

NAVIGATING DATING AND ROMANTIC RELATIONSHIPS
AS AN ADULT WITH TOURETTE SYNDROME:
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Abstract

Tourette Syndrome (TS) is a neurological disorder defined by recurrent and intrusive involuntary tics that begin in childhood. Individuals with TS often face significant psycho-social challenges, given the public nature of their tics and the fact that their symptoms are often misunderstood by others. This study explores how adults with TS navigate dating and romantic relationships, including the challenges they face and the strengths they have developed in this process. Five adult women with TS were interviewed using a semi-structured interview about their psycho-social experiences of living with TS and how the disorder has affected their dating experiences. The interviews were qualitatively analyzed as individual case studies and also compared and contrasted on the basis of five major research questions:

- 1) How do adults with TS navigate dating and romantic relationships?
- 2) What challenges and limitations do adults with TS face in dating and pursuing romantic relationships?
- 3) How do adults with TS go about explaining their symptoms to romantic partners?
- 4) How do the socio-emotional experiences of adults with TS with family and peers influence their dating experiences?
- 5) What factors are helpful for adults with TS in navigating dating and romantic relationships?

Findings from the study indicate several themes among the subjects' experiences: Choosing whether, why, when, how and what to disclose to partners; challenges of explaining tics and TS to others; reasons for concealing tics; impact of making

disclosures to romantic partners; family and peers' responses as a model for how romantic partners may respond; family and peers' responses as a motivation for getting different responses from romantic partners; and considering genetics and children. Implications for individuals with TS and their parents are discussed, and recommendations for mental health professionals working with such individuals are made.

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Chapter I

Introduction and Overview

Characteristics of Tourette Syndrome

Tourette Syndrome (TS) is a neurological disorder characterized by the presence of tics. Tics are “sudden, repetitive, stereotyped motor movements or phonic productions that involve discrete muscle groups” (Leckman & Cohen, 1999, p. 24). These abrupt movements and vocalizations begin in childhood and are perceived by affected individuals as involuntary and difficult to suppress. Motor movements are defined as motor tics, while phonic productions are termed vocal tics. Each can be simple or complex in nature. Simple motor tics are brief, meaningless movements that usually last less than one second. Eye blinking, facial grimacing, mouth movements, head jerks, shoulder shrugs, and leg and arm jerks are common examples of simple motor tics. Simple vocal tics are sudden meaningless noises or sounds that include sniffing, throat clearing, grunting, barking, and high-pitched squeaks.

Complex motor tics are longer in duration than simple motor tics and appear slower and more purposeful, although spontaneous. Examples include sustained looks and facial gestures, touching objects or oneself, throwing, banging, gesturing, gyrating and bending. Gesturing can include copropraxia, which is the use of obscene or offensive gestures. Similarly, complex vocal tics are longer and appear more purposeful than simple vocal tics. Syllables, words or phrases, and patterns of speech characterized by sudden changes in rate, volume and/or rhythm are common examples. Echolalia, or the repetition of one’s own or another’s phrases, and coprolalia, inappropriate, obscene, or

aggressive words or phrases, are also forms of complex vocal tics (Leckman & Cohen, 1999). Unfortunately, both coprolalia and copropraxia are often confused with voluntary misbehavior. It is worth noting that only 10% - 33% of all patients with TS will exhibit coprolalia (Comings & Comings, 1985; Singer, 2005).

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (2000), a diagnosis of Tourette Disorder applies to individuals who have experienced “both multiple motor and one or more vocal tics” (p.114) at some point in their lives, with the onset of tics being before the age of 18 years. In order to qualify for the diagnosis, individuals must experience tics “many times a day, nearly every day, or intermittently throughout a period of more than a year; and during this period, there was never a tic-free period of more than three consecutive months” (APA, 2000, p.114). The disturbance must “not [be] due to the direct physiological effects of a substance (e.g. stimulants) or a general medical condition (e.g. Huntington’s chorea or post-viral encephalitis)” (APA, p. 114).

The DSM-IV-TR also lists three additional tic disorders, all of which are less severe than TS. These include Chronic Motor or Vocal Tic Disorder, Transient Tic Disorder, and Tic Disorder Not Otherwise Specified. Chronic Motor or Vocal Tic Disorder is diagnosed when one or more either motor or vocal tics (but not both) have been present for more than 12 consecutive months and there has never been a tic-free period of more than 3 consecutive months. Transient Tic Disorder applies to individuals whose motor or vocal tics have been present for at least 4 weeks but for no longer than 12 consecutive months. Tic Disorder Not Otherwise Specified is diagnosed when tics have

been present for less than 4 weeks or when the age of onset is greater than 18 years (APA, 2000).

Etiology: Genetics and Neurological Bases

TS is understood as a neurological disorder that has a strong genetic basis. Family studies over the years have repeatedly shown that relatives of individuals with tics are at increased risk for developing tics compared to the general population. One such study found a 53% concordance rate for TS among monozygotic twins compared with 8% in dizygotic twins (Price, Kidd, Cohen, Pauls, & Leckman, 1985). Other twin studies have found concordance rates for TS as high as 94% in identical twins (Woods, Piacentini, & Walkup, 2007). When looking at the occurrence of tics in general, monozygotic twins have been found to have a 77% concordance rate versus a 23% concordance rate for dizygotic twins (Price et al., 1985). Environmental influences for the expression of tics and TS may include prenatal events or viral exposure (Walkup, 2001).

