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Sleep-Related Problems in Youth with Tourette's Syndrome and Chronic Tic Disorder

Eric A. Storch[1,2], Vanessa Milsom[3], Caleb W. Lack[4], Steven L. Pence Jr.[1], Gary R. Geffken[1,2], Marni L. Jacob[1], Wayne K. Goodman[1] & Tanya K. Murphy[1]

[1]*Department of Psychiatry, University of Florida, Florida, FL32610, USA. Email: estorch@psychiatry.ufl.edu*
[2]*Department of Pediatrics, University of Florida, Florida, FL32610, USA.*
[3]*Department of Clinical and Health Psychology, University of Florida, Florida, FL32610, USA.*
[4]*Department of Behavioral Sciences, Arkansas Tech University, Russellville, Arkansas, 72801, USA*

This study reports the prevalence and symptom correlates of sleep related problems (SRPs) in a sample of young people with Tourette's Syndrome (TS) or Chronic Tic Disorder. Fifty-six young people (and one of their parents) with a tic disorder were administered the Yale Global Tic Severity Scale. Children completed the Pediatric Quality of Life Inventory and Multidimensional Anxiety Scale for Children. Parents completed the Pediatric Quality of Life Inventory – Parent Proxy and Child Behavior Checklist. Overall, SRPs were widely endorsed, with 80.4% experiencing at least one SRP and 19.7% experiencing four or more. SRPs were negatively associated with quality of life and positively associated with internalising and externalising behaviours. Children with comorbid anxiety disorders had more SRPs than those without. We conclude by recommending that SRPs be assessed in young people with tics (particularly when comorbid anxiety is present), and highlight the role of psychotherapeutic and pharmacological intervention in reducing SRPs.

Key Practitioner Message:

- Sleep related problems (SRPs) are relatively common in young people with tic disorders and suggest the need for SRPs to be included in the comprehensive assessment and management of young people with tics
- SRPs were positively linked to both anxiety and internalising and externalising behaviours and negatively related to child- and parent-rated quality of life
- Should SRPs be present and clinically meaningful, treatment per evidence-based guidelines may be warranted

Keywords: Tourette's syndrome; sleep; tics; assessment; anxiety

Introduction

Sleep-related problems (SRPs) are surprisingly widespread among children and adolescents (Anders & Eiben, 1997; Meltzer & Mindell, 2006) and encompass a wide range of difficulties, including nightmares, nighttime phobias, trouble initiating or maintaining sleep, and difficulty sleeping alone or away from the home (Alfano, Ginsburg & Kingery, 2007; Fallone, Owens & Deane, 2002). Not surprisingly, SRPs have been linked to impaired functioning in academic, social, and interpersonal arenas (Beebe et al., 2004; Mindell, Owens & Carrskadon, 1999) and are predictive of poor psychosocial adjustment later in life (Gregory & O'Connor, 2002; Gregory et al., 2005). In identifying populations that may be at risk for SRPs, reviews suggest that SRPs are common among children and adolescents with emotional and behavioural difficulties (Ivanenko, Crabtree & Gozal, 2004), with specific studies linking SRPs to diagnoses of paediatric anxiety disorders (Alfano et al., 2007), depression (Gregory and O'Connor, 2002), and obsessive-compulsive disorder (Bobdey et al., 2002; Storch et al., in press b).

The presence of SRPs has also been noted among children with Tourette's Syndrome (TS), a neuropsychiatric disorder characterised by the occurrence of at least one vocal (phonic) tic and multiple motor tics (American Psychiatric Association, 2000). In addition to tics, TS in children and adolescents is associated with a number of co-occurring clinical features, including disruptive behaviour (Budman et al., 2000; Sukhodolsky et al., 2003), mood and anxiety disorders (Carter et al., 2000; Coffey et al., 2000; Coffey & Park, 1997; Robertson et al., 2002), social and interpersonal difficulties (Carter et al., 2000; Kurlan et al., 1996; Storch & Lack et al., 2007; Storch et al., in press a), and learning

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disabilities (Comings & Comings, 1985; Robertson, Trimble & Lees, 1988). The majority of studies examining SRPs among patients with tic disorders have utilised adult samples. For example, among adults with TS, studies utilising standard full-night polysomnography have demonstrated decreased sleep quality (i.e., lowered sleep efficiency and slow wave sleep percentage, and higher sleep latency, awakenings, and sleep stage changes) and increased sleep-related non-tic movements (Iranzo, 2001; Silvestri et al., 1995), including periodic limb movements (Voderholzer et al., 1997). Cohrs and colleagues (2001) similarly used polysomnography to examine the effect of symptom severity (assessed via the Tourette's Syndrome Severity Scale) on sleep quality and movement patterns among 25 adult TS patients (*mean age* = 29 years). Results demonstrated that increased symptom severity was significantly associated with sleep disturbances, including increased awakenings and sleep stage changes and decreased sleep efficiency.

