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PREVIEW

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**Stress and the waxing and waning of Tourette's syndrome
symptoms**

Palter-Zadek, Cheryl Elise, Psy.D.

Pace University, 1991

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300 N. Zeeb Rd.
Ann Arbor, MI 48106

PREVIEW

**Stress and the Waxing and Waning
of Tourette's Syndrome Symptoms**

by

Cheryl Palter-Zadek

**A Doctoral Project Submitted in Partial Fulfillment of the Requirements
for the Degree of Doctor of Psychology in the Department of Psychology at
Pace University**

New York

1991

This study explored the relationship between stress, the ability to cope, and the waxing and waning of Tourette's Syndrome symptomatology. The aim of this study was to obtain a fuller understanding of the impact of stress on the severity of Tourette's Syndrome symptoms. Although there has been much clinical speculation regarding the relationship between stress and the waxing and waning of Tourette's Syndrome symptoms, there were no empirical studies previously conducted.

Forty-one Tourette's Syndrome children between the ages of 5 and 15 and their parents were studied. The subjects were drawn from the Pediatric Neurology Clinic at a major urban teaching hospital as well as from the National Tourette's Syndrome Association (NTSA). Subjects were identified by DSM-III-R (1987) diagnostic criteria. Only subjects who were not currently taking medication to control their Tourette's Symptoms were studied.

The independent variable, Severity of Stress, was measured in two ways - in an overall stress measure using the "What Do You Think?" (WDYD) scale by E. Jorgensen, and on a daily stress measure in which both the parents and children independently rated their perception of the severity of child symptoms for that day. Weekday and weekend ratings were taken.

The hypotheses predicted a positive relationship between Severity of Stress and Severity of Symptoms. The hypotheses also predicted a negative relationship between Coping Ability and Severity of Symptoms. The hypotheses were tested using a Pearson product-moment correlation coefficient.

The hypotheses concerning Severity of Symptoms and Severity of Stress were only partially confirmed. There were no statistically significant correlations between the overall (WDYD) stress measures and the overall (TSGS) and daily severity of symptom measures. However, there were statistically significant correlations at the .01 probability level or higher between the daily Severity of Stress measures and the daily Severity of Symptom measures. That is, both parents and children independently reported the relationships, and these relationships were replicated using weekday and weekend data. The hypotheses relating to coping scores were not confirmed. Results indicate that a special scale to define and measure coping skills for a Tourette population needs to be developed and suggests future research in this area. The importance and clinical implications of the relationship between stress and severity of symptoms on a daily basis were also recognized. The intent of this study was to provide insights and to facilitate medical and psychological treatment that would be most effective in helping children with Tourette's Syndrome. The study underscores the need for adequate coping and stress management skills in this population.

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Stress and the Waxing and Waning Symptoms
of Tourette's Syndrome

Chapter I

A. Introduction

Review of Literature

Shapiro & Shapiro (1982) reported that the first recorded account of an individual with possible Tourette's Syndrome was in a 15th century publication called the "Witches Hammer", in which they described a priest with motor and phonic tics. Tourette's Syndrome was believed at this time to be caused by demonic possession and people displaying Tourette's Syndrome symptoms were believed to be witches. "Treatment", therefore, consisted of burning at the stake or exorcism. In fact, the movie "The Exorcist" was based on a description of a patient with Tourette's Syndrome.

Today, we are more enlightened about this disorder that was once greatly feared and severely punished. Cohen et al., (1988) recently recognized that in every culture and social class one may find the clinical picture of a child who blinks, makes faces, sticks out his/her tongue, shakes his/her arms, jerks his/her legs, coughs, barks, spits, curses, shouts various phrases, and moves without stopping. In 1885, this syndrome of multiple motor and phonic tics with strange behavioral symptoms was identified by Georges Gilles de la Tourette and the disorder was subsequently named Tourette's Syndrome. The major clinical manifestations of this disorder are the multiple motor symptoms that affect all muscle groups and many forms of speech with one symptom ceasing

and another taking it's place, waxing and waning over hours, weeks, and months and the capacity for the patient to suppress symptoms for shorter or longer periods of time.

