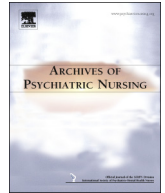




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## Impact of Perceived Stress, Anxiety-Depression and Social Support on Coping Strategies of Parents Having A Child With Gilles de la Tourette Syndrome

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### ABSTRACT

**Purpose:** Previous reports have indicated that raising a child with Gilles de la Tourette syndrome (GTS) could be considered a stressful experience. Thus our study aimed to assess the impact of perceived stress (i.e. parental cognitive perception of their child's disorder) and social support (number of people surrounding the subject providing support) on coping strategies—defined as processes of restoring balance between excessive demands and inadequate resources—of parents having a child with GTS.

**Methods:** Twenty-eight parents of 21 patients with GTS (aged 6 to 16 years) completed questionnaires on perceived stress (ALE Scale), social support (SSQ6), coping strategies (WCC-R) and anxiety–depression (HAD).

**Results:** Principal component analysis showed a negative correlation between social support on one side and perceived stress and anxiety/depression on the other. Problem- and emotion-focused coping both correlated with social support, all of them being independent from perceived stress and anxiety/depression. Hierarchical ascendant classification showed three clusters of individuals in our parents' groups: *i*) those having high scores in perceived stress and anxiety–depression; *ii*) those having high scores in social support associated with low scores in perceived stress; *iii*) parents having lower than average scores on both problem- and emotion- focused coping and social support.

**Conclusion:** Our results reinforce the need for developing training programs for parents with GTS children to better understand and tolerate the disorder to decrease their stress.

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Gilles de la Tourette syndrome (GTS) is a chronic neurodevelopmental disorder characterized by multiple motor and one or more vocal/phonic tics. Recent studies suggest that the prevalence of GTS is around 0.8% in school-age children (Knight et al., 2012). Comorbidity occurs in approximately 90% of GTS patients, with attention-deficit/hyperactivity disorder (ADHD) and obsessive–compulsive disorder (OCD) being the most common (Cavanna, Servo, Monaco, & Robertson, 2009). There has been growing evidence demonstrating that as a complex chronic condition, the quality of life in young people with GTS is reduced when compared with healthy control populations (Cavanna, David, Orth, & Robertson, 2012). It also appears that GTS can have a significant effect on relatives of the patients, especially parents, as raising a child with a developmental disorder is considered a stressful experience (Evans, Wittkowski, Butler, Hedderly, & Bunton, 2015; Lee, Chen, Wang, & Chen, 2007). Several

studies have been conducted on parental stress as well as adjustment and coping strategies in families having a child with special needs such as a chronic illness or psychiatric disorders (Crnic & Greenberg, 1990; Hanson & Hanline, 1990; Willingham-Storr, 2014). However, very few studies have been conducted on the psychological impact of having a child with GTS. Angold et al. (1998) have shown that the severity of the child's symptomatology and functional impairment has the most effect on parental perceived difficulties. Cooper, Robertson, and Livingston (2003) reported that parents of a child with GTS experience higher levels of perceived negative impacts than parents having a child with asthma. Thus, it appears—at least based on this example—that for parents of children with GTS the burden can be heavier than for parents of children with chronic illness. The psychiatric component is most likely responsible. Indeed, parenting a child with GTS can be more complicated due to a higher occurrence of comorbid disorders (Piacentini et al., 2010). For instance, parents may be more concerned about their children's disruptive behaviors than their tics (Ginsburg, Kingery, Drake, & Grados, 2008). Also, one major problem for these parents seems to be the uncertainty about which behavior their child can control or not.

Competing Interests: The authors have declared that no competing interests exist.

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A considerable amount of studies have described the negative consequences of caring for a child with special needs, especially in autism spectrum disorders (ASD) (Ruiz-Robledillo, De Andrés-García, Pérez-Blasco, González-Bono, & Moya-Albiol, 2014). It has been shown that these parents have increased odds of reporting poor social relations (as neighborhood and friends; Hock & Ahmedani, 2012), more difficulty in adjustment (with coping strategies; Hastings, 2002; Walsh, Mulder, & Tudor, 2013) and lower level of mental health (high levels of stress and anxiety; Almansour, Alateeq, Alzahrani, Algeffari, & Alhomaidan, 2013; Ruiz-Robledillo & Moya-Albiol, 2013; Seymour, Wood, Giallo, & Jellet, 2013). These findings also revealed that child behavior difficulties may add to parental stress which is well known to be associated to many negative outcomes including anxiety and depression, and may in return influence the use of ineffective coping strategies (Ji et al., 2014; Walsh et al., 2013). To be more precise on the definition of stress and coping in this type of studies, one can add that the notion of “stress” is generally defined as the relationship between individuals and the environment they appraise and in which the person's resources are exceeded (Lazarus & Folkman, 1984). In these family studies, stress is associated with the child's disorder and the multiple daily organizations it requires. It has been shown that high levels of parenting stress are associated with negative parenting practices and insufficient monitoring and control (Anderson, 2008; Baker, Blacher, Crnic, & Edelbrock, 2002; Walsh et al., 2013). Furthermore, parents have to develop strategies to cope with their child's disorder and the daily challenges they face. Coping strategies are currently defined as parents' conscient plans by which they respond to threats of stress, *i.e.* the appraisal of their child disorder. Finally, coping strategies are widely grouped into two general types, problem-based coping (with strategies aiming at doing something to change the source of stress; *e.g.* planify to do an action) and emotion-based coping (strategies aiming at reducing feelings of distress associated with the stressor). All these notions are based on Lazarus and Folkman (1984) proposing direct and indirect relationships between the stressor (in our study GTS), parental stress, coping strategies, and social support. Social support is the resources an individual can find in the social relationships created around him (friends, family, neighbors). Social support is known as an interesting moderator of coping because there is evidence for a causal impact of social relationships on health (House, Umberson, & Landis, 1988). Social support can also protect individuals from potentially harmful effects of stress, being thereby coping-related.