While the predominantly genetic basis of TS has been substantiated, its underlying causes are still being studied. Recently, researchers have found some evidence that a gene mutation that causes low histamine levels may be involved in tic disorders (Ercan-Sencicek et al., 2010). However, to date, no biological markers of a genetic vulnerability for TS have been conclusively identified, and the specific causal mechanisms involved are not yet fully understood (Cohen, Bruun, & Leckman, 1988; Woods et al., 2007). Genetic research suggests there are many genes, each with equal and additive effect, that contribute to the expression of the disorder (Kurlan, 2005).

Neurological studies have shown that the interactions of several parts of the brain are implicated in tics and TS (Cohen, Goetz, & Jankovic, 2001; Kurlan, 2005; Leckman, Woods et al., 2007). Abnormalities in the cortico-striatal-thalamic-cortical (CSTC) circuits appear to play a central role, as these circuits are composed of a variety of excitatory and inhibitory signals. Two main pathophysiological hypotheses for TS have emerged with regard to these signals. The first is excess thalamic excitation; the second is impaired cortical inhibition (Woods et al., 2007). It is presumed that dopaminergic systems in the frontal/subcortical tracts are involved in tic expression because of substantiated tic reduction in response to dopamine blocking agents (Freeman et al., 2000). Therefore, neurochemically speaking, TS is likely related to a hypersensitivity to the neurotransmitter dopamine.

Additional hypothesized abnormalities include disruptions in the frontal cortex and striatum, as abnormalities in the frontal cortex are implicated in difficulties with executive functioning, including planning, organization, sequenced behavior, and inhibition of behavior, which (to varying degrees) are impaired in individuals with TS (Woods et al., 2007). Additionally, dysfunction in the basal ganglia is associated with movement disorders in general, and studies have identified changes within the basal ganglia in patients with TS (Woods et al., 2007). While advances are being made in understanding the physiological basis of TS, no concrete conclusions are available yet, rendering a possible cure for the disorder an elusive goal.

Course

The mean age of onset for TS is between 6 and 7 years (APA, 2000; Freeman et al., 2000). However, TS may develop as early as 2 years of age (APA, 2000). Simple motor tics emerge first, typically including eye blinking, facial, head or neck tics (Woods et al., 2007). Vocal tics tend to develop several years after the motor tics, and complex tics tend to emerge around the age of 11 or 12 years. On occasion, both multiple motor and vocal tics emerge quickly over the period of only a few weeks (Woods et al., 2007). Maximum tic severity generally occurs between the ages of 8 and 12 years (Leckman Zhang, et al., 1998).

While TS is a lifelong disorder, it is possible for affected individuals to go through periods of remission lasting anywhere from a few weeks to several years. Tics are known to wax and wane over time, which is related to common psychosocial stressors, illnesses, levels of fatigue and excitement, as well as random symptom fluctuation (Woods et al., 2007). It is common for the severity, frequency, and variability of TS symptoms to diminish during adolescence and adulthood, and in some cases, the symptoms disappear entirely by early adulthood (APA, 2000). Leckman, Zhang, et al. (1998) followed 42 youngsters with TS and found that by the age of 18 years, nearly 50% of the cohort was practically tic-free. However, there is some evidence that adults with TS subjectively rate themselves as having fewer tics than would be observed by others. For instance, Pappert, Goetz, Louis, Blasucci, and Leurgans (2003) observed 31 adult individuals with TS over the age of 20 who claimed that they were currently tic-free. The authors found that 50% of these in fact displayed objective evidence of tics when

observed by blinded raters. Therefore, individuals with TS may be less aware of their tics as adults than they were in their youth.

Epidemiology

The precise prevalence of TS is difficult to establish, as epidemiological studies vary in terms of the sample sources, age ranges, diagnostic criteria, and sample sizes used. As is to be expected, studies using clinical samples differ greatly from those using community samples, and it is understood that a large portion of individuals with TS remain undiagnosed (Freeman et al, 2000). Robertson, Eapen, and Cavanna (2009) reviewed the findings of different community studies conducted by TS experts around the world and note the variability in study designs used and subsequent prevalence rates found. They estimate the overall international prevalence rate to be about 1%. Findings from studies with youth suggest that between 5 and 15% of school-age children may develop transient tics during childhood (Zohar et al., 1992). Studies have repeatedly shown that TS and tic disorders occur more frequently in male than female individuals, at a ratio of about 4.3:1. This gender difference is more pronounced in children (5.2:1) than in adults (3:1) (Freeman et al., 2000).

Comorbid Symptoms and Diagnoses

TS is rarely solely characterized by tics; often, the comorbid symptoms or diagnoses present more of a challenge to the affected individuals than the tics themselves. On average, youth with TS will meet criteria for two additional psychiatric conditions (Freeman et al., 2000). Furthermore, at all ages, only 12% of individuals with TS have no

reported comorbidity (Freeman et al., 2000). The most common comorbidities include Obsessive-Compulsive Disorder (OCD), Attention Deficit and Hyperactivity Disorder (ADHD), learning disabilities, and behavioral difficulties (Leckman, Bloch, Scahill, & King, 2006). The latter include aggression, impulsivity, and rage attacks.