Although once believed to have a psychological etiology compared to hysteria, there now appears to be a genetic transmission of this neuropsychiatric condition with a sex dominance ratio of males to females being 3 to 1. Neuroleptic medications, such as haloperidol, have been found to be an effective treatment of Tourette's Syndrome symptoms. However, the symptoms are also influenced by environmental contexts.

Although previously believed to be a rare disorder, Cohen et al., (1988) reported that it is now known that Tourette's Syndrome may affect up to one person in every 2500 in its full blown form and perhaps a single person in several hundred in its milder variations. At this point in the history of our knowledge about Tourette's Syndrome, it is recognized that it is necessary to balance the expanding knowledge about neurobiological and genetic factors with an appreciation of all the other factors that help a patient achieve normal psychological development and social adjustment. There is evidence that all of these factors may mediate the expression and severity of the disorder. Individuals with Tourette's Syndrome must deal with serious and persistent problems of their disorder and treatment. Therefore, the developmental tasks of children and adults with Tourette's Syndrome can be enormous. Little is known about what makes the difference between milder expressions of Tourette's Syndrome and

serious, disabling forms of the disorder. It is hoped that this study might shed light upon the impact of stress on the severity of symptoms in order to enhance medical and psychological treatment since it is believed that stress can overcome the beneficial effects of medication.

1. Objective

The purpose of this study is to explore the relationship among stress, the ability to cope, and the waxing and waning of Tourette's Syndrome symptomatology. It is intended that the results of this analysis will provide a greater understanding of this relationship, in order to facilitate further research and to permit more effective treatment procedures. Although there has been much clinical speculation regarding the relationship between stress and the waxing and waning of Tourette's Syndrome symptoms, there have been no empirical studies conducted to date. The current project will, therefore, investigate three stress related variables through the use of structured questionnaires and semi-structured interviews with subjects diagnosed with Tourette's Syndrome and their parents. The variables will include: 1) stress coping style, 2) cognitive perception of life event stressors, and 3) subjective analysis of daily stressful events. The ultimate aim of this study is to obtain a fuller understanding of the impact of stress on the severity of Tourette's Syndrome symptoms.

2. Background Summary

A French physician, George Gilles de la Tourette, was the first to describe the symptoms characteristic of Tourette's Syndrome in 1885, and the disorder bears his name. Up until the early 1970's, Tourette's Syndrome was considered to be a rare affliction, but in recent years it has come to be recognized as a fairly common disorder. It is characterized by repetitive motor and/or phonic tics which wax and wane in intensity. Initial symptoms are often motoric and usually involve the head, face or eyes, and include such movements as blinking, grimacing, twitching, or jerking (Cohen, et al., 1988; Shapiro and Shapiro, 1980 and 1982). Later, facial tics progress to include other body parts, such as the limbs. The onset of phonic or vocal tics usually occur after the development of motor tics. Like the motor symptoms, these tics often progress lasting from brief to sustained periods of time. Vocalizations can include barking, grunting, sniffing, squeaking, coughing, spitting, shouting and throat clearing. Also present in some individuals are one or more of the following: coprolalia (use of socially inappropriate words, e.g., cursing); echolalia (repeating last word or phrase of others); palilalia (repeating own last word or phrase), echopraxia (repeating movements); and mental coprolalia and palilalia. Motor tics have been categorized as either simple (sudden, brief and meaningless), or complex (purposeful, stereotyped and longer) (Cohen, et al., 1988). Other symptoms associated with Tourette's Syndrome include touching self and others, exhibitionism and violent behaviors (Cohen, et al., 1988). Kanner

(1937) described the symptoms of Tourette's Syndrome as quick, sudden and frequently repeated movements of circumscribed groups of muscles, serving no apparent purpose. Corbett (1971) postulated that these various tics tend to be more persistent in adolescence. Over 60% of people with Tourette's Syndrome recover from their tics or are no longer handicapped by them in adult life.