Although few studies have been conducted among paediatric samples, initial evidence suggests the SRPs are prevalent among young people with tic disorders. For example, in a sample of 48 young people with TS (*mean age* = 11.2 years), 13 (27.1%) reported SRPs, including poor sleep efficiency, frequent arousals, sleep talking and walking, nightmares, and difficulty initiating sleep, rates that exceed those in non-clinical samples (Saccomani et al., 2005). Further, a polysomnography study conducted among 17 unmedicated children with TS (*mean age* = 11.1 years) illustrated impaired sleep efficiency, including longer sleep time and sleep latency as well as difficulty with sleep initiation (Kostanecka-Endress et al., 2003).

Whilst a number of investigations have demonstrated that sleep-related problems are associated with tic disorders, no studies in young people have examined the specific relationship between sleep-related problems and symptom severity (i.e., increased tic frequency and impairment) in a sample of young people with tics. Information about the presence of SRPs in young people with tic disorders may guide targeted assessment, as well as sleep intervention efforts. Thus, the primary aim of the current study is to determine whether SRPs among young people with tic disorders are associated with tic symptom severity, anxiety, internalising and externalising behaviour problems, and child and parent-proxy ratings of quality of life. Secondary aims of this study were: (a) to examine if the frequency of SRPs varied by gender or age; and (b) to examine if young people with comorbid anxiety disorders experience more SRPs relative to young people with tics and no comorbid anxiety disorders.

Method

Participants

Fifty-six children and adolescents (16 females) with TS or Chronic Tic Disorder (CTD) participated in this study.[1] Participants represented consecutive referrals to a university based clinic for pharmacological or behavioural treatment of tics. The age range of the sample was 7 to 17 years old (M = 11.46 ± 2.63 years) with an ethnic distribution consisting of Caucasian (96.4%) and Hispanic American (3.6%). A board certified child psychiatrist with 12 years of experience made TS or CTD and comorbid diagnoses in accordance with the *Diagnostic and Statistical Manual of Mental Disorder – Fourth Edition – Text Revision* (DSM-IV-TR; American Psychiatric Association, 2000) by using best estimate procedures recommended by Leckman and colleagues (1982). Considered the gold standard diagnostic method, best estimate diagnostic procedures integrates all available clinical data, which in this study includes data from the Yale Global Tic Severity Scale (YGTSS; Leckman et al., 1989), a semi-structured clinical interview with the psychiatrist, and responses to other measures (e.g. Child Behavior Checklist, Tourette's Disorder Scales). A licensed clinical psychologist confirmed all diagnoses based on a discussion of symptoms with the psychiatrist and review of quantitative data. In the rare instance that a disagreement took place, this was resolved through discussion; in the infrequent instance that this was not possible, the final decision was made by the psychiatrist. Comorbid diagnoses, when present, consisted of the following: Attention Deficit Hyperactivity Disorder (n = 26), OCD (n = 24), Major Depression (n = 6), Generalised Anxiety Disorder (n = 7), Oppositional Defiant Disorder (n = 6), Social Phobia (n = 2), Asperger's Disorder (n = 3), and Panic Disorder (n = 1). Fifteen young people had only one comorbid disorder, while 25 of the young people had multiple comorbidities.

