrome (TS) on the physical, social, occupational and psychological functioning of adults with TS and their quality of life.

The findings suggest that many adults with TS have a relatively poor quality of life. However, no correlation was found between the severity of their tics and the perceived quality of life in adults with TS. This means that mild tics are not necessarily associated with a better quality of life and adults with mild symptomology may still assess their tics as disruptive for their life.

Furthermore, the quality of life in adults with TS was not conditioned by sociodemographic variables such as gender and age, but was to some degree dependant on being employed or not and the extent to which the participants had experienced discrimination.

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

(1) American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-V)*, American Psychiatric Association, Arlington, VA.

(2) Knight T, Steeves T, Day L, et al. (2012) Prevalence of tic disorders: A systematic review and meta-analysis, *Pediatric Neurology*, 47, 77–90.

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INTERVIEWS

The interviews looked at whether individuals with TS needed social care and how the condition had impacted their social identity and sense of self.

The main themes that emerged from the interviews included:

■ The practical needs of adults with Tourette's syndrome

Participants attested that the tics were sometimes debilitating and they required help with simple everyday chores in the house like cooking:

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)

In addition, the severity of the tics caused pain or mobility difficulties and made it very difficult for adults with TS to live independently:

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 tic attack. (Participant 3)

However, these needs were not always apparent during the adult social care assessment. A participant describes how social care workers are not aware of the fluctuating nature of the tics and worries arise in relation to tic-free periods:

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? (Participant 4)

■ The shame and desperation of asking for help

Participants were hesitant about asking for any form of help as they thought it would affect their social identity and make them feel less human:

And then there is a part of ourselves that feels less of a person because of asking for the help. (Participant 2)

But they also pointed out the shame that is linked to receiving disability benefits:

...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)

As difficulties arising from the condition are met by their family and friends, participants felt that only people that had poor social networks should ask for social care or benefits:

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)

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However, bestowing the responsibilities of a carer to family members is not always appropriate and feasible. A participant also discussed that receiving social care would mean losing the idea that things could get better:

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)

■ The social exclusion of Tourette's syndrome

Participants experienced loneliness. Childhood and adolescent memories of being singled out, victimised or mistreated because of their TS are particularly poignant examples of how involuntary isolation occurred:

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)

The interviewees were also often excluded from the workforce. Participants described how, from their viewpoint, employees failed or refused to make reasonable adjustments which in turn inhibited them from becoming employed or sustaining a job:

Imagine in pubs and working in a bar and stressful nights and stuff like that and you start ticcing 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)

Many participants pointed out that there was a lack of social care resources for adults with TS. Although they maintained that social and emotional support was available for children with TS and their parents, resources for adults were limited and could not be easily accessed. Whilst TS is not a condition restricted to childhood, the participants asserted that there was no continuity of care and that individuals with TS were at a high risk of failing to transition successfully to adult services:

At the age of 16, I was just pushed over the edge and told to get on with life. I've not had any inquiries or contact from anyone regarding it ... since the age of 16. That was it. That was the end of my care as far as anyone was concerned. (Participant 15)

In addition, participants felt that their social support needs were not adequately addressed. They did not have access to support groups that were specifically for adults with TS, and subsequently, rarely had the chance to meet and befriend other adults with the same condition who might have lived through similar experiences and might be able to provide them with information about the condition:

A lot of information they [relevant] 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. (Participant 9)



CONCLUSIONS & IMPLICATIONS

- Adults with Tourette's Syndrome (TS) 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. They may even be struggling to accept their condition or be in denial of the reality and hesitant to ask for help. Participants were concerned about the knowledge and understanding adult social care staff had about TS.
- As tics fluctuate in severity and frequency adult social care assessments may not be adequate to capture the debilitating effects of having TS. Participants were concerned that during tic-free periods adult social care practitioners could not understand the severity of their condition.
- The sense of impaired functioning in adults with TS might be determined by more than the core symptomology of TS. Social care practitioners should be aware of the psychosocial challenges related to living with TS. The study indicates that alleviating the severity of the tics is not necessarily adequate; emphasis should be placed on reducing the tic related impairment in order to improve the quality of life of adults with TS.
- Adults with TS may experience feelings of isolation, and stigma due to their condition. They may be excluded from the workforce due to environmental factors such as employers' attitudes, and their refusal to provide reasonable adjustments. Social care workers need to have specialist knowledge in relation to TS and its psychosocial consequences. Most importantly, they need to have a knowledge and understanding of the nature of TS so they can respond holistically to people's needs.
- There are gaps in the transition between children's and adults' services. Social care should prepare for a smooth transition to adult services with details of the anticipated treatment and services that the young person will require.

COMMENTS

The study suggests that the emotional needs of people with Tourette's are not adequately met and that the practical financial needs are met by family members and friends. A member of the advisory group commented:

"Adults with Tourette's come this far probably without social care in some area and a lot of them don't know that there are aspects that they can get help with. They should".

"This is the first study of its kind and reflects the lives of so many adults living with TS. Whilst the social care needs for adults is crucial it is very difficult to access leaving so many isolated and suffering from enhanced anxiety. Society has to understand the neuro-developmental conditions that will affect people throughout their lives and recognise that they need help to remain productive members of society".

Suzanne Dobson
Chief Executive, Tourette's Action

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

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