OCD is the most common co-occurring diagnosis among individuals with TS. Approximately 23% of TS patients meet criteria for OCD, and up to 46% demonstrate OCD symptoms in the subclinical range (Woods et al., 2007). These include obsessions and compulsions. Obsessions are recurrent and persistent thoughts, impulses, or images that are experienced as intrusive and inappropriate, causing marked anxiety or distress. Compulsions are ritualized or stereotypic behaviors in which the individual must engage to prevent the anxiety or some feared event from occurring (APA, 2000). Among individuals with both OCD and TS, it can be challenging to differentiate to what extent a symptom, such as repetitive tapping or touching, reflects a complex tic or a simple compulsion (Woods et al., 2007). This often poses significant treatment challenges for the clinician. Individuals with both OCD and TS may have higher rates of affective, anxiety, and substance use disorders, as opposed to those with either diagnosis in isolation (Coffey et al., 1998), which highlights the complexity of difficulties that these individuals face.

Comorbid ADHD is also common in TS, with 40-60% of children with TS in clinical samples meeting criteria (Sheppard, Bradshaw, Purcell, & Pantelis, 1999). Individuals with TS are much more likely to suffer from ADHD than the general population, with the incidence of ADHD being seven to eight times greater for those with TS (Walkup et al., 1999). As with comorbid TS and OCD, the combination of TS and

ADHD poses difficulties that are notably different from those found in TS or ADHD only. Depression, anxiety, and disruptive behaviors are common in comorbid TS and ADHD (Woods et al., 2007).

The incidence of learning disabilities in children and adolescents with TS is about 22% (Abwender et al., 1996). Research in this area has shown that children with TS are at risk for school-related problems in general, but that the nature of these problems is multifactorial. For instance, children with comorbid TS and ADHD are at greater risk of having learning problems than children with TS alone (Kurlan, 2005). The most common learning disabilities found in youth with TS include deficiencies in arithmetic and written language skills (Kurlan, 2005).

Behavioral difficulties in TS include anger, rage attacks, aggression, and noncompliance. Freeman et al. (2000) found that 37% of patients with TS reported a history of anger control problems, while 25% had current problems with anger control. In a study of 250 individuals with TS, D. E. Comings and B. G. Comings (1985) found discipline problems and/or problems with anger and violence in 61% of the sample. Children with TS often report having a lack of control over aggressive behavior and exhibit behavioral impulsivity. It is not clear whether these problems are due to the burden of having TS, or whether neurological abnormalities in the CSTC circuits contribute to difficulties with response inhibition, or both (Woods et al., 2007). Studies have shown that disruptive behavioral disorders may be accounted for by comorbidity with ADHD (e.g. Spencer et al., 1998), which implicates problems with executive functioning and inhibition. For the individual with TS and aggressive symptoms, the

latter are a leading cause of morbidity and further complicate the picture of TS (Kurlan, 2005).

Treatment for Tourette Syndrome

Because TS generally includes other comorbid diagnoses and/or symptoms, the management and treatment of the disorder is usually no straight-forward matter. For some individuals with TS, their tics are so impairing that treating the tics themselves is a priority. For others, the symptoms of OCD, ADHD and behavioral difficulties will supersede the need to treat the tics. For many, treatment needs to address the multiple difficulties associated with the disorder, including the psychosocial impact of TS. It is important to keep in mind that there is no cure for tics and TS, and that treatment should focus on the reduction of tic severity, related symptoms, and associated distress (Woods et al., 2007). Treatment can be divided into three main categories: medical treatment, behavioral treatments, and psychoeducation and support. Often, treatment will involve some sort of combination of these.

Medical treatments. Medications used to treat TS and associated disorders include typical neuroleptics or antipsychotic medications, atypical neuroleptics, beta-blockers, selective serotonin reuptake inhibitors (SSRIs), tricyclic antidepressants (TCAs), atypical antidepressants, and stimulants (Riddle & Carlson, 2001; Woods et al., 2007). While the neuroleptics and beta-blockers are generally used for a reduction in tic severity, SSRIs and TCAs typically target symptoms of OCD, as well as anxiety and depression. Atypical antidepressants and stimulants are usually prescribed for ADHD

(Riddle & Carlson, 2010). Often, different classes of medication will need to be used in conjunction to treat the symptoms of the TS patient. Finding the right dosages and combinations of medications while minimizing their side-effects can be a tricky task for the prescribing psychiatrist, and a frustrating process for the patient.

In extreme cases of TS, in which tics are debilitating and medications fail, a surgical approach called deep brain stimulation (DBS) may be an option. This is a surgical procedure in which a medical device is implanted into the patient's brain. The device sends electric impulses to specific areas in the brain and thereby interferes with the neural activity that is responsible for the individual's tics. There have been documented cases for which DBS has been very successful, but more clinical trials using the procedure will be needed before it becomes widely accepted and used (Neimat, Patil, & Lozano, 2006).

Behavioral treatments. Behavioral interventions to treat tics and related problems include several approaches. One of these involves the manipulation of the environment in order to control the antecedents and consequences of behaviors that are to be altered. In one study, youth with TS and their parents were asked to rate increases and decreases in tic behaviors based on given environmental factors. Being upset or anxious was found to be strongly implicated in increasing tics (Silva, Munoz, Dinohra, Barickman, & Friedhoff, 1995). Similarly, stress, over-excitement, exhaustion, and unpredictability have been found to increase tics (Kurlan, 2005; Leckman & Cohen, 1999). Research has also shown that the suppression of tics may be reinforced by environmental factors. One study found that rewarding tic suppression led to significant

reductions in tic behavior, whereas tic suppression without rewards did not (Woods & Himle, 2004). Furthermore, tics often diminish during periods of concentration and engagement in sports (Leckman & Cohen, 1999). Behavioral treatments may therefore aim to identify, anticipate, and control the environmental factors that maintain and/or minimize tic expression.