Measures

Yale Global Tic Severity Scale. The clinician-rated YGTSS (Leckman et al., 1989) provides an assessment of motor and phonic tic severity over a one-week interval. The interviewer first records the presence of motor and phonic tics after an interview with the child and parent. Thereafter, motor and phonic tics are separately rated on the dimensions of: number, frequency, intensity, complexity, and interference (10 items in total). A one-item impairment rating is also included that captures distress and impairment in interpersonal, academic, and occupational realms that is related to tic severity. The YGTSS yields five scores (Total Motor Tic Score, Total Phonic Tic Score, Total Tic Score, Overall Impairment Rating, and Global Severity Score). The YGTSS has shown strong psychometric properties including excellent internal consistency, inter-rater reliability, and 7-week stability (Leckman et al., 1989; Storch et al., 2005), a stable factor structure (Storch & Murphy et al., 2007), positive correlations with other measures of tic severity, and weak correlations with measures of divergent constructs (depression, anxiety; Leckman et al., 1989; Storch et al., 2005).

Pediatric Quality of Life Inventory. The Pediatric Quality of Life Inventory version 4.0 (PedsQL; Varni, Seid & Rode, 1999) contains 23-items that measure four quality of life domains, including: physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five

[1]The gender imbalance found in this study (approximately 3:1 in favor of males) is consistent with the literature supporting the strong male preponderance in childhood tic disorders (Jin et al., 2005; Swain et al., 2007).

items). These scales are combined to yield physical (equivalent to the physical functioning domain), psychosocial (sum of emotional, social, and school functioning domains), and total health scales (all four domains). Widely used to assess paediatric quality of life, considerable clinical data support its psychometric properties (Bastiaansen et al., 2004; Varni et al., 2003; Varni, Seid & Kurtin, 2001).

Child Behavior Checklist. The 118-item Child Behavior Checklist (CBCL; Achenbach, 1991) was used to assess the parent's perceptions about the frequency and severity of behavioural and emotional problems in their child over the past six months. Items are rated on a 0–2 scale anchored by 0 = 'Not True' and 2 = 'Very True or Often True.' Eight syndrome scales (withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent behaviour, and aggressive behaviour) are included within the CBCL; two composite, higher order scales are also derived that reflect overall externalising and internalising problems. Only the two composite scales were used in this study. Widely used and studied, the CBCL has well-accepted psychometric properties (Achenbach, 1991).

Multidimensional Anxiety Scale for Children. The Multidimensional Anxiety Scale for Children (MASC; March et al., 1997) is a 39-item, child-report measure of anxiety symptoms. Items are rated on a 4-point scale with higher ratings/scores indicating more severe anxiety. The MASC has demonstrated strong psychometric properties, including good internal consistency, test-retest reliability, and construct validity (March et al., 1997, March, Sullivan & Parker, 1999).

Sleep Related Problems. Based on the work of Alfano et al. (2007), a composite measure of SRPs was created using six items from the CBCL and one item from the MASC. Given that these two measures differ in response format, responses were recoded so that any positive endorsement of an SRP (i.e., rating of '1' or '2' on the CBCL, rating of '1,' '2,' or '3' on the MASC) was recoded as '1.' '0' ratings were not recoded. These seven items were summed to create a composite SRP score. Cronbach's alpha for this index was .47.

Procedures

All study procedures were approved by the University of Florida Institutional Review Board. During their clinic visit, a research assistant approached all eligible subjects.. They were informed that participation was voluntary, confidential, and involved $5 compensation given to the child. The vast majority of families who were approached agreed to participate (91%).

After obtaining appropriate written consent from the parent and assent from the child, the nature of motor and phonic tics was defined for families by a masters or doctoral level clinical psychology student or psychiatric nurse. All clinicians were trained by the first or final author and had extensive experience working with children with tics prior to their involvement in this research. Training for the YGTSS included an instructional meeting, four mock practice interviews, and four interviews observed by the first or final author. After providing the relevant definitions, the clinician administered the YGTSS. The YGTSS was administered to parent(s) and children jointly, with the final ratings based on an integration of both responses, clinician judgment, and behavioural observation of tics. In 10 randomly selected participants, inter-rater reliability for the YGTSS was kappa = .98. After the YGTSS was completed, parents and children completed their relevant questionnaires.

Data analysis

Data were analyzed using SPSS 14.0 statistical software. Chi-square and paired sample *t*-tests were used to examine possible differences in SRPs based on age, gender, and the presence of a comorbid anxiety disorder. Pearson's *r* correlation coefficients were used to examine the relationship between SRPs and study variables (YGTSS, CBCL scores, PedsQL, and MASC). Given the preliminary nature of this study, no statistical correction was used on significance levels in order to minimise the chance of obscuring potentially important relationships.