To our knowledge, no study has been made in GTS on the relationship between parental stress, coping strategies and social support. Moreover, if stress has a real impact on coping strategies (Seymour et al., 2013), this may also impact social support which relates to parental functioning (Anderson, 2008; Raikes & Thompson, 2005), improves parental mental health (Strazdins, O'Brien, Lucas, & Rodgers, 2013) and decreases stress (Pinderhughes, Dodge, Bates, Pettit, & Zelli, 2000). Thus, the aim of our study was to assess the impact of perceived stress and social support on coping strategies of parents having a child with GTS. As this was an exploratory study, the method used is descriptive, and no *a priori* hypothesis was formulated.

## METHODS

### Participants and Sample

The study was proposed over a 2 year period (2010 to 2012) to parents having a child diagnosed with GTS and coming for a follow-up visit at the “Centre de Référence Gilles de la Tourette” in Paris. A family was included once one of the two parents gave their consent. As the interview lasted almost 2 hours, many parents refused to participate as they were living far from Paris. A total of 28 participants, representing parents of 21 children with GTS, were recruited through outpatient clinics at the “Centre de Référence Syndrome Gilles de la Tourette” in Paris. The study was approved by the Medical Ethical Committee of

the Pitié-Salpêtrière Hospital, Paris, France. All participants gave their written consent.

### Parents

The study was proposed to both the child's parents. A family was included once one of the two parents gave their consent. Parents who participated in this study had to meet the following criteria: (1) have a child who has been diagnosed with GTS (2) be a French native speaker, (3) give written consent to participate. There were no strict exclusion criteria. Of the parents who participated, 17 (60%) were mothers, 11 (40%) were fathers. More mothers than fathers therefore agreed to participate in the study, which is a common characteristic in family studies (Smith, 2008). Their mean age was 43.3 years (SD = 5.2), ranging from 34 to 50 years. Ninety-three percent lived in a relationship, while the rest was separated. Professionally, 2 (7.1%) parents of our group were in between jobs, and 3 (10.7%) were in-house parents (one man and two women). All parents were French native speakers.

### Patients

Patients were aged from 6 to 16 years ( $m = 9, 6$ ;  $SD = 2, 3$ ), and 81% were male. The general medical history as well as the GTS history was collected for all patients included in the study. The inclusion criteria were DSM-IV diagnosis of GTS, with the ability to give written informed consent. The exclusion criteria were evaluated by administering the French version of Mini International Neuropsychiatric Interview (M.I.N.I.; version 5.0.0; Sheehan et al., 1998) to all patients by trained psychologists before entering the study. Patients suffering from concomitant psychosis, current major depressive episode, autistic spectrum disorders, or mental deficiency were excluded from the study.

The severity of tics was rated using the tic portion of Yale Global Tic Severity Scale (YGTSS; Leckman et al., 1989). Severity of tics ranged from mild (YGTSS score, 11–19) for 4 patients, to moderate and to severe tic symptoms (YGTSS score,  $\geq 20$ ) for the others. Age at onset ranged from 3 to 11 years ( $m = 6, 17$ ). Seven of the 21 patients had no comorbidities, the others had either anxiety disorder (7 patients) or ADHD (2 patients), and 4 both ADHD and anxiety disorder; one patient had oppositional defiant disorder. Patients suffering from concomitant psychosis, current major depressive episode, and autistic spectrum disorders were excluded. Eight (38%) of our patients received no medication.

### Psychological Assessments

All clinical assessments were carried out in the same order. First, we performed the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), a self-assessment scale, which was developed to detect states of depression and anxiety. A review of the literature on the validity of the HAD showed that a two-factor solution is in good accordance with the HADS subscales for Anxiety (HADS-A) and Depression (HADS-D), respectively (Bjelland, Dahl, Haug, & Neckelmann, 2002). The correlations between the two subscales varied from .40 to .74 (mean, .56). Cronbach's alpha for HADS-A varied from .68 to .93 (mean, .83) and for HADS-D from .67 to .90 (mean, .82). HAD has a total of 14 items, with responses being scored on a scale of 0–3, with 3 indicating higher symptom frequencies. Scores for each subscale (anxiety and depression) can range from 0 to 21 with scores categorized as follows: normal (0–7), mild (8–10), moderate (11–14), severe (15–21). Parents were asked to “fill the questionnaire completely in order to reflect how you have been feeling during the past week” (Zigmond & Snaith, 1983). Next, the ALE Scale (ALES; Ferguson, Matthews, & Cox, 1999) which is a self-reported questionnaire that can be used retrospectively, asking respondents to reflect on the impact of a previously experienced stressful event, was performed. The psychometric properties of the ALE-Scale, including factor structure have been

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