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CHILD AND DEVELOPMENTAL PSYCHIATRY (M GRADOS, SECTION EDITOR)

The Psychosocial Aspects of the Gilles de la Tourette Syndrome: Empirical Evidence from the Literature

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Abstract

Objective A literature review suggests that Gilles de la Tourette syndrome (GTS) is common but under-diagnosed and under-reported, and the consequences and impact are not fully understood. This review is focussed on the adverse psychosocial consequences experienced by many GTS patients which, in turn, cause significant distress and disadvantage to both the patients and their families.

Method A review of the literature was conducted using Pubmed and Medline under the headings Tourette, psychosocial, stigma, stress and suicide, and also, cross-references were made from relevant sources based on the authors' experience in the field.

Results Many of the difficulties of GTS are experienced within the individual (the "inner sensations"), but some are due to the loud vocal tics as well as socially stigmatising nature of some of the motor tics (e.g. spitting) and the "*possibly offensive*" copropraxia. In other instances, this may be linked to the co-morbidity (e.g. ADHD, OCD) and co-existing psychopathology (e.g. depression, conduct disorder) that occur in up to 90% of people with GTS. More quantitative research into the psychosocial aspects and sequelae of having GTS are suggested.

Conclusions Apart from managing and treating the individual with GTS in a comprehensive way, the education of the general public, teachers, doctors and employers is of vital importance to improve the psychosocial aspects of the person with GTS.

Keywords Tics · Tourette syndrome · Psychosocial · Co-morbidities · Stress · Stigma

Introduction

Whilst reflecting on the psychosocial aspects of Gilles de la Tourette syndrome (GTS), it is worth noting the history of the disorder. Both Itard [1] and De La Tourette [2] documented the case of the French noblewoman, the Marquis de Dampierre, who is a very good example of the psychosocial effects of GTS on the individual and also on society. Despite her noble status, she lived a socially isolated lonely life ostracised by society because of her symptoms and thus all the psychosocial sequelae that GTS would entail.

Thus, a good way to illustrate the subject of psychosocial issues in people with GTS may well be the stories of people with a diagnosis of GTS and also the stories of some successful people with GTS, i.e. those who overcame many psychosocial difficulties. However, relatively few individuals with GTS have documented their personal experiences. These include Joseph Bliss [3], Peter Hollenbeck PhD, a neuroscientist [4], and two physicians, Dr. Lance Turtle [5] and Dr. Sam

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Zinner [6]. All give insights into having GTS, far beyond what research can teach us.

It is to be noted that they often had late or no formal diagnoses, and they described the internal sensory experiences as the core of the "GTS internal world" that no other person [without GTS] can really fully understand. It is this internal sensory world that we must try to understand—to even try and grasp some of the psychosocial consequences of having GTS—never mind the obvious tics and coprophenomena—by which, even today, many doctors, DSM, ICD and the media erroneously "define" GTS.

The Tourette Phenotypes and the Person with GTS Living in the Social World

It is important to realise that the individual with GTS who has to interact with the society and vice versa is first and foremost a person, a whole person who just happens to have tics, some with tics only, whilst the majority (90%) also have co-morbid disorders or co-existent psychopathology, which has been demonstrated in both clinical cohorts [7] and also in community settings [8–10]. The most common co-morbid disorders are attention-deficit hyperactivity disorder (ADHD), obsessive-compulsive behaviours (OCB) and disorder (OCD) and autistic spectrum disorder (ASD), whilst the most common co-existent psychpathologies include depression, oppositional defiant disorder (ODD), conduct disorder (CD), substance abuse and personality disorders [11–15]. It is often these co-morbidities and co-existent psychopathologies ("GTS plus") that more often lead to psychosocial difficulties and adverse quality of life experiences than tics alone ("pure GTS").