A behavioral treatment that targets tics directly is known as Habit Reversal Training (HRT), originally developed by Azrin and Nunn (1973). HRT involves training an individual to become aware of the sensory premonitory urges that precede the tics. Once the individual becomes sufficiently aware of the urges that signal the onset of a tic, he or she is instructed to use a competing response that is physically incompatible with the tic, but compatible with maintaining participation in ongoing activities. The individual engages in the competing response until the urge to perform the tic has subsided, and at least for one minute. In HRT, the individual therefore learns to tolerate and habituate to the premonitory urge until it declines by initiating a voluntary behavior. Through repeated practice, the individual is able to resist the urges to perform the tic, ultimately leading to a decrease in tic frequency and severity (Woods et al., 2007). Several studies have demonstrated the efficacy of HRT for tic reduction (e.g., Azrin, Nunn, & Frantz, 1980; Azrin & Peterson, 1990; O'Connor et al., 2001; Wilhelm et al., 2003). Recently, HRT has been subsumed under a treatment called Comprehensive Behavioral Intervention for Tics (CBIT). In addition to HRT, CBIT includes relaxation training and a functional intervention to address situations that sustain or worsen tics through the management of antecedents and consequences, as mentioned previously. In a recent randomized control trial by Piacentini and colleagues (2010), the authors found

that CBIT led to a significantly greater decrease in tic severity than supportive psychotherapy and education alone among a sample of 126 children with TS or chronic tics.

Psychoeducation and support. While psychoeducation and support alone are unlikely to lead to a reduction in tics and related symptoms of TS, it is considered therapeutically beneficial for TS patients to understand their disorder and correct any misconceptions they may have about it. It is crucial for any medical or behavioral treatment to include these elements in order to enhance patients' socio-emotional well-being and minimize any adverse impact that the disorder may have. Upon first recognizing and understanding their diagnosis, these individuals typically feel relieved and supported by talking to a well-informed and knowledgeable professional (Leckman & Cohen, 1999). Awareness of TS in the general community is still limited, and children with TS often experience ridicule, fear, punishment, and social isolation as a result of their symptoms (Kurlan, 2005). It is not uncommon for others to perceive their tics as voluntary, deliberately annoying acts of defiance or a lack of self-control (Leckman & Cohen, 1999). Clinicians working with individuals with TS therefore do well by including family members, teachers, and classmates or coworkers in the education process, thereby creating a supportive and informed environment for the patient. This may also lead to the implementation of accommodations in schools that can help children and adolescents deal with any impairing difficulties related to having TS (Kurlan, 2005).

Psychosocial Impact of Tourette Syndrome

The diverse symptoms of TS and its common comorbid conditions can influence a child's psychosocial development in significant ways. In the words of Leckman and Cohen, "the role of tics in the story of the child's life may be overshadowed by a decade or two of derailment in emotional, educational, and social development; by a saga of treatments tried and failed; by the emotional scarring of disappointments, alienation, and medical side effects; and by profound disruptions in family life and family economics" (Kurlan, 2005, p. 481). As discussed previously, children with TS are often teased by their classmates, and their symptoms are likely to be misunderstood by teachers, family members, and the community at large. This may lead to low self-esteem, poor adaptive abilities, poor relationships with peers, and social withdrawal and isolation (Coffey & Park, 1997; Lambert & Christie, 1998; Lerer, 1987; Murray, 1997; Wigley et al., 2000). The challenges faced by youth with TS would appear to be relevant to their later adult social functioning and their ability to engage in satisfying dating experiences. While there has been little written about the psychosocial impact of TS among adults, there is a fair amount of research on the psychosocial aspects of TS among children and adolescents. This section focuses on the findings of these studies.

Peer relationships. Because children with TS display behavior that often does not conform to that of their unaffected peers, they are at risk of being singled out as different, which may adversely impact their contact and relationships with peers. A number of studies have examined the effects of this by looking at factors such as popularity, friendship, teasing, and other peer problems among youth with TS. A study

by Jagger et al. (1982) employed a sample of individuals with TS aged 8 to 57 years, in which participants and their parents responded to a detailed questionnaire about TS and its impact. In the overall sample, 56.5% of individuals reported that the quality of their social contact was moderately to severely affected by having TS. Among the children aged 5 to 12 years, 75% reported being teased about their TS symptoms by classmates.

Nomura, Kita, and Segawa (1992) surveyed 53 Japanese adolescents with TS (87% male) about their experiences with the disorder. Among the sample, 62% said that others pointed out their TS symptoms, and 50% of respondents admitted to feeling hurt when this happened. Champion, Fulton, and Shady (1988) surveyed 120 Canadian children and adults with TS and found that 40% reported problems in making and keeping friends. In a similar study done in North Dakota, 72% of 39 individuals with TS aged 3 to 31 years (and/or their parents) felt that TS adversely affected their social life (Burd, Kerbeshian, Cook, Bornhoeft, & Fisher, 1988). Among the children aged 5 to 12 years in this sample, 51% reported being teased about their symptoms by classmates. Among children aged 13 to 18 years, 42% had been teased by peers about their symptoms.