Diagnosis of Tourette's Syndrome is currently based on the classification of tic disorders provided by the Diagnostic and Statistical Manual of Mental Disorders (APA, 1980 and DSM-III-R, 1987). The following criteria must be present in order to make a diagnosis of Tourette's Syndrome: onset between ages 2 and 15; recurrent involuntary motor movements; multiple vocal tics; ability to suppress tics for minutes to hours; variation in intensity; duration for more than one year.

There have been multiple theories offered as explanation of the cause of Tourette's Syndrome and the varied expression of its symptoms. However, the exact etiology of the disorder remains unknown. Centuries ago, individuals currently believed to have Tourette's Syndrome were considered to be witches who were possessed by the devil. The prevailing theory for the past seventy years up until the last decade has been that Tourette's Syndrome was caused primarily by psychological conflicts (Shapiro, et al., 1988). A review of psychoanalytic theories revealed that Freud compared Tourette's Syndrome to hysteria; Sadger considered Tourette's Syndrome to be an unconscious muscular eroticism toward the

father; Abraham thought it was a form of anal sadism (Friedhoff & Chas, 1982).

Mahler's (1943) belief that the precipitating mechanism of Tourette's Syndrome is a sudden threat, trauma, or inner conflict is still accepted by some authors as playing a role in the clinical disease. The importance of psychodynamic factors have been postulated and supported through case reports. For instance, Yergani (1983) presented a case report involving an anxious patient whose tics were believed to serve as her only way of relating to her dominant father and to her peers. Her tics were also seen as a withdrawal response to a physical assault or an expression of inner hostility through non-verbal means. Patients' illnesses have also been thought of as a means of maintaining family homeostasis in families with strained relationships (Yergani, 1983).

With the advent of drug therapy, and neurological tests such as EEG's and CAT scans, Tourette's Syndrome came to be recognized as being at least partially biologically based. Central nervous system abnormalities were discovered in some people with Tourette's Syndrome because they were found to have subtle neurological deficits, abnormal EEG's and CAT scans, intelligence test score variability, and neuropsychologic deficits. Eastern European Jews and Italian ethnic groups were found to have a higher incidence of Tourette's Syndrome. It was also found more frequently in males than females, with a sex ratio of 3 to 1 (Shapiro and Shapiro, 1982). Approximately, 100,000 people were reported by Shapiro

and Shapiro (1982) to have Tourette's Syndrome in the United States.

Tourette's Syndrome is now generally viewed as a hereditary, neuropsychiatric disorder with a childhood onset. Both genetic and environmental factors are seen as operating over the course of an individual's development. Many authors, such as Leckman, et al., (1986) believe that this interactive process is responsible for the variability of the expression of Tourette's Syndrome symptoms over time. Neurochemical systems, especially the dopamine system, have been cited as playing a strong role in the pathophysiology of Tourette's Syndrome (Riddle, et al., 1988). Other causes suggested for Tourette's Syndrome include birth damage, infectious diseases, early traumatic events and family dynamics (Abuzzahab & Anderson, 1976; and Yaryuva - Tobias, 1981).

Cohen & Leckman (1984) have proposed a stress diathesis model of the pathogenesis of Tourette's Syndrome. They describe a vicious cycle in which adverse events lead to tic symptoms, which is experienced as a major stress, and thus leads to a greater exacerbation of symptoms. Many authors have reported that psychological stress and/or stimulant medications can exacerbate and/or precipitate Tourette's Syndrome symptoms (Dorsey, 1987; Leckman, et al., 1987; Bruun, 1984; Ascher, 1948, & Cohen, et al., 1988). This is supported by Brunn (1984) and Cohen, et al., (1988), acknowledged that the period of adolescence has been found to be one of the most difficult times, perhaps because of the physical changes and emotional factors associated with this time of life.