It has been reported that tics only or pure GTS occurs in only about 10% of GTS cases, whilst the majority (about 90%) have GTS plus (coined by Packer 1997) with co-morbid disorders or a variety of co-existent psychopathologies [16•]. Thus, it is important to recognise and appropriately manage psychosocial difficulties due to tics per se as opposed to those arising from co-morbid disorders or both.

Psychosocial Aspects of the Actual Tics and, in Some Cases, Unusual Tics on the Individual with GTS

It may seem obvious that loud or continuous vocal/phonic tics and severe motor tics will have psychosocial consequences. The severe or unusual tics may result in the person with GTS having to keep away from other people, being excluded from a class at school or asked to leave a theatre performance: All these situations would clearly have a negative impact on the person with GTS, such as them becoming depressed and/or having a lower quality of life (QoL). Similarly, the shouting of obscenities in public will have adverse effects on the individual with coprolalia. Coprolalia occurs in approximately 20–30% of GTS clinic populations [17, 18] and only in a few members in the community samples of GTS [19]. The American Tourette Syndrome Association suggests that as few as 10–15% of all people with GTS exhibit coprolalia.

Spitting occurs in several patients with GTS, and, once again, spitting in the presence of others, especially at meal times, causes the person with GTS enormous distress and is also awkward for the people who are in their company.

Very obvious tics such as severe arm flailing are documented, although it is unclear how common they are. These patients could be viewed as "aggressive", whereas they mean no harm to others—and this would have obvious consequences on the patient and those around them.

Pain as a prominent feature of GTS is mostly due to the discomfort produced by sudden or repeated and extreme ticking (i.e. of musculoskeletal origin) but can also be due to neuropathies or at times from trying to suppress the tics [20]. Stress fractures of both peroneal bones due to complex tics [21], as well as neuropathies as a result of severe neck tics, have also been described. The pain can be treated by analgesics, but at times, patients may have to wear a neck collar or be voluntarily bound to a wheel chair to prevent any further physical injury and pain. Clearly wearing a neck collar or being in a wheel chair, in addition to the tics, further highlights the individual as "being different" from others.

Several unusual tics have been described in GTS, and these patients have had to have many *unnecessary* (with hindsight) investigations, which, in turn, increase anxiety in the patient and family and thus have adverse psychosocial consequences. Thus, vomiting [22], symptoms mimicking asthma [23], a "falsetto" voice [24], perineal touching [25] and aerophagy (air swallowing) [26], pollakiuria [27], etc., have all been described as tics, and this may be very distressing for both the patient and family.

Children with GTS may exhibit sudden and unexpected noises or movements which may have an influence on their daily activities and cause difficulties with interaction with their peers (e.g. at school). A self-report Stress Index for Children and Adolescents with Tourette Syndrome (SICATS) has been published [28], and it is hoped that this can help evaluate stress and thus help in intervention for youngsters with GTS.

The Relationships Between Psychosocial Functioning and Schooling in Young People with GTS

Numerous studies have examined the effects of GTS and particularly the association with ADHD in children. A few studies have specifically examined the schooling of youngsters with GTS [29], whilst others have compared children with GTS only, with GTS + ADHD, ADHD only and unaffected controls, e.g. [30, 31–33]. These studies have shown that GTS only patients did not differ from unaffected controls on many ratings, apart from more internalising symptoms. In contrast, children with GTS + ADHD had more psychiatric co-morbidities, higher ratings on disruptive behaviours, internalising behaviour problems and poorer social adaptation than children with GTS only or controls.

A study [9] examining locus of control (LOC), perceived maternal parenting style and symptoms of anxiety and depression in 65 children with GTS (9–16 years) found that anxiety and depression in GTS are markedly influenced by psychosocial factors, extending beyond ADHD and OCS in GTS. An internal LOC, which is associated with an accepting and autonomy-granting parenting style, appears to be a protective factor against anxiety and depression.

Other studies [70•, 71] specifically examining the psychosocial functioning and effects of ADHD and OCD as comorbid disorders within GTS have reported significantly more psychosocial problems in the youngsters with GTS than controls with a higher rate of problems occurring if ADHD and/or OCD were present.