Other studies have looked at how children with TS are viewed by their peers without TS. For instance, Friedrich, Morgan and Devine (1996) studied the attitudes of 153 children in the third and fifth grades toward a boy presented on videotape either with or without symptoms of TS. They found that these children rated the peer presented with TS less positively than they did the peer presented without TS. Whether or not information about TS was provided did not affect these ratings. On the other hand, Holtz (2000) found that children who watched an educational video on TS reported more

knowledge and positive attitudes toward a child with TS than those children who had not received the intervention. Findings from these two studies suggest that education on TS may or may not affect children's views on a peer with TS.

Stokes, Bawden, Camfield, Backman, and Dooley (1991) used the Pupil Evaluation Inventory in the classes of 29 children with TS aged 8 to 15 years. They found that the youth with TS were rated as less popular than their classmates of the same sex without TS. Noteworthy is that tic severity was not found to be related to popularity. In a follow-up study (Bawden, Stokes, Camfield, Camfield, & Salisbury, 1998), the researchers included a control group of children with diabetes mellitus to determine whether the psycho-social difficulties of children with TS were distinct from those of children with other chronic illnesses. As in the previous study, the Pupil Evaluation Inventory was used for peers in each class to rate each other's social behavior. Results showed that the children with TS were rated as significantly less likeable than their classmates as a whole and were more at risk for peer relationship problems than children with diabetes. Once again, tic severity did not correspond with the degree of likeability. Furthermore, peer relationship problems existed independently of family dysfunction, assessed among parents using the Minnesota Multiphasic Personality Inventory-2 and the Family Assessment Measure-3. Based on their findings, the authors suggest that the peer relationship problems of children with TS are not due to having a chronic illness in general, such as diabetes mellitus. Rather, they are likely related to the unique features of TS as a disorder.

A more recent study in 2007 compared 59 youth aged 8 to 18 years with chronic tic disorders with children with type 1 diabetes and healthy controls (Storch et al., 2007).

Using the Schwartz Peer Victimization Scale, they found that children with tics displayed higher rates of peer victimization than both the children with diabetes and healthy controls. As in the previous study, tics appear to be related to peer relationship problems in a way that diabetes is not. In this study, however, peer victimization was found to be positively correlated with tic symptom severity. Furthermore, peer victimization among youth with tics was correlated with loneliness, assessed using the Asher Loneliness Scale.

Adaptive functioning. Adaptive functioning among children with TS has been studied in terms of social skills, self-concept, self-esteem, and behaviors such as withdrawal and aggression. In the 1982 study by Jagger et al., 40% of the children with TS aged 5 to 12 years were judged by their teachers to be more awkward and clumsier than their same-aged peers without TS. Among the children aged 12 to 18 years, 35% were judged to be more awkward and clumsier than their unaffected peers. Using the Pupil Evaluation Inventory, both Stokes et al. (1991) and Bawden et al. (1998) found that youth with TS were rated as significantly more withdrawn and more aggressive than their classmates of the same sex. Interestingly, in the study by Stokes et al. (1991), individuals with TS did not report having problems with self-esteem, as per the Piers-Harris Children's Self-Concept Scale. Similarly, in the follow-up study by Bawden et al. (1998), children with TS denied self-esteem problems or social skills deficits, as per the Harter Perceived Self-Competence Scale for Children or Adolescents and the Matson Evaluation of Social Skills measure, respectively. The authors suggest that children with TS may lack insight into their social difficulties. Also noteworthy is that in both studies, children with both TS and ADHD were reported to be more aggressive than the rest of the sample.

Comorbid ADHD is therefore likely to place children with TS at greater risk for adaptive behavior problems.

Dykens et al. (1990) administered the Vineland Adaptive Behavior Scales to the parents of 30 non-medicated children with TS (ages 7 to 14 years) to assess their adaptive functioning. The Vineland scales assess adaptive behavior in the areas of Communication, Daily Living Skills, and Socialization. Socialization skills, which include interpersonal relationships, use of play/leisure time, and coping skills, emerged as a significant weakness in children with TS only, as well as children with both TS and ADHD. In a similar study, Carter et al. (2000) studied 72 children (ages 8 to 14) with TS alone and with comorbid TS and ADHD. They found that children with both TS and ADHD had poorer social adaptation than unaffected controls, as well as children with TS alone. No association between tic severity and social adaptation was found.

Other variables have been found to influence a child's adaptive functioning in the context of having TS. Edell & Motta (1989) found that among a sample of 30 children with TS aged 7 to 15, parents' reactions to the disorder predicted emotional adjustment. Children's perceptions of their parents' behavior explained most of the variance in their self-concepts (as per the Tennessee Self-Concept Scale) and levels of anxiety.

The findings of studies examining peer relations and adaptive functioning among youth with TS provide ample evidence that these children are at risk for being teased about their symptoms, for being rejected, as well as for exhibiting aggression and withdrawal. While findings about impaired self-esteem and self-concept are inconclusive in studies of children, there is some evidence of this among adults with TS. Thibert, Day, and Sandor (1995) found that among a sample of adult TS patients, the presence of

prominent obsessive-compulsive symptoms, rather than tics alone, contributed to impaired self-concept and decreased self-esteem. (The Tennessee Self-Concept Scale and the Revised Self-Consciousness Scale were used to assess these variables.) One can certainly imagine that the challenges youth with TS face in developing friendships are likely to have an adverse impact on their socialization process and that the effects of this may be felt well into adulthood.