Results

Age and gender effects

The frequencies of the sleep reported problem items are presented in Table 1 by age group and gender. Only 19.6% of the sample did not report any sleep-related problems, with 19.7% of the sample reporting four or more SRPs. The most commonly reported problems were having nightmares and being overtired upon waking.

Gender. There was a statistically significant difference between mean number of SRPs for males and females

Table 1. Percentage of reported sleep-related problems by gender and age

Sleep Related Problems	Total (*N* = 56)	Male (*n* = 40)	Female (*n* = 16)	Ages 6–11 (*n* = 31)	Ages 12–17 (*n* = 25)
Nightmares	39.3	40.0	37.5	45.2	32.0
Overtired	42.9	40.0	50.0	41.9	44.0
Sleeps less than most kids	23.2	20.0	31.3	32.3	12.0
Sleeps more than most kids	17.9	17.5	18.8	16.1	20.0
Talks or walks in sleep	14.3	12.5	18.8	12.9	16.0
Has trouble sleeping	35.7	32.5	43.8	41.9	28.0
Sleeps next to someone in family	35.7	30.0	50.0	41.9	28.0
Mean no. SRPs (*SD*)	2.09 (1.61)	1.93 (1.61)	2.50** (1.59)	2.32* (1.68)	1.80 (1.50)

*$p < .01$, **$p < .001$

(t (1, 55) = 3.79, $p < .001$), with females showing a greater overall number of SRPs (M = 2.50 versus 1.93). Among the individual SRP items, however, there were no significant gender differences.

Age. A statistically significant difference was found between age groups, with younger children (M = 2.32) showing a greater total number of SRPs than the older group (M = 1.80), t (1, 55) = 2.73, p = .009. As with gender, differences among the individual SRP items were not found.

Tic severity and impairment

Table 2 reports Pearson's r correlations for the relationship between total reported SRPs and measures of tic severity, anxiety, internalising and externalising behaviours, and quality of life. The measures of quality of life, internalising and externalising behaviours, and anxiety were significantly related to total SRPs. PedsQL score for both child- and parent-report indicated a negative relationship between SRPs and quality of life. Parent-rated internalising and externalising behaviour were directly related to SRPs. While the YGTSS total score was not significantly related to total SRPs, the YGTSS Motor scale was negatively related to total number of reported sleep problems. In other words, as the number of motor tics increased, sleep problems decreased.

Sleep problems and comorbidity

In order to examine the impact of a comorbid anxiety disorder of any type on reported SRPs, children with a tic disorder alone were compared to children with a tic disorder and any of the following types of anxiety disorders: Obsessive-Compulsive Disorder, Generalised Anxiety Disorder, Social Phobia, Panic Disorder, and Anxiety Disorder NOS. A statistically significant difference was found, with those children without a comorbid disorder (n = 25) showing less SRPs (M = 1.60, SD = 1.50) than children with a tic disorder and an anxiety disorder [(n = 30, M = 2.48, SD = 1.61), $t(1, 55) = 7.42, p < .001$]. On individual SRP items, significant differences were found on two items, with tic disorder-only children showing fewer reports of sleeping less than other children [χ^2 (1, N = 55) = 5.87, p = .02], and having trouble sleeping [χ^2 (1, N = 55) = 7.65, p = .01].

Discussion

Although a link has been established between SRPs and tic disorders, there is limited research examining this relationship in young people. This study reports on the prevalence and symptom correlates of SRPs in a large sample of paediatric tic patients. Overall, SRPs were widely endorsed, with 80.4% of young people experiencing at least one SRP and 19.7% experiencing four or more. These results suggest that SRPs figure prominently in the clinical presentation of young people with tic disorders, a finding that was not surprising given the generally strong associations that have emerged between SRPs and paediatric psychiatric disorders (see Ivanenko et al., 2004, for a review). Evidence from clinically anxious paediatric samples suggests that SRPs are related to anxiety severity, and this is supported by the results that those children with a comorbid anxiety disorder experienced significantly more SRPs than those children with TS and no comorbid anxiety disorder. Further, our clinical experiences suggest that SRPs related to anxiety often contribute further to anxiety symptoms by virtue of increasing the child's fatigue and overall stress level, as well as decreasing adaptive coping functions. In the most rigorous published study of clinically anxious young people (Alfano et al., 2007), 88% experienced at least one SRP and over 55% experienced three or more SRPs. Given these high rates and the results presented above, further research is needed to determine if the presence of a comorbid anxiety disorder may account for the observed SRPs across other psychiatric disorders.