A number of studies have found school-related issues [8, 9, 34, 35] with one study noting that the facilitation of social acceptance for a child with GTS is extremely important to successful classroom integration: It stressed the importance of teacher understanding and flexibility, as well as parent/school communication [36]. Further, school phobia (separation anxiety disorder) has been documented in youngsters with GTS as a side effect of several neuroleptic drugs especially haloperidol [37] and pimozide [38], the latter author proposing the term “neuroleptic separation anxiety syndrome” as a result.

Psychosocial Stress and Certain Infections in Young People with GTS

Some studies have invoked a role of psychosocial stress in the prediction of severity, and thus prognosis of GTS. A study by Lin et al. [39] monitored psychosocial stress levels in children and adolescents with GTS and/or OCD and found that subjects with GTS and OCD experienced significantly more psychosocial stress than did controls. The same investigators [40] undertook a longitudinal study during which they examined both group A beta-hemolytic streptococcal (GABHS) upper respiratory infections as well as psychosocial stress in children and adolescents with GTS and/or OCD and compared them to controls. Their model observed the power of psychosocial stress in predicting future tic and OCD severity, enhanced by a factor of 3. Estimates of psychosocial stress were also predictive of future depressive symptoms, and current levels of psychosocial stress and depression were independent predictors of future tic severity, even after controlling for the effect of advancing chronological age. Several other studies have [41, 42, 43, 44] reported the occurrence of depression in GTS patients, and significant correlates of depression included tic severity, older age, OCD, ADHD and childhood conduct disorder [45].

Culture (Social Environment) and Psychosocial Functioning in Young People with GTS

Culture, GTS and psychosocial functioning have, to date, only been formally studied once [46] when a consecutive series of 35 GTS patients of Arab descent ascertained from the Child Psychiatry clinics in Al Ain, United Arab Emirates (UAE), were compared to 35 age-matched and gender-matched Caucasian GTS patients attending a GTS specialist clinic in London, UK. Rates of occurrence of OCD and ADHD were similar in the two cohorts. Coprolalia was higher in the UK cohort and was correlated with the severity of GTS. Both ODD and CD were also higher in the UK cohort, but this was not linked to any other clinical feature or severity of GTS. The findings illustrate the similarity in the core clinical symptoms and associated clinical features between the two populations, thus emphasising the underlying biological and genetic basis of these symptoms. However, the higher rates of aggression and oppositional behaviours (ODD and CD) in the UK cohort were noteworthy. Although the UK cohort was chosen from a tertiary referral specialised clinic for GTS with higher mean scores for YGTSS and DCI (indicating more severe form of the disorder), the lack of association between severity and any of the variables other than coprolalia seems to suggest that severity alone cannot explain these differences. This raises the issue of environmental and other influences on the behaviour of these young people. It was suggested that other possible reasons for increased behavioural problems in the UK compared to the UAE may be due to sociocultural-religious-penal differences between the two countries. This suggests possible sociocultural influences on co-existent psychopathologies and psychosocial functioning in youngsters with GTS.

The Effects of GTS on Psychosocial Functioning in Adulthood

In order to examine the psychosocial functioning of adults with GTS, one may question the following as to how people function at school (and attain grades), obtain employment or enter and graduate from tertiary education and have successful careers, meaningful long-term friends and eventually long-term partners, marriage and children. Relatively few studies have, however, examined these aspects of GTS.

An international study [32] of 3500 GTS individuals found that 21% of males and 15% of females had problems with social skills. Eapen et al. [47] reported on a cohort of 91 adults with GTS of whom 61 (67%) were single, 21 (23.1%) were married, 4 (4.4%) were co-habiting and 5 (5.5%) were divorced. Miller et al. [48] have recently reported that people with GTS are from lower socioeconomic classes (SES). Potential explanations include differential exposure to environmental risk factors or parental psychopathology as a measure of an increased genetic risk leading to decreased parental SES.