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Environmental factors during critical brain development such as uncontrollable stresses are believed to activate developing endogenous brain systems (Cohen & Leckman, 1984). In other words, Cohen & Leckman (1984) believe that a neurochemical responsivity to stress may explain some of the underlying vulnerability to Tourette's Syndrome.

Learning theorists, such as Yates (1958), have described tics as conditioned avoidance responses, evoked initially by stress and then reinforced by a reduction in anxiety. Stefl (1984) recognized that the daily stress of living with an illness can exacerbate the symptoms, as can the psychosocial and adjustment difficulties of dealing with a chronic illness. Also believed to exacerbate Tourette's Syndrome symptoms are impatient anticipation, anxiety, excitement, distress (Cohen, et al., 1988), fatigue, novel situations (Harcherik, et al., 1984), caffeine, (Dorsey, 1988) and emotional trauma (Jagger, et al., 1982). Any exposure to uncontrollable stress is believed to increase Tourette's Syndrome symptoms.

In addition to psychic tension, other factors such as viral infections, exposure to allergens, and premenstrual phase in women (Brunn, 1984) have all been correlated with increases in Tourette's Syndrome symptoms. Dorsey (1987) found that coexisting anxiety disorders have been related to the severity of symptoms. Attention Deficit Disorder, hyperactivity, learning disabilities, sleep disorders and enuresis have also been reported to be associated with Tourette's Syndrome to a

significant degree. Other associated symptoms include obsessive-compulsive, sexually inappropriate, and antisocial behaviors (Cohen, et al., 1988). These difficulties can all, in turn, produce significant amounts of stress. Family dynamics, such as coping with more than one member with Tourette's Syndrome, are also believed to contribute to the patient's symptoms of Tourette's Syndrome (Leckman, et al., 1986).

The effects of relaxation and concentration have been debated and are less clear, although they clearly play a role. It has been reported by Brunn (1984) that concentration on mental tasks, such as playing a musical instrument, will produce a decrease in the severity of symptoms while concentrating on not doing a tic can bring it on. Cohen, et al., (1988) believe that concentrating on a mental task usually suppresses tics because this interferes with unpleasant sensations which precede tics. Relaxation, such as produced by watching television has been reported to both increase as well as decrease tics. Some authors believe that watching TV increases tics because of the relaxation without involvement operating during this activity, while others report that relaxation decreases tics, with the exception of when tics have been suppressed earlier during the day in public. Cohen et al., (1988) confirm that Tourette's Syndrome symptoms worsen in the privacy of one's home. This release of symptoms in a comfortable environment is believed to be a result of prior voluntary suppression of symptoms. Comings & Comings (1985) found that patients with a late age of onset tend to develop more severe symptoms and that patients with milder symptoms are able to

completely suppress both motor and vocal tics for up to several hours a day. The fact that symptoms can be inhibited for periods of time suggests that it is not accurate to call tics and vocalizations involuntary (Brunn, 1984). This notion that tics can be at least temporarily controlled was confirmed by Bliss (1980), in his retrospective case study about his own experiences with Tourette's Syndrome. Bliss (1980) described his ability to shift his tics from one part of his body to another, through symptom substitution, or even to project his sensory impressions onto other people or objects.

Surwillo, et al., (1978) recognized that Tourette's Syndrome symptoms' frequency and severity increased when patients were faced with a stressful situation with which they had difficulty coping. They found that stressful life events overcame the positive effects of medication and that the symptom levels varied greatly with the activities in which the child was engaged. Emotional stress related to life events were believed to influence symptoms. Stressful life events were identified such as starting school and beginning Little League baseball season and these events were found to increase symptoms. Symptoms were likewise found to be lowest when children were sleeping or playing with younger children. Symptoms were higher when children watched violent, aggressive television programs as opposed to more placid, mildly arousing shows.