In the current investigation, the most common SRPs were experiencing nightmares and being overtired upon waking. In the Alfano et al. (2007) study, the most frequently reported SRPs were insomnia, nightmares, and refusal/reluctance to sleep alone. Although there was some symptom overlap between these studies (e.g., nightmares), there were also some differences in symptoms that were endorsed raising the possibility that certain SRPs distinguish paediatric tic patients from those with anxiety disorders. Information on whether or not different SRPs are associated with different paediatric psychiatric disorders may guide targeted assessment and treatment for the presence of SRPs in each respective population. If specific SRPs are

Table 2. Correlations for sleep-related problems, psychological functioning, and impairment

	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Total SRP	–								
2. YGTSS-M	−.278*	–							
3. YGTSS-P	−.060	.537***	–						
4. YGTSS-T	−.115	.793***	.893***	–					
5. MASC	.380**	.054	.169	.175	–				
6. PedsQL-C	−.450***	−.116	−.306*	−.331*	−.745***	–			
7. PedsQL-P	−.503***	.098	−.175	−.170	−.347**	.652***	–		
8. CBCL EXT	.351**	−.058	.170	.167	.110	−.322*	−.640***	–	
9. CBCL INT	.564***	−.192	.083	.035	.307*	−.484***	−.667***	.691***	–
Mean (*SD*)	2.09 (1.61)	14.15 (5.69)	8.03 (7.34)	41.70 (23.58)	38.93 (16.30)	71.27 (16.33)	71.53 (16.44)	11.59 (8.95)	13.00 (10.09)

Note: SRP = Sleep-related problems, YGTSS-M = Yale Global Tic Severity Scale – Motor Score, YGTSS-P = YGTSS – Phonic Score, YGTSS-T = YGTSS – Total Score, MASC = Multidimensional Anxiety Scale for Children, PedsQL-C = Pediatric Quality of Life Inventory child total, PedsQL-P = Pediatric Quality of Life Inventory parent total, CBCL INT = Child Behavior Checklist Internalizing, CBCL EXT = Child Behavior Checklist Externalizing, SD = Standard deviation.
*$p < .05$, **$p < .01$, ***$p < .001$

associated with particular paediatric psychiatric disorders, clinicians should address the relevant SRPs through various evidence-based treatment modalities (e.g., cognitive-behavioural therapy, pharmacotherapy). For example, accommodating family behaviours that maintain SRPs (e.g., allowing children to sleep with parents) may become a target of family-based behavioural psychotherapy. At present, there is limited data on the effect of treatment on SRPs, as well as the impact of SRPs on anxiety-based treatment outcome. If existing interventions for treating paediatric psychiatric disorders are insufficient in adequately reducing SRPs, detailed information about the SRPs associated with particular disorders would greatly assist in the development of structured treatment protocols targeting such symptoms.

Significant gender and age differences were found, with females and younger children endorsing a greater overall number of SRPs than males and adolescents. Total SRPs were positively associated with anxiety, internalising, and externalising behaviours and were negatively related to child- and parent-rated quality of life, findings consistent with recent studies (Alfano et al., 2007; Storch et al., in press b). Given that the current study was correlational in nature, speculations regarding directions of causal effects must be supported by prospective research. With that said, one possibility is that a reciprocal relationship exists between increased anxiety and SRPs (Alfano et al., 2007; Dahl, 1996). Intuitively, young people with TS who are experiencing multiple SRPs are more likely to be stressed by virtue of increased fatigue. Most concerning about this is the well-established relationship between stress and tic severity (increased stress levels being associated with increased tic frequency; Lin et al., 2007) which may suggest a cycle whereby tics (and comorbid anxiety disorders) impact SRPs, which in turn exacerbate stress levels, contributing further to tic exacerbations. As noted above, younger children and females may be especially prone to becoming trapped in this cycle. Evidence for such a reciprocal relationship comes from recent data implicating childhood SRPs as a predictor of adulthood anxiety disorders (Gregory et al., 2005). Specifically, anxiety may contribute to SRPs, which in turn contributes to more anxiety, which then further contributes to SRPs. Given that both anxiety and sleepiness are associated with attention and/or behavioural problems (Fallone et al., 2002), the positive relationship with externalising problems may be explained by increases in these behaviours that coincide with SRPs. In fact, a review of the literature on sleepiness in young people singles out attention problems as being a likely contributor to parent-reported behavioural difficulties (Fallone et al., 2002). Prospective studies will be needed to determine the course of SRPs in young people with tics, and if there are variables (e.g., gender, presence of a comorbid anxiety disorder) that affect clinical course and treatment outcome.