Few studies have specifically examined psychosocial outcomes in adult patients with GTS, using specific schedules and/or different phenotypes. In this regard, Haddad et al. [49] studied 80 adult patients with GTS only and compared them to 64 with GTS + ADHD, reporting that GTS + ADHD patients had significantly more depression, anxiety, obsessive-compulsive behaviours and maladaptive behaviours (e.g. significantly more drug and alcohol abuse, aggression, forensic encounters) than patients with GTS only indicating that in adult GTS patients, psychopathology and maladaptive behaviours seem to be associated with ADHD rather than GTS per se.

Altman et al. [50] studied psychosocial outcomes in individuals with GTS using a self-report questionnaire survey of 180 adult patients and found that personal acceptance and medication use were the most important factors in coping with the disorder. In addition, the severity of vocal tics had a much greater influence on adult psychosocial functioning than did the severity of motor tics.

A longitudinal study [51] where GTS patients aged 18 years were studied at an average of 7.3 ± 3.1 years after initial clinical evaluation observed that children with GTS typically have impaired functioning as older adolescents in several psychosocial domains and high rates of co-morbid disorders compared to matched community controls. More severe tics, ADHD and OCD symptoms in childhood are associated with poorer outcomes in late adolescence.

In summary, it does appear that in adulthood, GTS continues to affect the individual, in that they are likely to be single, unemployed, rely on their families for support and continue to have behavioural difficulties and co-morbidities such as ADHD and OCD, and it also appears that vocal tics and co-morbidity are likely to be of importance in determining this. Needless to say, much of this has to do with GTS severity.

The Effects of the Physical Environment on Individuals with GTS (i.e. Environmental Stressors)

A study [52] assessing the effects of emotional stimuli on tic severity in children with GTS concluded that tics appear to be influenced differentially by various emotional states but that the effect did not seem to be autonomically mediated.

Other Predictors of Psychosocial Outcome of GTS

Bloch et al. [53] documented how fine motor skill deficits in childhood predict adulthood tic severity and also poor global psychosocial functioning in people with GTS.

Pringsheim et al. [54] undertook a nested case-control study of patients with GTS + ADHD ($n = 181$) and GTS only (controls $n = 172$). Youngsters with GTS + ADHD had a greater odd of exposure to prematurity, breathing problems, low birth weight status and maternal smoking when compared with GTS only youngsters, and after logistic regression, GTS + ADHD was particularly associated with the latter two.

Motlagh et al. [55] also determined whether or not prenatal and perinatal risk factors such as maternal smoking and severe psychosocial stress during pregnancy were associated with GTS and/or ADHD in their children. After logistic regression, compared to mothers of unaffected controls, the mothers of youngsters with ADHD alone reported higher rates of heavy smoking (>10 a day) during pregnancy and higher levels of severe psychosocial stress. The GTS + ADHD and the GTS alone also had higher rates of maternal smoking and psychosocial stress, but the differences were not statistically different.

In the Avon Longitudinal Study of Parents and Children (ALSPAC) study, Mathews et al. (2014) found that GTS was associated with prenatal and perinatal factors such as maternal alcohol and cannabis use, inadequate maternal weight gain and parity. However, this study did not find an association with low birth weight and/or maternal smoking during pregnancy.

Miller et al. [56] using the same 6768 ALSPAC study participants found that GTS and chronic tic disorder are associated with lower socioeconomic status. The authors suggested that this may be due to differential exposure to environmental risk factors or due to parental psychopathology as a measure of an increased genetic risk leading to decreased parental SES.

Aldred and Cavanna [57] in 137 adult patients with GTS observed more tic severity in unemployed patients as compared to patients in the highest socioeconomic class.

Man et al. (2014) studied 48 adult GTS patients above 40 years of age, and in comparison with those aged 25 to 39 years, the former group had more social impairment and an uneventful forensic history and past alcohol abuse as well as higher rates of anxiety and depression.

