

# Social stigma and self-perception in adolescents with tourette syndrome

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**Abstract:** Tourette syndrome (TS) is a complex neurodevelopmental disorder characterized by multiple motor and vocal tics, which commonly presents with multiple behavioral problems, including co-morbid attention-deficit and hyperactivity disorder and obsessive-compulsive disorder. Both tics and co-morbid conditions have been shown to potentially affect patients' health-related quality of life. While TS typically presents in childhood, its manifestations peak in severity during adolescence, a critical period in which affected individuals are exposed to potential stigma from peers. Physical and behavioral manifestations can also contribute to stigma, which subsequently leads to poorer health outcomes, discrimination, and a reduced willingness to seek help. The available evidence suggests that young patients with TS can experience reduced social acceptance from peers and difficulties establishing relationships. There is also evidence that some health care professionals share the unhelpful belief that young patients with TS should be disciplined in order to correct their disruptive behavior, based on the erroneous assumption that tics can be consciously controlled. Studies focussed on self-perception in patients with TS have yielded inconsistent results, with some studies showing problems in the domains of self-concept and self-esteem. Feelings of isolation, loneliness, and experiences of bullying have been reported more consistently. Interventions are required to reduce misconceptions about the condition and thus reduce stigma through targeted education and behavioral interventions. A multi-faceted approach that focuses on educating children, adults, and educators about TS would be beneficial to help alleviate stigma. This can be combined with self-advocacy and tailored psychological therapies for young patients with TS. The present paper reviews the current literature on stigma and self-perception in adolescents with TS in order to inform clinical decisions about management strategies and possible interventions to improve health-related quality of life.

**Keywords:** tourette syndrome, tics, stigma, self-perception, adolescents

## Introduction

Tourette syndrome (TS) is a complex neurodevelopmental disorder characterized by the chronic presence of sudden, repetitive, nonrhythmic, involuntary movements, and vocalizations, known as motor tics (at least two) and vocal tics (at least one).<sup>1</sup> TS is also a neuropsychiatric disorder and is classified in the current edition of the Diagnostic and Statistical Manual for Mental Disorders (DSM-5) within the spectrum of tic disorders.<sup>2</sup> Other tic disorders include persistent (chronic) motor and/or vocal tic disorders, lasting more than 1 year, and provisional (transient) tic disorder, lasting <1 year.<sup>2-4</sup> The prevalence of TS is estimated to be around 0.3–1% for school-age children, with a male to female ratio of 3–4:1.<sup>1</sup> The onset of tics is most

commonly reported in early childhood (at the age of 4–6 years), with a tendency for motor tics to develop prior to vocal tics.<sup>2,3,5</sup> Tic severity typically fluctuates over time, peaking during adolescence, with many patients experiencing an improvement in symptoms as they enter adulthood. Around one-third of patients diagnosed with TS in childhood no longer report problems related to their tics by the time they reach adulthood.<sup>6</sup>

Tics are typically preceded by uncomfortable premonitory urges and abnormal sensory experiences, that appear to be related to higher tic severity, anxiety and obsessive-compulsive symptoms.<sup>7</sup> Less common features of TS include coprophenomena (swear words or rude gestures as complex tics), echophenomena (repetition of other people's words/phrases or imitation of others' gestures), and paliphenomena (repetition of the last word/syllable of a sentence or repetition of the same action, usually until it "feels right"). Although the definite etiology of TS is still unknown, there is evidence of dysfunction within the cortico-striato-thalamo-cortical pathways.<sup>8</sup> No single gene defect has yet been identified (genetic heterogeneity); however, twin and family studies have demonstrated a complex genetic contribution to the development of TS<sup>9,10</sup> acting through different neurotransmitter pathways, including the dopaminergic, serotonergic, and histaminergic systems.<sup>11</sup>

