CHAPTER 1

Introduction to Clinical Management of Tourette Syndrome

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In recent years there has been an explosion of interest in Tourette syndrome (TS). Not only has TS captured the attention of researchers and clinicians, but the popular media has begun to focus on the disorder, by including people with TS as characters in movies, guests on talk shows, and as the focus of cable documentaries. Despite this increased attention and the growing scientific knowledge about TS, there are limitations in our knowledge and understanding of what causes the disorder and how to cure it. In this book we take advantage of what is known about TS to describe a comprehensive, multidisciplinary approach to its management in children and adults. This volume focuses primarily on children and adolescents because TS presents early in life, usually from age 4 to 6, and peaks in adolescence. For some, it dissipates, but for others, it persists into adulthood. Several chapters consequently look beyond childhood and into adulthood in order to convey a more complete understanding of the disorder.

Although multidisciplinary care has become increasingly popular for many neuropsychiatric disorders, multidisciplinary care for TS is a relatively recent development. To appreciate the evolving nature of treat-

ment approaches in TS, a brief discussion of the history of the disorder, its conceptualization, and treatment is warranted.

Tic disorders have been recognized in humans throughout recorded medical history, but it was not until 1885 that Gilles de la Tourette, a French neurologist, identified a cluster of behaviors as the syndrome that would eventually bear his name. Given Tourette's training as a neurologist, it is not surprising that he viewed the disorder as a hereditary, biologically based condition. However, with the lack of effective treatments in neurology at that time and the early successes of psychoanalysis (e.g., with hysteria) in the early 20th century, the initial biological conceptualizations quickly gave way to a primarily psychoanalytic explanation, wherein tics were viewed as a result of underlying psychic conflicts or repressed sexual or aggressive impulses (e.g., Ferenczi, 1921; Kushner, 1999). The lack of other effective treatments and the rising interest in psychoanalysis and psychotherapeutic approaches, in general, in the first half of the 20th century resulted in a psychological model for TS and psychotherapy as the treatment of choice. One unfortunate complication of this initial psychological conceptualization of TS was the implication that those with tics lacked willpower or had a deficit in character. Even now, patients who in their late 50s or older often report a very difficult time trying to reconcile their personal experience with TS with the psychological model that was operative when they were first diagnosed.

The psychological conceptualization of TS held fast until the mid-1960s, when a combination of factors—including basic brain research on movement processes (i.e., the role of the basal ganglia and dopamine in movement control), the discovery that antipsychotic medications could effectively reduce tics, and the growing influence of practitioners such as Arthur and Elaine Shapiro in championing the biological model—coalesced and resulted in more effective TS management strategies. Since that time, the biological/neurological conceptualization of TS has become dominant; it has fostered an explosion of research on the etiology and treatment of TS and an expanding armamentarium of new medically based treatment options (Kushner, 1999).

In the 1970s–1980s the biological nature of the disorder was no longer in question, but the historical battles between biological and psychological conceptualizations had taken their toll. As the pendulum swung to the biological model, the reaction against psychology in the understanding and treatment of TS was significant. With the growing understanding of TS's neurological underpinnings as well as the emergence of medications as an effective management strategy, it became unpopular to consider the possibility that psychological science—and beyond that, psychological treatment—may be useful in understanding and treating TS symptoms. Within the TS community researchers and

practitioners began to recommend against the use of nonpharmacological treatments for tics, although largely supportive psychological interventions were still seen as useful in learning to cope with the disorder (e.g., Bruun, 1984; Comings, 1990).

The negative reactions to psychological conceptualizations and treatment alternatives for TS were at least partly the result of the negative effects of the early psychological conceptualizations of TS. Invoking the unconscious in the etiology of TS, blaming early parent–child interactions, and simplistically holding patients accountable for an inability to control themselves was an unfortunate result of these early psychological theories.

Ironically, concurrent with the development of medical approaches to TS in the late 1960s, psychological and early genetic studies suggested that environmental factors were involved in tic severity and that psychiatric comorbidity in TS was common (e.g., Doleys & Kurtz, 1974). In addition, a number of small but carefully controlled studies showed that the use of primarily behavioral psychological approaches (as opposed to psychodynamic approaches) could be effective in reducing tic severity (e.g., Azrin, Nunn, & Frantz, 1980). Regrettably, this newer psychological understanding of TS and approach to treatment did not take hold until more recently (as reviewed in Himle, Woods, Piacentini, & Walkup, 2006).