Eysturoy et al. [58] in a study of 314 children with GTS observed that children with genetic predisposition had more severity, co-morbidities and psychosocial and educational difficulties than those with GTS and no genetic predisposition.

Espil et al. [59] based on parental perception of tic frequency and intensity found that both frequency and intensity predicted tic-related functional impairment in several domains including family and peer relationships, school interference and social endeavours, even when controlling for the presence of co-morbid anxiety symptoms and ADHD status.

In a study [60] of Australian parents of young people with GTS, strong relationships emerged between adverse quality of life outcomes and insecure attachment to peers, increased tic severity and the presence of comorbid disorder. The same authors [61] found significantly increased levels of symptoms of conduct and mood disorders in GTS youngsters as compared to peers without GTS and showed significantly higher rates of problems in peer relationships, difficulty making friends, stigmatisation and lower levels of social functioning for the GTS group, with higher rates of neuroticism acting as a significant barrier to friendship for individuals with GTS [62]. Parents also reported shortcomings in health and education services with low levels of understanding of GTS by health professionals, and half of the sample reported stigmatisation. The study confirmed the challenges confronting youth with GTS and highlighted the need for increased awareness and education for both professionals and the wider community [63]

Hesapçıoğlu et al. [64] studied 57 patients aged between 6 and 16 years who were diagnosed with chronic tic disorder and 57 age-matched and gender-matched controls and found GTS patients to have lower self esteem, particularly in females below 12 years of age, and that lower self esteem was associated with lower quality of life.

In summary, it appears that GTS + ADHD is significantly associated with prenatal and perinatal risk factors and lower socioeconomic status and also higher levels of severe psychosocial stress leading to insecure attachment, peer relationships and stigmatisation.

The Length of Time from Onset to Diagnosis

It is a matter of concern that there is often a lag between age at onset of GTS and age at diagnosis. This can have several consequences including the parents blaming themselves for the child's behaviour or problem or the professionals even accusing the parents of bad parenting. Both of these situations clearly will have adverse psychosocial consequences for the whole family. Examples of the lag include those of Robertson et al. [17] in which the age at onset of 90 GTS patients was 7 years (SD 2.9), whilst the age at diagnosis of GTS was 21.5 years. On the other hand, Freeman et al. [7] reported on 3500 individuals in an international study, and although 93% were symptomatic by the age of 10 years, only 16% of individuals were not diagnosed until adulthood. The results of the two papers published only 12 years apart certainly is a reflection of both public and professional knowledge about GTS having increased enormously during this period.

Effect of GTS on the Person, Social Functioning and the Quality of Life in People with GTS

One of the earliest studies in the area was conducted by the Canadian Tourette Syndrome Foundation which indicated that whilst 30% of respondents reported some problems in coping, more than 50% rated their mental health as good or excellent [65]. Many studies have relatively recently emerged documenting the QoL of individuals with GTS. As would be anticipated, an individual with severe tics and in addition with added co-morbid disorders may be expected to have negative effects of their GTS on their lives. In this regard, Erenberg et al. [66] reported that 88% of their GTS patients reported that tics had interfered with their lives. Others have reported that patients with GTS were in a lower social class than their parents [17, 67] and had high unemployment rates [68]. Cooper et al. [69] reported in a controlled study that parents of youngsters with asthma were statistically significantly more ethnically diverse and of a higher social class than those with GTS

Several studies recently have examined the QoL and related issues in GTS which was the subject of a recent review, and, in general, they indicate that QoL is reduced in GTS and that the co-morbid disorders (OCB, OCD, ADHD) and coexistent psychopathology (anxiety, depression) all adversely affected the QoL [70•]. A recent study [71] further confirmed this in that having three or more co-morbidities, and in particular ADHD, and the presence of coprophenomena were noted to be significant predictors to negative health-related QoL. Thus, whilst tics are the defining feature of GTS, it appears that it is the presence of co-morbidities that have a greater impact on course, outcome and health-related QoL. Further, GTS has been found to be associated with significant differences in aspects of QoL related to home and social activities, involving peer and family interactions. In conclusion, although social aspects of QoL may be more vulnerable to GTS in general, co-morbid conditions make an important contribution in determining which aspects of QoL are most affected in the individual.