About 90% of patients with TS have a co-morbid behavioral diagnoses, most commonly attention-deficit and hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD).<sup>12</sup> Other associated conditions include depression, anxiety, autism spectrum disorder, and disruptive behavior disorders.<sup>13</sup> Both tics and behavioral co-morbidities have been shown to potentially affect health-related quality of life (HR-QoL).<sup>14,15</sup> Specifically, a recent study focusing on the transition between adolescence and adulthood showed that patients with TS and more severe co-morbid anxiety symptoms reported lower HR-QoL across all domains. These findings highlighted the impact of co-morbid anxiety on subjective well-being at a critical stage of development.<sup>16</sup> In patients with TS, tics typically reach their peak severity around the age of 10–12 years.<sup>17</sup> This period of development can be difficult for all children, even those without significant physical or mental illnesses. The onset of puberty and its associated hormonal changes, as well as social challenges such as bullying, peer pressure, shifting relationships with parents, pressure from the education system and the development of one's self-perception and role in society are all

significant risk factors that need to be considered by health professionals when assessing the role of social stigma and self-perception in adolescents with TS. The present paper provides an up-to-date review of the available literature on stigma and self-perception in adolescents with TS, with the aim of informing clinical decisions about management strategies and possible interventions to improve patients' HR-QoL.

## Stigma in adolescence

Children and adolescents who have behavioral or physical characteristics which make them "different" from the norm may be at higher risk of experiencing bullying and difficulties in socializing and may be stigmatized for their differences. Stigma is defined as a "mark of disgrace associated with a particular circumstance, quality, or person".<sup>18</sup> This may present as bullying by peers, discrimination by the educational, recreational, or workplace environment, and can be related to poor self-esteem. Unrelenting stigmatization and discrimination may lead to the development of specific psychiatric symptoms, including anxiety and affective symptoms, which can in turn result in further stigmatization and discrimination.

Psychiatric disorders are among the most stigmatized conditions in modern society, and considerably add to the burden of psychological stress on the individual, in terms of reduced opportunities and worsened symptoms.<sup>19</sup> Stigma can also act as a barrier to treatment through multiple mechanisms. Firstly, mental symptoms may be considered to be signs of weakness or character flaws, as opposed to symptoms of a medical condition. This may mean that seeking psychological support or treatment is delayed or even prevented. Secondly, there may be a degree of shame associated with mental symptoms, which may come from either the family or the sufferers themselves. Shame may also act as a barrier to seeking and accepting health-promoting interventions. Finally, there is often disparity between health care resources and funding allocated to services for physical conditions and mental health, with mental health services often receiving disproportionately less than general medical services.<sup>20</sup> Service provision for child and adolescent mental health appears to be particularly inadequate, with longer waiting times and paucity of inpatient facilities, resulting in young people being often placed a significant distance away from family at a particularly distressing time.<sup>21</sup> All of these factors may prevent a young person from seeking help, and may result in further deterioration of their condition.

Certain physical illnesses and disabilities can themselves also be a significant source of stigma, as well as poor self-perception. It has been shown that the incidence of depression is significantly higher in children and adolescents with chronic medical conditions, the strongest association being in those with chronic fatigue syndrome, fibromyalgia, cleft lip/palate, migraine, and epilepsy.<sup>22</sup> Further studies involving adolescents and young people with chronic conditions reveal that they are often reluctant to disclose their illness to peers. The main reasons behind this issue include perceptions of being seen as “different”, fear of social rejection, and concerns about “being pitied”.<sup>23</sup>

## Stigma in TS

Stigma is a difficult concept to quantify and investigate, as it is strongly related to both personal and societal factors. The scientific literature focussing on the stigma associated with both mental and physical illness is rapidly expanding, however there is a relative paucity of research looking specifically at patients with TS.<sup>24</sup> Moreover, the distinction between physical and mental illness can be blurred in a quintessentially neuropsychiatric disorder such as TS.<sup>12</sup> Young patients with TS may be at a particularly high risk of stigmatization for a number of reasons. Motor and vocal tics are difficult to conceal, and attempting to mask these symptoms often produces anxiety and uncomfortable sensory experiences, with subsequent worsening of symptoms. Furthermore, some members of the public may lack understanding of the nature of TS, and may be under the impression that symptoms are voluntary and controllable. This could lead to detrimental attitudes towards patients with TS, particularly where tics could be deemed to be acts of antisocial behavior. This is particularly relevant to patients with coprophenomena, aggressive motor tics, loud vocal tics, or other socially inappropriate actions.<sup>25</sup>