Surwillo, et al., (1978) used children's parents to count symptoms and to assess the course of symptoms. These observations were found to be reliable and valid suggesting that future clinical studies may use parents

as reliable and accurate observers of symptoms trends. Based on these findings, one can conclude that when Tourette's syndrome symptoms vary, environmental factors should be examined before concluding that a change has occurred in the underlying disorder.

Psychotherapy and behavioral therapy techniques have been given mixed reviews as affective treatment methods for Tourette's Syndrome. The major form of treatment at this time is drug therapy, primarily haloperidol, clonidine, or pimozide, with haloperidol being the treatment of choice because of its high improvement rate (Shapiro et al., 1988; & Yaryuva - Tobias, 1981).

To date, there appear to be no empirical studies existing on the effects of stress on the severity of Tourette's Syndrome symptoms. Only clinical experience and pilot epidemiological studies of Tourette's Syndrome have indicated that periods of increased anxiety and emotional stress regularly produce exacerbations of Tourette's Syndrome symptoms. (Cohen, et al., 1988). Cohen et al. (1988) recognize that there is a need for better controlled and more detailed clinical and empirical studies on the relationship of stress and Tourette's Syndrome. They have proposed that a history of prior intermittently stressful periods and an appraisal of individuals with Tourette's syndrome is needed. Therefore, the current study plans to investigate the effects of stressful daily and life events on the course of symptoms in Tourette's Syndrome.

3. Rationale

Stress and Life Events

In order to fully understand the impact of stress upon Tourette's Syndrome, a review of the relationship among stress, coping abilities and illness is necessary. Previous research on stressful life events has shown that stress and physical illness are interrelated. For instance, Germazy and Rutter (1983) revealed that the risk of upper respiratory infections markedly increased following stressful events. Hypertension, headache, diabetes mellitus, and asthma were recognized by Weiner (1987) as diseases which can be exacerbated by stress. Brown, Pelcovitz, and Kaplan (1984) recognized that stress was connected to the following somatic disorders in children: eating and digestive problems such as stomachaches, constipation and nausea, vague aches and pains, headaches, sleep difficulties, and eye problems such as blurred and double vision. Similarly, Holmes and Rahe (1967) reported that many kinds of illnesses increased following stressful periods. They attributed their findings to the major coping responses that are required at such times. Monet and Lazarus (1985) suggested that illnesses are more likely to occur when an individual is unable to successfully adapt to a stressful experience. Stressful life events can be either positive or negative experiences which require an individual to change his/her behavior in response to the event. Stress is experienced when the individual is unable to adapt to these changes in the environment. According to Germazy and Rutter (1983),

stress is defined as a form of stimulus, a force requiring an adaptive change, a mental state or a bodily reaction.

Scientists who study the physical world have long viewed it as a system which seeks to maintain balance or equilibrium. Cannon (1932) formulated a concept of "homeostasis" which he described as, "organisms, composed of material which is characterized by the utmost inconstancy and unsteadiness, have somehow learned the methods of maintaining constancy and keeping steady in the presence of conditions which might reasonably be expected to prove profoundly disturbing." The term homeostasis "does not imply something set and immobile, a stagnation", but rather refers to an equilibrium that is constantly being upset and just as constantly being reestablished by the organism.

Stressors are external events or conditions that serve to disrupt these steady states (Goldberger and Breznitz, 1982). They point out that cognitive styles and coping strategies play a key role.

Selye (1956), in his classic description of the interaction between the environment and body, described the effects of stress in his General Adaptation Syndrome. He posited an initial alarm reaction followed by a stage of resistance and finally the stage of exhaustion. He noted that the first stage was similar to childhood "with its characteristic low resistance and excessive response to any kind of stimulus" (Selye, 1974). Selye's work also has given support to the concept that social and