Parenting Stress, Caregiver Burden and GTS

The first to examine this aspect of GTS were Hubka et al. [72] who evaluated the impact of GTS on the family. Results showed that 58.5% of the respondents indicated that having a person with GTS in the family interfered to some extent with the rest of the family's daily activities. Thereafter and almost 20 years later, Lee et al. [73] assessed the stress of parents and its influencing factors in caring for children with GTS and found that the greatest predictors of parenting stress, explaining 42% of the total variance, were GTS severity and family income [73].

Cooper et al. [69] then reported the first controlled study when they evaluated caregiver burden and GTS and also examined parents for psychopathology, using a structured interview and other schedules. Parents of children with GTS experienced greater caregiver burden, with 76.9% achieving "caseness" on the General Health Questionnaire [GHQ-28] compared with 34.6% of the parents of children with asthma; this effect remained significant after controlling for demographic variables. The authors concluded that parents of children with GTS are at risk of psychiatric morbidity; they suggested that an intervention targeting caregiver burden might be helpful in reducing this.

Robinson et al. [74] reported findings from secondary analysis of data from the 2007 National Survey of Children's Health (USA). Parents of youngsters with GTS were significantly more likely to fall into the "parenting aggravation index" category compared with parents of youngsters without GTS. Similarly, Sukhodolsky et al. [66] observed that aggression and delinquency scores added unique contributions to impairment in social and family functioning, controlling for age, gender and diagnostic status. Pringsheim et al. (2009) [54] reported that children with GTS + ADHD ± OCD experience impairment in all aspects of psychosocial health. For children with GTS only, psychosocial health was not different from that of the normative population in the majority of domains tested. This suggests that treatment of ADHD and OCD should be the priority in children with multiple diagnoses.

Non-Obscene Socially Inappropriate Behaviours and Self-Injurious Behaviours in GTS and Psychosocial Functioning

A collaborative study between two dedicated GTS clinics suggested that non-obscene socially inappropriate (NOSI) behaviours were common with approximately a third of patients having resultant social difficulties [75].

As with NOSI, self-injurious behaviours (SIB) pose another problem to the individual with GTS and are a typical and characteristic behaviour, encountered not only in between 14 and 60% GTS clinic patients [7, 76, 77] but also those mildly affected with GTS such as in family members [19].

Of importance with SIB encountered in GTS is that these are deliberate acts, but the intention of the individual is neither to die nor to actually harm themselves (e.g. wrist cutting): They just "have to" punch their face, press their eye or bang their heads. This is in broad contrast to deliberate self-harm (DSH), suicide attempts and actual suicide—which occur within people with typically different psychopathologies such as people with personality disorders (DSH) and severe major depressive illness or psychosis (suicide).

The Law or Forensic Aspects of Having Tourette Syndrome

Given that some of the symptoms of GTS include coprolalia (10–15%), copying others (echolalia and echopraxia), spitting, NOSI, SIB, rage attacks and hitting others, it is surprising that relatively little is documented about GTS and the law.

In an early paper, Robertson et al. [17] documented how some patients with GTS had inappropriate sexual behaviours out of a cohort of 90 individuals (both adults and youngsters). Robertson et al. [17] also documented that 28/90 GTS patients had been physically aggressive to other people, animals and property. Freeman et al. [7] subsequently reported in a large international study including 3500 patients with GTS that 6% of males and 4% of females had sexually inappropriate behaviours.