Implications of TS for Dating and Romantic Relationships

Given the significant challenges in the psychosocial realm among individuals with TS, one would expect that adults with the disorder may have difficulties in navigating dating and romantic relationships. For instance, adults with TS may be hesitant to date because it entails exposing their tics and other symptoms to potential romantic partners. Given the negative socio-emotional experiences they may have had growing up with TS, adults with TS may still feel stigmatized by their symptoms and fear rejections by others. Adults with TS may also have had limited opportunities to develop the social skills involved in dating, given their potential social isolation as children and adolescents. At this time, there has been very limited published research examining the impact of TS on dating. Only one such study was identified. In this, Champion, Fulton, and Shady (1988) interviewed 210 individuals with TS and found that almost one half of the adults with TS reported problems with dating as a result of having TS. The nature of these problems was not explored, however.

Some research has focused on topics that are indirectly related to the subject of TS and dating. Specifically, research has been done on how having OCD or a genetic

disease impacts romantic relationship variables. In their study of 64 adults with OCD, Abbey, Clopton, and Humphreys (2007) found that the severity of obsessions was negatively correlated with emotional, social, sexual, intellectual, and recreational intimacy with romantic partners. The authors also found that individuals who worried about telling their romantic partners about their obsessions or compulsions were less likely to disclose personal information to them. The phenomenon of concealment of obsessions in OCD is further examined by Newth and Rachman (2001). These authors describe the shame, embarrassment, and fear of rejection that many patients with OCD experience around sharing the often disturbing nature of their obsessions with others. Given the similarities and overlap between OCD and TS, it is likely that individuals with TS may face similar challenges with romantic intimacy and the process of talking about their symptoms with partners.

Klitzman and Sweeney (2011) interviewed 64 adults with a genetic illness, or those who were highly at risk for one, about how they made disclosures to others about the genetic nature of their illness. The illnesses included Huntington's disease, breast cancer, and Alpha-1 antitrypsin deficiency. The authors found that the participants who were considering or involved in dating faced several dilemmas: Whether, why, when, how, and what to disclose. They found that individuals typically chose to share information about an illness because of a sense of ethical obligation, because someone else in their family had a disease that could not be hidden, because future children may be affected, or because it was hard to hide their diagnosis. Subjects who chose not to make disclosures tended to cite a fear of rejection. Individuals in the sample often struggled with how much to say to romantic partners about the genetic illness in question. In terms

of when to make disclosures, individuals reported feeling challenged in deciding when they felt close enough to a partner to talk about their illness or genetic risk. They also reported waiting to make disclosures until they felt the relationship had potential for the future. Some subjects chose to share their diagnosis or genetic risk only if asked, others did so only after a relationship ended. Several participants reported avoiding dating altogether in order to avoid all these dilemmas.

The findings of Klitzman and Sweeney's study (2011) are relevant to the subject of TS and dating in several ways. For one, TS is a genetic disorder that may be passed on to offspring, and affected individuals may have concerns about discussing this risk with romantic partners. Furthermore, adults with TS may be forced to disclose their diagnosis to romantic partners because they cannot conceal the symptoms of the disorder. Like the individuals in Klitzman and Sweeney's study, individuals with TS may be concerned about discussing their condition with partners because of a fear of rejection. They are likely to face similar struggles with whether and how to disclose their diagnosis to partners, as well as when to do so. Finally, adults with TS may also avoid dating situations entirely because the notion of exposing and talking about their disorder is too stressful.

At the same time, individuals with TS are likely to face unique challenges in dating that probably differ from those faced by individuals with other genetic illnesses like Huntington's disease, breast cancer, and Alpha-1 antitrypsin deficiency. Perhaps most importantly, unlike these conditions, TS is not a fatal disease that leads to serious medical problems. Therefore, the idea of sharing the genetic nature of TS with a partner and facing the possibility of passing on the condition to one's children is arguably less

daunting. Additionally, TS is a condition that tends to be poorly understood, in that tics are often perceived as voluntary by observers. Tics typically draw unwanted attention to people with TS, leading to a heightened self-awareness in public that may involve shame and embarrassment. As such, individuals with the neurological disorder are likely to have unique experiences in how and when they choose to explain their symptoms and how they choose to manage their symptoms with partners.

Klitzman and Sweeney (2011) describe their study as “the first to explore several key aspects of disclosures of genetic information in dating” (p. 98). This underscores that fact that literature on the impact of genetic illnesses on dating is scarce in general, and very little is known about TS and dating specifically. The current study seeks to address the question of how TS affects the dating process, by interviewing adults with TS about their experiences with dating and pursuing romantic relationships. It is hoped that the data obtained will provide a rich understanding of how TS impacts dating, how affected individuals deal with any challenges, and how other variables, such as the reactions of peers and family to TS, influence the dating experiences of adults with the disorder.

Chapter II

Methodology

Participants

Only women were chosen to be interviewed for this study, as the interviewer, the principal investigator of this study, is also female. Due to the intimate nature of discussing the topic of TS and dating, a same-gender interview process was used with the intention of creating an optimal comfort level for subjects. It was anticipated that female subjects would be more open than male subjects with the writer about their dating experiences, ultimately leading to richer data.