A small number of studies have evaluated attitudes toward young people with TS, mainly focussing on the attitudes of the patients’ peer group. In an early study,<sup>26</sup> a child actor performed three different recordings talking about himself: in the first one, he did not display symptoms of TS; in the second one, he displayed symptoms of TS; in the third one, he displayed symptoms of TS and provided an explanation of TS. The child actor had been trained in TS symptomatology, and his recordings had been reviewed by health care professionals, psychologists, and parents of children with TS for accuracy. This study found that the study population (schoolchildren in grades 3

and 5) rated the child not displaying symptoms of TS more favorably than the child displaying symptoms of TS. Interestingly, being given information about TS did not seem to improve the children’s attitude toward their peer. A similar study involved high-school students watching videos of peers with either motor tics or trichotillomania.<sup>27</sup> The results of this study showed that participants rated those displaying repetitive behaviors significantly lower on the social acceptance scale compared to those without symptoms.

A further study evaluated the perceptions of adolescents (average age 16.7 years) toward patients with TS.<sup>28</sup> Levels of existing knowledge about TS were considered to be “good”, as the participants had recently attended specific teaching sessions. Two-thirds of adolescents in the study recognized that levels of self-esteem were likely to be low in patients with TS, however only just over half of them stated that they would agree to sit near someone with TS in class, and the same percentage stated that they would agree to develop friendships with adolescents with TS and invite them into their home. Furthermore, over a quarter of participants stated that patients with TS should be severely punished in order to correct their disruptive behaviors. These findings are concerning, as they show that negative attitudes and significant levels of stigmatization toward patients with TS can persist despite “good knowledge” of the condition.

The attitudes and perceptions of health care students toward TS were recently evaluated in a UK-based study.<sup>29</sup> Ninety-four university students attending medical, nursing, pharmacy, and biomedical/healthcare science courses completed questionnaires concerning knowledge of TS and epilepsy, and attitudes toward patients with these conditions. Among the health care students, 22% stated that they would object to their children marrying someone with TS and 5% stated that they would not wish their child to play with someone with TS. These findings show that negative attitudes and stigmatizing beliefs are present even across members of the health care profession.

A more recent online study researching attitudes toward TS within the general public showed similar findings.<sup>30</sup> In this study, participants were exposed to either a video of a patient with TS or a neutral video of natural scenery. After watching the video, the two groups of participants were asked to complete the Stigma Attribution Questionnaire (AQ-9), with reference to a case vignette of a young man with TS. The authors found that the group who had watched the video of the

patient with TS scored significantly higher on the AQ-9 questionnaire than the control group. Furthermore, respondents with a higher educational level showed a higher degree of stigmatization towards persons with TS.

Reports of bullying and teasing are relatively common in young patients with TS.<sup>31</sup> A survey involving 69 parents/guardians of young patients with TS found that two-thirds of the children had experienced teasing, with over a quarter having been exposed to rejection because of their tics.<sup>32</sup> In a Danish study population, almost 45% of young patients with TS reported being teased, with a positive correlation between victimization and the presence of behavioral co-morbidities.<sup>33</sup> The evidence on the relationship between victimization and co-morbidity was corroborated by the findings of a large study of 740 parents of children with TS.<sup>34</sup> These findings were complemented by the results of another study, which showed that victimization rates were higher in patients with higher symptom severity.<sup>35</sup> From reviewing the limited available evidence, it appears that patients with TS are highly susceptible to negative and stigmatizing attitudes. The reviewed findings also show that educational level or existing knowledge of the condition do not appear to act as protective factors.