Gullucayir et al. [78] discussed an individual with GTS who was evaluated to consider his criminal responsibility after swearing at a referee during a football game. As is well known, GTS is often co-morbid with ADHD, and there has been a substantial literature on individuals with ADHD and increased encounters with the law [79]. Further, Robertson et al. [80] studied a cohort of 578 consecutive patients with GTS and found that 14.5% had CD and that the presence of CD was related to the presence of ADHD, as well as, and importantly, a family history of aggressive and violent behaviour and forensic encounters.

As there is a substantial literature suggesting that people with ADHD are at risk of substance and alcohol abuse and, indeed, crime, it is suggested that it is the GTS individuals with associated disorders such as ADHD in the main and probably not GTS alone that renders them at risk for legal difficulties.

Suicide Deliberate Self-Harm in People with GTS

Probably the "worst" psychosocial "outcome" of a disorder is that an individual is so distressed by the disorder and its consequences that they commit suicide.

The first report was by Riddle et al. [81] who documented a fluoxetine overdose in an adolescent. Thereafter, the authors' group [45] documented two cases of GTS patients who committed suicide (one in UK and one in the Netherlands). Further, Dávila et al. [82] reported three successful completed suicides (CS, a fatal self-inflicted destructive act with explicit or inferred intent to die) and seven attempted suicides. The group [82] also reviewed the literature (1966–2009), reporting a further one case of suicide and six attempted suicide. Thereafter, there have been a few more reports [83]. In a recent study [84] of 196 young people aged 6 to 18 years, 19 youths with chronic tic disorder (9.7%) reported to have experienced suicidal thoughts and/or behaviours frequently in the context of anger and frustration and was associated with tic severity, tic-related impairment as well as OCD, ADHD, depression and anxiety severity. This was significantly elevated compared to three youths (3%) who experienced these thoughts in a community control sample of 100 youths of the same age (*P* = 0.03).

Other Psychosocial Difficulties and Consequences Associated with Having GTS

Rage attacks have been described in about 23–40% of GTS patients with one study [85] observing that rage was the most "worrying" factor in GTS which affected the attitudes of others towards people with a diagnosis of GTS and invariably resulted in family, social and peer difficulties.

Psychosocial difficulties may also arise from the unpleasant side effects of medication prescribed for GTS including an increase in weight, cognitive dulling, dyskinesias and feeling drugged [86].

Self-Concept, Self Esteem and the Understanding of Disability in People with GTS

Edell-Fisher and Motta [87] who investigated self-concepts in GTS indicated that, whilst the mothers of GTS children had lower self-concept than the control mothers, the children with GTS were no different to the control children.

Thibert et al. [88] then examined 98 Canadian adults with GTS and found that those with high OC symptoms, but not GTS alone (pure tics), had significantly lower self-concept than the general population.

Pringsheim et al. [54] attempted to understand how children with GTS with or without ADHD and OCD experienced disability and found that the most significant predictor of the psychosocial summary score was ADHD symptom severity. For the children with GTS only, the psychosocial health was not different from the normative population in the majority of domains tested.

Attitudes of the Public, Stigma Towards People with GTS

With reduced QoL and also obvious tics in many cases and disruptive behaviours in many people with GTS, one would assume that people with GTS may well be vulnerable to stigmatisation, but public attitudes to GTS have seldom been studied.

Friedrich et al. [89] in a study randomly assigned grade 3 and 5 students to one of three conditions, no GTS, GTS or GTS/information, and found that, on the attitude measure, children rated the peer presented with GTS less positively than they did the peer presented without GTS, and providing information about GTS did not affect ratings.

Wang and Kuo [90] documented that the single most important factor affecting young people (aged 6–12 years) with GTS was the *understanding and acceptance* of their family, friends and teachers towards GTS.

