



## On being your own worst enemy: An investigation of socially inappropriate symptoms in Tourette syndrome



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### ABSTRACT

Non-obscene socially inappropriate symptoms (NOSIS) in Tourette syndrome (TS) include urges to make insulting remarks about a person's physical characteristics (e.g. "big nose") and other socially disruptive behaviors (e.g. shouting "bomb" at an airport). We aimed to explore the characteristics of NOSIS in TS, and determine whether individuals who experienced NOSIS reported differences to those who did not in terms of quality of life (QoL) and common clinical symptoms. Finally we aimed to identify significant predictors of the presence of NOSIS. Patients were sixty patients with TS from a specialist outpatient clinic. They completed clinical measures assessing NOSIS, QoL, tic severity, premonitory urges for tics, depression, anxiety, obsessions and compulsions, attention problems, coprophenomena and conduct problems. Two-thirds of our sample admitted experiencing urges to make socially inappropriate remarks and/or carry out socially inappropriate actions. However, not all urges led to actions. Obsessions, attention problems, coprolalia and conduct problems were all significantly more common in patients with NOSIS than those without. Moreover, the presence of NOSIS was associated with significantly poorer QoL, and higher scores on measures of tic severity, obsessive-compulsive symptoms, attention problems and premonitory urges. However, only the presence of coprolalia and severity of obsessive-compulsive symptoms and premonitory urges were significant predictors of the presence of NOSIS. Our findings may imply that elevated self-consciousness and obsessionality could comprise risk factors for the development of NOSIS. As NOSIS exert a specific detrimental impact on QoL, these symptoms should be employed as a marker of therapeutic efficacy.

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### 1. Introduction

Non-obscene complex socially inappropriate symptoms (NOSIS) include urges to make insulting remarks about a person's physical characteristics (e.g. "big nose") and other socially disruptive behaviors (e.g. shouting 'bomb' at an airport). Importantly, their definition does not include the involuntary use of obscene language or gestures (coprolalia/copropraxia), which can also be present in patients with Tourette Syndrome (TS). NOSIS are portrayed as a core symptom associated with TS throughout popular culture and have sparked interesting debate on the subject of desire, free will and moral responsibility (Schroeder, 2005).

NOSIS were first defined and systematically described by Kurlan et al. (1996), who surveyed 87 adolescent or adult patients with TS

about the presence, characteristics, and functional impact of socially inappropriate behaviors. Reported NOSIS included insulting others (22%), making other socially inappropriate comments (25%), and socially inappropriate actions (14%). Sometimes these urges were effectively suppressed, and the actual behavior was not performed. Thus the number of patients reporting urges to perform behaviors within these three categories was slightly higher (30%, 26%, and 22%, respectively). The authors of this landmark study further explored the different settings in which NOSIS occurred, and the social difficulties which commonly resulted from them. They concluded that NOSIS were both frequent and potentially socially disabling. Indeed, such symptoms may help explain reports of social avoidance and discrimination in TS (Conelea et al., 2013). Despite this, there have been very few (if any) studies which have further explored the nature or impact of these intriguing symptoms in patients with TS. While factor analytic studies have included other complex socially inappropriate symptoms such as coprophenomena and self-injurious tics (Cavanna et al., 2011; De Groot et al., 1995) the clinical correlates of NOSIS are rarely considered.

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Socially inappropriate behaviors may fall within the wider category of externalizing behavioral problems. Externalizing behaviors are often seen in children with TS and can negatively impact social interaction and peer relationships (Bawden et al., 1998; Dykens et al., 1990), along with quality of life (QoL) in general (Cutler et al., 2009; Eddy et al., 2011; Elstner et al., 2001; Jalenques et al., 2012). Furthermore, as NOSIS can be disruptive, destructive and antisocial, they may encourage sufferers to be labeled as having conduct disorder or even autistic spectrum disorders, as socially inappropriate behaviors could be assumed to result from deficits in theory of mind (the understanding of people's mental states). Further investigation of these symptoms is needed in order to reduce the likelihood of inaccurate assumptions which could have negative implications for individuals who have NOSIS. Moreover, the presence of NOSIS may have a direct impact on QoL, and this has yet to be investigated.

This study had three aims. The first was to establish the prevalence of NOSIS in a group of patients seen at a specialist outpatient clinic for adults with TS and characterize the nature of these symptoms. Secondly, we aimed to explore whether individuals with TS who experienced NOSIS reported differences to those who did not have NOSIS across a range of clinical variables, including QoL and the severity of tics, premonitory urges, depression, anxiety, obsessions, compulsions and attention problems, and the presence of coprolalia, copropraxia and conduct problems. Finally, we aimed to determine whether any of the aforementioned variables were significant predictors of the urge to perform socially inappropriate behaviors.

