

ImPACT project: Improving the psychosocial experiences of adolescents with TS

Research report

This report summarises the findings from the research project 'Improving the psychosocial experiences of adolescents with Tourette Syndrome' (ImPACT), focusing on the psychosocial issues impacting on adolescents with TS and the situational factors or events that have been reported to reduce or exacerbate tics. So far, 15 young people, aged between 11 and 16 years, have taken part in in-depth interviews about their experiences of having TS. We are currently analysing these interviews but preliminary analysis has enabled us to identify a number of important personal and social issues for young people with TS as well as a number of factors that impact tic frequency.

Psychosocial issues impacting on adolescents with TS

There have been a number of previous research studies that have looked at social and psychological issues in individuals with Tourette syndrome (TS). These studies have been thoroughly reviewed by the research team and suggest that some young people with TS do experience social and personal difficulties. There is some evidence that school children with TS are judged less positively than classmates in terms of popularity and likeability. In addition, parents report that their children with TS can have social difficulties such as making friends and being bullied. Children and adolescents with TS have also reported experiencing more bullying compared to other children. Quality of life ratings obtained from individuals suggest TS can have an adverse effect on well-being, but it is not yet clear whether young people with TS tend to have self-esteem problems.

Very little research has looked at these social and personal issues from the point of view of the young people themselves. In the first year of this project we have carried out a study in order to collect detailed information on these issues from young people with TS.

The young people we interviewed described problems around how other people respond to their tic behaviour, particularly in school but also outside of school: "some of the teachers do not understand at all". Some young people talked about, and even worried about, what other young people thought of them: "everybody just thinks I'm weird". Most of the young people had friends, and some highlighted the support and acceptance their friends give them: "they hardly even notice it anymore". However, sometimes they felt like avoiding or leaving certain social situations. Some of the young people we spoke to said that they deal with having TS very well, but the strategies they use to cope do vary.

Factors in or outside school affecting tic frequency

Previous research on activities that impact tic frequencies have also been reviewed by the team. General factors such as stress or anxiety, working under pressure, fatigue and boredom are commonly associated with tic exacerbation. Other events or activities seem to help reduce the frequency of tics or help control the urge to tic. Such activities include relaxation, interactions with familiar people, leisure activities, habitual actions, and physical activities, such as participating in sport. Nevertheless, TS remains a puzzling disorder to understand since symptoms are not apparent all the time. For example, children with TS claim that they can be relatively tic-free in the classroom or clinic because they try to suppress their tics when in public, whereas they tic excessively when they are at home or alone. Other children have reported that focusing on a particular activity can help attenuate their tics but the type of activity that may help reduce tics varies. Also,



LOTTERY FUNDED



while it has been reported that physical activity in particular, reduces tic severity, there are certain other activities, which despite being sedentary, also reduce tics perhaps because they are attention-demanding (e.g. playing computer games).

Improved understanding of activities that play an important role in tic regulation is crucial but there have been very few studies which have gone beyond self-reports or parental surveys. One of the next steps of this study is to recruit a further sample of young people with TS who will participate in a number of common everyday physical or sedentary activities during which the frequency of their tics and their urge to tic will be directly observed and measured (using video-recording and other techniques). Based on the reports we have acquired so far from the interviews with the fifteen young people with TS, the factors that worsen tics are in line with what has been reported in previous studies. For example, stressful situations, such as working under pressure, were reported to lead to exacerbation of tics. Frustration was also frequently reported to be a factor that worsens tic expression, especially when in the presence of other people who are not knowledgeable about the disorder or do not understand: "...they tend to make it worse because I'm agitated and frustrated at them because of the circumstances I'm put in." On the other hand, tics are reduced in the presence of certain people, especially friends. Relaxation exercises, listening to or playing music or playing computer games were amongst the extra-curricular activities reported to be helpful in reducing tics. Importantly, children also stated that a relaxed school environment and attitude plays a major role in their ability to control tics and consequently in their school performance as they get less distracted from tics.

Once our analysis of these interviews is complete we will have a much more detailed picture of the experiences of young people with TS. Improved understanding of the factors that affect tic frequency will help young people with TS enhance their strategies of tic control and improve their educational attainment. This information will make a valuable addition to what we already know from previous research studies in this area.

For more details on Tourettes Action research projects, [please contact TA Research Manager, Seonaid Anderson](#).