The participants are five adult women in the New York/New Jersey area who have been diagnosed with TS. Their ages range from the 20s to the 50s, representing a wide range of life and developmental stages. While recruitment targeted women who were both single or in a romantic relationship, all subjects are either married or in a long-term romantic relationship. Participants were recruited through word of mouth and a networking sample associated with TS Organizations. Advertisements were also placed on websites relevant to individuals with TS (see Appendix A). Women with developmental disabilities and other serious psychiatric disorders, such as psychosis and bipolar disorder, were excluded, as these conditions are likely to have an additional impact on the women's dating experiences above and beyond their TS. (This study focuses specifically on the impact of TS and common accompanying symptoms, such as obsessive and compulsive symptoms and inattention and hyperactivity, on adult adults' dating experiences.) Subjects were offered no compensation for participation.

Measures and Data Collection

Subjects were interviewed in person in their home or in a place that was comfortable, quiet, and ensured privacy. Interviews lasted between 1.25 to 2 hours. At the beginning of the interview, a brief Demographics Questionnaire (see Appendix B) was administered to participants in order to gather their demographic information, as well as information about when they first started experiencing tics and when they received their TS diagnosis. The questionnaire also requests information about other psychiatric diagnoses and symptoms. Participants' current tic severity was assessed using the Yale Global Tic Severity Scale (YGTSS), a clinical rating instrument for tics (Leckman, Riddle, Hardin, Ort, Swartz, et al., 1989). (See Appendix C). The YGTSS scores provide an indication of the levels of severity, frequency, and impairment of each participant's tics.

A semi-structured interview (see Appendix D) was used to gather rich, qualitative information about the participants' experiences that serves as the main data for this study. The interview includes open-ended questions about the participants' socio-emotional experiences of growing up with tics and their experiences of dating with TS. It is flexible in nature, allowing for participants to elaborate on topics they find to be important, and for the investigator to use follow-up questions. The semi-structured interviews were audio-taped and transcribed for subsequent analysis. Data were de-identified in order to maintain confidentiality. All study procedures were in compliance with regulations set forth by Institutional Review Board for the Protection of Human Subjects in Research at Rutgers University.

Data Analysis

The primary data gathered from the interviews is qualitative, descriptive, and content-rich. The purpose of the analysis is to present in-depth illustrations of the experiences of the five subjects, drawing on their narratives and perspectives. Furthermore, the analysis aims to identify common themes among the women pertaining to dating and pursuing romantic relationships. Accordingly, a qualitative data analysis approach is used. Corbin and Strauss (2008) describe qualitative analysis as “a process of examining and interpreting data in order to elicit meaning, gain understanding, and develop empirical knowledge” (p. 1). The analysis is comprised of two dimensions. The first is a multiple case study design. Here, the data from the five interviews are summarized, and the women’s experiences are presented in depth (Chapter III, Results - Part 1). The second form of analysis follows a grounded theory approach, in which common themes are identified across the five cases and are presented and discussed (Chapter III, Results - Part 2). In conjunction, these two analyses address the five guiding research questions: 1) How do adults with TS navigate dating and romantic relationships? 2) What challenges and limitations do adults with TS face in dating and pursuing romantic relationships? 3) How do adults with TS go about explaining their symptoms to romantic partners? 4) How do the socio-emotional experiences of adults with TS with family and peers influence their dating experiences? and 5) What factors are helpful for adults with TS in navigating dating and romantic relationships?

The overall structure of the analysis can be conceptualized as a matrix: The first component follows as a vertical pattern, in which each case is analyzed in depth (multiple case studies). This analysis is presented in Results - Part 1. The second component

reflects a horizontal approach, in which major categories of data are examined across subjects (grounded theory). This constitutes Results - Part 2. Here, the responses from the five interviewees are compared and contrasted within those categories. It is hoped that the use of these two qualitative analysis techniques will result in a rich, descriptive, and critical understanding of the complex and interacting experiences of the subjects, which will be relevant to adults with TS at large.

Multiple case study. According to Yin, (2003), the case study method is ideal when seeking to understand “complex social phenomena,” while retaining “the holistic and meaningful characteristics of real-life-events.” (p. 2). He explains that when seeking to answer *how* and *why* questions, case studies are an especially suitable choice of research design. Additionally, when the investigator has no control over behavioral events and the focus is on contemporary, rather than historical phenomena, a case study approach is often used (Yin, 2003). These criteria are consistent with the goals and characteristics of the present study. Thus, a multiple case study approach was chosen for the vertical pattern of analysis in order to explore the socio-emotional experiences of five adults with TS. A focus is directed toward their dating and romantic experiences. The specific analytic strategy followed is what Yin (2003) describes as developing a case description, in which the investigator develops a descriptive framework for organizing the case studies. In the present study, the subheadings under ‘Results - Part 1’ in chapter III constitute this framework.

Grounded theory. Auerbach and Silverstein (2003) suggest that using grounded theory allows researchers to begin a research study without having to test a hypothesis. Instead, the investigator is able to “develop hypotheses by listening to what the research participants say.” (p. 7). Questions of interest are driven by the responses of participants, rather than being rooted solely in preexisting theories. As such, this kind of research is often referred to as hypothesis-generating, rather than hypothesis-testing (Auerbach & Silverstein, 2003). This approach is well-suited to the present study, for which almost no pre-existing theories are available. Grounded theory was therefore used for the horizontal pattern of analysis.