## Self-perception in TS

Along with other physical and mental health conditions, TS is associated with significantly poorer quality of life compared to the general population.<sup>15</sup> HR-QoL in TS is affected by a number of different factors, including tic severity, presence of behavioral co-morbidities, and social impact of the disorder.<sup>14,36</sup> Self-perception, defined as the way we see ourselves in relation to others and the world around us, is known to have a deep influence on HR-QoL. It can be defined along two domains: self-concept and self-esteem. Self-concept describes what a person thinks about themselves, whereas self-esteem refers to how someone feels about their self-concept.<sup>37</sup> High levels of self-esteem are predictive of good outcomes in both physical and mental health, as well as positive relationships, higher levels of academic achievement, and job satisfaction. Conversely, low self-esteem is related to self-contempt and lack of self-respect, negatively impacting health, work, education, and relationships.<sup>37</sup>

A small number of studies have examined the effects of self-concept and self-esteem in young people with TS, with relatively inconsistent results.<sup>38</sup> The majority of studies found that young persons with TS reported lower self-concept compared to those without TS, however others

found that there was no difference. Specifically, the results of three studies<sup>39,40,41</sup> showed that reported self-concept was significantly lower in patients with co-morbid OCD or ADHD compared to patients with TS only (“pure” TS). Other studies found little difference in reported self-concept between patients with TS and individuals without TS,<sup>42,43</sup> although interestingly in one study the patients’ mothers reported lower self-concept than the controls’ mothers.<sup>42</sup> The published literature on the relationship between TS and self-reported self-esteem is also relatively inconsistent. In a controlled study conducted in Turkey, patients with TS reported lower self-esteem than healthy controls.<sup>44</sup> Furthermore, the results of this study showed that lower levels of self-esteem were more prevalent in female patients and in patients under the age of 12. Similarly, a study of 29 young people found that patients with TS reported average self-esteem, with associated social withdrawal, aggression, and being less popular than their classmates.<sup>45</sup> In contrast, a Canadian study found that patients with TS did not consider themselves to have significant self-esteem problems. In this study, poor relationships with peers were reported by patients, particularly by those with co-morbid ADHD. Both of the latter two studies demonstrated higher levels of social problems in patients with TS, however these did not appear to be related to tics themselves, neither in terms of their severity or frequency.

Self-perception is a difficult concept to measure quantitatively, as perception and feelings about oneself are intrinsically subjective. Every patient will have different life experiences which will influence their self-perception, as well as subjective feelings about their condition. The existing studies in the literature used a variety of self-report questionnaires, predominantly the Tennessee Self-Concept Scale and the Piers-Harris Children’s Self-Concept Scale. One of the main limitations of these instruments is the use of closed questions and Likert-type scoring scales: as responses are characterized by a high degree of subjectivity, patients experiencing similar perceptions or emotions may score these differently. This limits the role of quantitative research in a research area where qualitative research may yield more robust data in terms of assessing with precision the feelings of patients with TS. Conversely, qualitative research would not allow direct comparison between groups, or enable identification of statistically significant associations.

Findings of ten qualitative studies researching the perspectives of individuals on their experiences of living with

TS were reviewed in a recent publication.<sup>46</sup> The majority of the reviewed studies on lived experiences described cultural issues and social stigma associated with TS. These problems exist across the whole spectrum of daily life, affecting education and employment, interactions with peers and organizations, and relationships. One common theme was the public perception that tic behaviors were intentional and controllable, with young people struggling to fit into societal expectations of what is deemed to be “normal behavior”. Some patients reported feeling that others perceive them as badly behaved or annoying, as well as feeling pitied or discriminated against. Difficulties in either the school or workplace environment were frequently mentioned as relevant issues by patients with TS. Reported problems included struggling with school work and difficulties keeping up with peers. These issues often lead to further worsening of self-esteem. Furthermore, a number of patients reported difficulties with attention, with tics being distracting to both the patient themselves and others in the classroom or workplace. TS can also have a negative impact on relationships, both with teachers or colleagues, and with family members or friends. A few young patients reported feeling stigmatized within their own family environment, with parents or other relatives trying to conceal or justify their tics. This is likely to have further negative impact on self-perception, and young persons with TS may feel that they need to suppress their tics, potentially resulting in an increase in uncomfortable sensory experiences and premonitory urges. Difficulties with both social and romantic relationships were described in the majority of the studies, including bullying, teasing, and feelings of isolation and loneliness.