## 2. Method

The study was approved by South Birmingham NHS Research Ethics Committee and carried out in accordance with the Declaration of Helsinki. Participants were recruited consecutively from an outpatient specialist TS clinic. All had been diagnosed with TS by an experienced neurologist (AEC) and screened using the National Hospital Interview Schedule for TS (Robertson and Eapen, 1996). Participants gave written informed consent to participate and were tested in the outpatient clinic. Data were collected for the eight measures described below.

### 2.1. NOSIS questionnaire

This questionnaire (Kurlan et al., 1996) records the presence of coprolalia, mental coprolalia, symptoms of other conditions commonly co-morbid with TS (e.g. obsessive compulsive disorder, attention deficit-hyperactivity disorder) and the presence and nature of NOSIS. All participants were given the option of answering questions in private. The difference between coprolalia (swearing tics) and NOSIS (socially inappropriate behaviors not including obscene features) was clearly explained. Furthermore, the NOSIS questionnaire offers examples of these different types of socially inappropriate urges. The questionnaire contains 3 sections which ask a range of similar questions about the existence and nature of socially inappropriate urges in terms of insults, other socially inappropriate remarks and socially inappropriate actions. Most of the questionnaire is in multiple choice format. For example, patients are asked whether they try to suppress urges or cover them up, how often the urges/acts occur, in what contexts they occur and what kind of problems they have led to.

### 2.2. Yale global tic severity scale (YGTSS)

This clinician rated instrument (Leckman et al., 1989) provides a measure of the overall severity of tics. Motor and vocal tics are scored in terms of tic number, frequency, complexity, intensity and

interference. Impairment is then scored and can be added to provide a score out of 100.

### 2.3. Premonitory urge for tics scale (PUTS)

The PUTS (Woods et al., 2005) includes 9 items designed to measure sensory and mental phenomena associated with premonitory urges linked to tics. Higher scores reflect greater frequency and/or intensity of premonitory urges.

### 2.4. Obsessive compulsive inventory-revised (OCI-R)

This self-report scale (Foa et al., 2002) can be used to assess the severity of obsessive compulsive disorder (OCD) symptoms. It contains 18 questions responded to using a 5-point Likert scale with higher scores indicating more severe OCD.

### 2.5. Adult ADHD self-report scale (ASRS)

The original scale contains eighteen questions used to assess attention deficit-hyperactivity disorder (ADHD) symptoms in adults. The subset of six questions used in the current study has been shown to outperform the full scale in diagnosing ADHD (Kessler et al., 2005).

### 2.6. Hospital anxiety and depression scale (HADS)

The HADS (Zigmond and Snaith, 1983) contains 14 items, half of which relate to depression, and half of which measure anxiety. In the current study we used the totals for each subscale.

### 2.7. The motor tic, obsessions and compulsions, vocal tic evaluation survey (MOVES)

This 20-item self-report instrument (Gaffney et al., 1994) assesses five domains specific to TS (motor tics, vocal tics, obsessions, compulsions, and tic-related symptoms such as copro-, pali-, and echophenomena).

### 2.8. Gilles de la Tourette syndrome quality of life scale (GTS-QoL)

This self-report disease specific instrument was developed to measure health-related QoL in patients with TS (Cavanna et al., 2008b). It contains 27 items, and lower scores indicate better QoL.

## 3. Results

Participants were 60 patients (37 males), of mean age 33 years (SD = 14, median = 28, range = 17–67), mean duration of TS 25 years (SD = 14, median = 21, range = 6–61). YGTSS scores (tic score plus impairment score) for the whole sample were mean 52.2/100 (SD = 14.50, median = 54.5, range = 18–80) indicating moderate severity (tic score only values: mean = 25.67, SD = 7.88, median = 29, range = 9–45). 35 patients exhibited uncomplicated TS. Co-morbid diagnoses were as follows: OCD  $n = 11$ ; ADHD  $n = 4$ ; OCD + ADHD  $n = 3$ ; depression  $n = 3$ ; anxiety disorder  $n = 2$ ; bipolar disorder  $n = 2$ . Thirty-eight patients were taking medication for TS and related co-morbid symptoms. These were aripiprazole ( $n = 12$ ), clonidine ( $n = 11$ ), risperidone ( $n = 5$ ), citalopram ( $n = 4$ ), sulphiride ( $n = 3$ ), fluoxetine ( $n = 3$ ), sertraline ( $n = 3$ ), haloperidol ( $n = 2$ ), quetiapine ( $n = 2$ ), olanzapine ( $n = 2$ ), venlafaxine ( $n = 2$ ), pimozide ( $n = 1$ ), tetrabenazine ( $n = 1$ ), clomipramine ( $n = 1$ ) and methylphenidate ( $n = 1$ ). Thirteen patients were on polymedication.

A subgroup of 40 patients (28 males, 12 females; age: mean = 28.7, SD = 13.5, median = 28, range = 18–67 years; YGTSS

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