The significant age and gender differences in combination with the unique pattern of SRPs observed in this study may hint at a potential neurobiological basis to SRPs. Indeed, research has demonstrated that there are significant differences in neuropsychological and neuromotor functioning between female and male youth with TS (Schuerholz, Singer & Denckla, 1998). Further evidence supporting the presence of a neurobiological contribution is provided by the presentation of SRPs in this study, which differs from those found in other anxiety disorders in terms of key symptomology (e.g., overtiredness when waking was prominent, as opposed to the insomnia, nightmares, and refusal to sleep alone. However, it remains unclear whether these neurobiological underpinnings may underlie TS or result from the actual tics, or both. Some researchers argue that SRPs in children with TS are due at least in part to heightened nighttime arousal, which may be inherent to the disorder and responsible for inciting daytime tics and other behavioural disturbances (Kostanecka-Endress et al., 2003).

Somewhat surprising, and inconsistent with adult data (Cohrs et al., 2001), no significant relationship was found between level of overall tic severity and total SRPs. Even more surprising, however, was the finding that increased motor tic frequency and total SRPs were inversely related; as motor tic frequency increased, young people reported fewer sleep problems. One possibility is that experiencing multiple motor tics throughout the day results in mental and physical exhaustion at night, thus preventing the presentation of SRPs. A second possibility is that some medications used for motor tics (e.g., risperidone, clonidine) are frequently associated with a sedating effect (Gaffney et al., 2002), thereby reducing the frequency of SRPs.

Limitations of the study should be considered. First, a standardised measure of sleep problems was not used, but rather a composite of child and parent responses from other questionnaires. Internal consistency for the SRP score was low, though the present findings provide construct validity support (i.e., correlations with measures of anxiety, internalising and externalising behaviours, and quality of life). Additional studies utilising a well-validated index of sleep behaviour such as the Children's Sleep Habits Questionnaire (Owens, Spirito & McGuinn, 2000) are warranted. On balance, a strength in using the CBCL to assess sleep problems is that this measure is widely available, has multiple translations, and is well validated; thus, the routine collection of information on SRPs could be easily incorporated into clinical practice. Also important to future research would be the inclusion of objective physiological sleep assessments (i.e., polysomnography) and an examination of potential SRPs not examined in the current study (e.g., poor sleep hygiene). Physiological sleep assessments would help to determine the prevalence of actual sleep disorders, rather than only SRPs, particularly since endorsed items may have been reflective of the child's tics and/or comorbid diagnoses. Additionally, SRPs were taken from two measures that were ultimately used in correlational analyses (CBCL and MASC), raising the possibility of measurement effects. Finally, Caucasians were disproportionately represented in the sample, so caution should be exercised in generalising the findings to other ethnicities.

In conclusion, the findings from this investigation indicate that SRPs are relatively common in young people with tic disorders and elevated relative to their healthy peers. If replicated, these findings suggest the need for SRPs to be included in the comprehensive

assessment and management of young people with tics. Though both pharmacological and cognitive-behavioural interventions targeting anxiety have shown promise in treating paediatric sleep problems in clinically anxious youth (Alfano et al., 2007; Storch et al., in press b), there are no published studies on the sleep related outcomes of youth with tic disorders who have undergone evidence-based treatment for tics (i.e., Habit Reversal Therapy, pharmacological management); research in this area would significantly advance this line of inquiry. In the interim, clinicians would be well advised to pay attention to SRPs in the treatment of young people with tic disorders in addition to other psychiatric conditions, as they were positively associated with both anxiety and internalising and externalising behaviours and negatively related to child- and parent-rated quality of life. Should SRPs be present and clinically relevant, treatment according to evidence-based guidelines (e.g., Mindell, 1999; Mindell et al., 2006; Morgenthaler et al., 2006) is warranted.

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