In an elegant treatise, Davis et al. [91] note that "Nothing so clearly or inevitably reveals the inner man [sic] than movement and gesture…the moment you move you stand revealed, for good or ill, for what you are" (Doris Humphrey, The Dance Notebook 1984). Acknowledging the fact that people with GTS have something [movements] "beyond normal", they examined the ways that people with GTS were perceived in public spaces, using published illness narratives and film documentaries to address the questions as to why the reactions to GTS by the public were so severe (e.g. by being "disruptive" to the health and order of public spaces). They specifically analysed the mechanisms of stigma formation produced by the complex relationships between the functioning of social spaces and the individuals' experiences of them.

Brook and Boaz [92] studied 99 pupils with a mean age of 16.7 years, observing that tolerant attitudes increased with advancing age and school grades. The attitudes were also more positive and comprehensive in families in whom someone suffered from emotional or psychiatric difficulties. However, 27% felt that the "GTS behaviours" should be punished, and a quarter felt that the police should be involved. On a better note, 56.6% were willing to make friends with a person with GTS.

Conelea et al. [93] explored the impact of GTS on youth during the Tourette Syndrome Impact Study in a "virtual community sample" (web-based internet survey completed by families with children who had GTS or chronic tics) of 740 parents and 232 of their children (aged 10 to 17 years). Results showed that a notable portion of youth with GTS experienced discrimination due to tics.

Zinner et al. [94] explored the associations between peer victimisation in youth with GTS and chronic tic disorders using the Internet Based Omnibus GTS Impact Survey, referred to earlier. Data from 211 eligible youth respondents and their parents/guardians showed that 26% reported peer victimisation. Victim status was associated with greater tic frequency, complexity and severity, explosive outbursts, internalising symptoms and a lower QoL.

Katona [95] examined knowledge of and attitudes to GTS and to epilepsy using a questionnaire survey in health-care students at one UK medical school. Results showed that 26% of medical students studied would object to having a son or daughter of theirs marry a person with GTS and 19% of people would object to the marriage of one of their children to a person with epilepsy indicating significant negative attitudes towards people with GTS.

The Scale of the Problem of the Psychosocial Aspects of GTS

GTS is now recognised to be common, affecting approximately 1% of the population [96, 15, 97, 98], and it is important that there is better understanding and tolerance towards individuals with GTS. In this regard, Lagiewka-Cook et al. [99] described a novel way to counteract the ignorance about GTS to members of the education profession, teachers and the general public by giving audiovisual presentations about the history, psychosocial aspects, educational aspects, symptomatology and treatment of GTS throughout the state of Manitoba in Canada. Further, McGuire et al. [100] used Living with Tics (LWT) treatment program in 24 youth (7–17 years) GTS and chronic motor tic disorder patients with psychosocial impairment and noted treatment gains such as reduced clinician-rated tic impairment and improved child-rated quality of life. In many countries, there are now Tourette Syndrome Associations or the equivalent, and one of the main *raison d'etres* is public education, tailored to fit the communities in each country.

Conclusions

It is clear that GTS is common, and the psychosocial consequences are also common. Many of the difficulties of GTS are experienced within the individual (e.g. Bliss', Hollenbeck's and Turtle's "inner sensations"), but many are due to the obvious loud vocal tics and the obvious motor tics such as the "*possibly offensive*" copropraxia. Others are due to the co-morbidity which occurs in 90% of people with GTS. Apart from managing and treating the individual with GTS (be it with behavioural methods, medications or even DBS), the *education* of the general public, teachers, doctors and employers is of vital importance to improve the psychosocial aspects of the person with GTS. As to the aetiology or causes of the psychosocial difficulties, these may be GTS related (e.g. violent motor tics, loud vocal tics, spitting, coprophenomena), co-morbidity related (e.g. ADHD, OCD) or indeed generic causes (e.g. generic causes of stress and aggression which leads to difficulties). More quantitative research into the psychosocial aspects and sequelae of having GTS are suggested.

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Compliance with Ethical Standards

Conflict of Interest Dr. Mary May Robertson and Dr. Valsamma Eapen declare that they have no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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