## Potential interventions

The reviewed evidence suggests that young patients with TS are at risk of stigmatization and discrimination, two issues showing a complex interplay with self-perception and HR-QoL. The authors of a controlled video intervention study evaluated children’s attitudes toward a peer with TS before and after an intervention consisting in an information video session.<sup>47</sup> Children in the video intervention group showed greater improvements in knowledge, positive attitudes, and behavioral intentions when compared to the control group. Overall, family psychoeducation has been shown to reduce stigma toward persons with severe mental illness.<sup>48</sup>

Based on the results of the available studies, it is clear that educational material should be targeted at both

students and staff within educational settings. Moreover, it appears that it would be preferable to show examples of patients from the whole neuropsychiatric spectrum of TS. For example, the misconception that TS is a condition where the individual swears and makes inappropriate comments is unhelpfully widespread. In fact, it has been shown that only about 10–30% of patients with TS display coprophenomena.<sup>49,50</sup> It would therefore be appropriate to explain that these complex tics are reported by a minority of patients, and, when present, are a small part of a much more complex condition. The media can have both a positive and negative impact on patients with chronic illness.<sup>51</sup> Increasing and improving public awareness of TS is likely to improve understanding, and may help to dispel any previous misconceptions. However, in some cases, media depiction may be unhelpful, as inaccurate portrayals may reinforce stereotypes and thereby strengthen or worsen stigmatizing beliefs and behaviors.

As well as improving attitudes of the public toward patients with TS, specific interventions could be offered to improve patients’ own self-perception. Existing qualitative research found that patients use adaptive coping strategies to help themselves manage their own condition.<sup>46</sup> Most strategies relate more directly to tic management, including implementation of regular time breaks to allow expression of tics, or avoidance of certain social situations altogether. Often patients develop their own techniques for hiding or disguising tics (“camouflaging”). These maneuvers can be perceived as uncomfortable, with a resulting build up in premonitory urges and heightened anxiety.<sup>52</sup> It is disappointing that patients with TS feel the need to disguise their condition, as it should not be something that they feel embarrassed by. Furthermore, responsibility should not be placed on the patients to reduce the stigmatization that they are subjected to. Nevertheless, any positive impact that patients can have on their own experience of living with TS will help to improve their HR-QoL. Some patients describe using self-advocacy effectively by means of educating peers through ad hoc presentations. Allowing children and adolescents to be their own advocates within the educational setting can result in a particularly empowering experience, with positive repercussions on both self-perception and stigmatization. Others report externalizing the problem onto those who discriminate against them, with the attitude that those who stigmatize are the ones with the problem, as opposed to the patients. Such strategies could be tailored to the individuals and effectively used by patients, in conjunction with improved

education and awareness levels in the general public, to help alleviate stigma and improve their own self-perception.

## Conclusion

TS appears to be associated with significant stigmatization and poor self-perception in a significant number of cases, with negative repercussions in terms of HR-QoL. Bullying and victimization are also commonly reported by patients with TS. Further research is needed to better characterize the complex relationship between TS, poor self-perception, and stigma, as no unified causative factor has been identified to date. Clinically relevant observations indicate that patients with behavioral co-morbidities such as ADHD and OCD might be more prone to present with problems across these domains. It is also possible that the presence of other co-morbidities (that are often under-investigated) can contribute to stigma and/or poor self-perception in this patient population through complex pathways. For example, insufficient sleep or other sleep problems are known as common features in TS and other tic disorders.<sup>53</sup> It has been shown that sleep problems can lead to a significant degree of emotional distress, which in turn may contribute to stigmatization among adolescents.<sup>54,55</sup> The reviewed evidence suggests that effective interventions should take a multi-component approach, including educating both patient families and the wider public about the neuropsychiatric spectrum of TS, as well as assisting the young person in the development of adaptive coping strategies. Specifically, further work could include the implementation of targeted psychotherapeutic interventions into the care pathways of young patients with TS, alongside the development of educational programs and materials for the wider public. Specifically, significant improvements in patients' HR-QoL can be achieved through simple steps, such as provision accurate information about TS to teachers, other staff and students within the educational setting.

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