Care for those with TS may have been restricted to medical practitioners had it not been for the work of Leckman and Cohen (1999), who highlighted the importance of an integrated approach to the understanding and treatment of individuals with TS. Perhaps it was the shift to an integrated approach that once again opened the door for psychology to become involved in the development of a more comprehensive understanding and treatment of TS. Indeed, since 1999, there has been a renaissance in the psychology of TS, with the creation of a comprehensive model that integrates neurobiological and environmental factors in the understanding and treatment of this disorder. Modern psychological approaches focus more on the here and now than the past, expect progress to occur over briefer treatment periods, and emphasize improved functioning and behavior change rather than the development of insight.

Based on this evolving integrated conceptual model of TS, the Tourette Syndrome Association formed the Behavioral Sciences Consortium (BSC) in 2002. Founding members of the BSC included Drs. John C. Piacentini (UCLA), John T. Walkup (Johns Hopkins University), Douglas W. Woods (University of Wisconsin—Milwaukee), Sabine Wilhelm (Massachusetts General Hospital—Harvard University), Alan Peterson (University of Texas Health Sciences Center—San Antonio), Lawrence Scahill (Yale University Child Study Center), Susanna Chang (UCLA),

Thilo Deckersbach (MGH/Harvard), and Golda Ginsburg (Johns Hopkins University). The BSC was charged with developing and researching an integrated model of TS and conducting research to evaluate the model and resulting psychosocial treatment options. Two large-scale clinical trials funded by the National Institutes of Health are now underway by BSC members to address these aims.

The purpose of this book is to give practitioners a guide on how to comprehensively treat those with TS. The approach to treatment outlined in this book is influenced by our emerging integrated model. A complete understanding of the model is not necessary to competently implement treatment, but a general understanding of the integrated model, especially the behavioral component, will put the assessment and treatment recommendations in this volume into an appropriate context.

OVERVIEW OF THE COMPREHENSIVE, INTEGRATED MODEL OF TS

The comprehensive, integrated model (CIM) suggests that the complex presentation of TS commonly observed in clinical settings is the result of two interacting forces. First, tics and associated features (e.g., premonitory urges) have a neurobiological substrate; tics emerge because of abnormal genetic and/or neurological factors. Second, tics do not occur in a vacuum; they occur in the world, and as a result, tic symptom expression reflects an underlying neurobiology that both influences and is influenced by a person's external and internal (i.e., inside the person's body) environments. Essentially, the *environment* in interaction with the underlying *neurobiology* shape tic expression in a context-dependent fashion, and it is this interaction that serves to shape the often complex and at times baffling presentation of some people with TS.

In the following chapters the authors describe tic disorders and their treatment across a wide array of domains. Each chapter offers something unique and important in the treatment of children and adults with tic disorders. Indeed, each chapter in this book could be pulled out and used in isolation, but we encourage you to refrain from this approach. The book was designed to be consulted/read as a whole, because we believe that the integrated approach to treating tic disorders is the best approach.

Chapter 2 provides an overview of tic disorders and their phenomenology. Chapter 3 addresses the assessment of tic disorders and Chapter 4, the assessment of comorbid conditions. Meaningful and ongoing assessment is critical to a comprehensive management of tic disorders. Chapter 5 provides an in-depth look at the genetic and neurological factors underlying tic disorders, and this discussion is extended in Chapter

6 by Chang's description of the cognitive manifestations of these neurological factors.

Comprehensive management strategies are described next. After a discussion in Chapter 7 of general medication strategies for tics and related conditions, nonpharmacological treatment options for tics are described in Chapter 8, nonpharmacological options for common comorbid conditions are described in Chapter 9 and the management of disruptive behavior disorders is described in Chapter 10.

Recognizing that the tic disorders impact more than just the person with tics, and that the contexts in which tics occur can have a tremendous impact on their expression, chapters are devoted to strategies for managing tic disorders and related problems in family settings (Chapter 11), in a variety of different environments, including school (Chapter 12), and in social and occupational settings (Chapter 13).

Of course, not all individuals with a tic disorder diagnosis will demonstrate impairment across all domains addressed in this book, nor will all need treatment for all of the issues described here. Nevertheless, the astute clinician, after reading this book, should be able to understand how tic disorders can impact the client's life, what issues should be assessed, and generally how tics should be managed. It is our hope that this book facilitates the comprehensive, integrated care of persons with TS and related tic disorders.

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