The data of this study is analyzed according to the steps delineated in the grounded theory approach by Strauss and Corbin (1990). In the first stage, referred to as open coding, the data are examined and categorized by similarities and differences. This is done by closely examining the transcripts of each study participant. Additionally, each transcript is analyzed as a whole to extract major themes. This allows for extracting general categories for smaller subsets of data, and data is collapsed into these categories. In the second stage, called axial coding, the relationships among the categories are identified. In the final stage, referred to as selective coding, categories that were previously identified are further collapsed to form the core categories of the model. Categories are connected through a paradigm model that forms the grounded theory, and the connection between the categories are refined and validated (Strauss and Corbin, 1990). These core categories are represented by the subheadings under ‘Results - Part 2’ in chapter III.

Chapter III

Results - Part 1

The Case of Jessica*

Identifying information and relevant history. Jessica is a heterosexual Caucasian lawyer in her mid 50s who lives in a suburban town. She is married with three children. Jessica first began experiencing tics at the age of 8 years, but did not receive an official diagnosis of TS until her early 20s. At that time, it was also determined that she had mild OCD. She currently takes a low dose of a benzodiazepine, as well as an antidepressant (SSRI) to help control her tics and manage symptoms of depression.

At the time of the interview, Jessica rated her tics to be in the moderate range, as per the YGTSS. When asked about her OCD symptoms, Jessica explained that she had experienced periods of trichotillomania (compulsive hair pulling), needing to touch or pick up things a certain number of times, and that she sometimes has obsessive thoughts about people dying or getting hurt. With regard to problems related to ADHD, Jessica recalled that she had difficulties sitting still and concentrating as a child, and that she tends to lose focus easily when reading.

Process of receiving diagnosis. When Jessica's motor tics first became noticeable at age 8, her parents took her to the pediatrician. The pediatrician informed Jessica's parents that she would grow out of her tics, and that they should not place undue pressure on her or try to make her stop engaging in her tics. As Jessica approached

* All names and other identifying information have been changed in order to maintain confidentiality.

puberty, her tics temporarily subsided, and her parents became hopeful that she was indeed “growing out” of them, as the pediatrician had predicted. But because she was still experiencing tics in her early teens, Jessica’s parents decided to take her to a neurologist, who prescribed her Haldol, a typical antipsychotic commonly prescribed for TS. Jessica noted that the neurologist did not give her a diagnosis of TS at the time, however. “To this day I’m puzzled because I don’t know why [the neurologist] gave me Haldol and no one said it was Tourette’s.” So while she gained some relief from her tics through the medication, Jessica remained unaware about the condition underlying her tics. She and her parents also had a limited understanding of what her tics actually were, let alone what was causing them.

Throughout her teenage years in the 60s and 70s, Jessica’s parents encouraged her to see a psychotherapist, whom they hoped would address the potential psychological problems underlying her tics. Jessica saw several therapists during this period who helped her to cope with family pressures and stress. However, none of them directly addressed her tics. She recalled her experience with one particular therapist. “[He] was wonderful... a nice man who kept telling me how great I was... It was nice to go to him, but [he] did absolutely nothing for my tics!” When Jessica was a student in college, she developed a severe and painful head shaking tic and became desperate for relief. At that point, her parents contacted a neurologist at a hospital who finally diagnosed her with TS. About receiving her diagnosis, Jessica said, “It was a giant relief for me... to know that it had a name, and I wasn’t crazy.”

Family’s response to tics. When asked how her family of origin responded to her tics, Jessica made a distinction between the period of time prior to being diagnosed with TS and the period of time following her diagnosis. Before Jessica was diagnosed in her 20s, her parents felt notably frustrated about her tics: “They were at their wit’s end at times. They thought they had a crazy child. They just were desperate to try to get me to stop.” Jessica also remembered her mother trying to help her to stop ticcing in a way that suggested Jessica’s tics were unnoticeable to her, but voluntary. “My mother would say, ‘We’ll have this little code between us, and when I see you across the room, like blinking your eye, I’m going to do something, and you’re going to stop.’”

After Jessica received her diagnosis, things shifted. She recalled that post-diagnosis, when her tics would be observable, her parents stopped pointed them out. “They didn’t do all those subtle things they did when I was younger, like, say, ‘Can you stop that?’ or ‘We have a crazy daughter!’” Jessica also noted that her parents were proud of her for taking the diagnosis and her symptoms as well as she did. Looking back, she sensed that her parents felt guilty that it took so long before she was diagnosed. Additionally, Jessica believed her father felt guilty because someone on his side of the family had had tics: “All of a sudden, he realized it was something that he could have passed down to me.”

Peers’ reactions to tics during childhood. Jessica felt that her close friends did not make much of her tics when she was growing up: “They didn’t seem to say anything or care... It didn’t seem to drive them away. Not that they wouldn’t want to be with me or that they’d be embarrassed to be with me.” She noted that some friends asked her why

she engaged in her tics, to which she would answer, “I don’t know.” With the other children at school with whom Jessica was not friends, things were different, as these peers sometimes imitated and teased her. While she did not elaborate on these experiences, Jessica did not appear to have been emotionally scarred by them.

Helpful and problematic responses from family and peers. What Jessica found helpful was when her family did not mention or point out her tics. She noted that her two siblings, whom she was very close with growing up, tended not be phased by her tics or compulsions. “I don’t know if it affected [my siblings] or not, but it never seemed to affect our relationship.” Something else she found helpful was her parents’ willingness to provide practical help in order to address the outcomes of her tics and compulsions. Jessica recalled one incident as a young adolescent in which she compulsively pulled out most of her eye lashes (a form of trichotillomania). “My mother was trying to be very helpful. She tried not to freak out, but instead she tried to get me eyeliner and tried to make it [alright], you know? That was a helpful thing. She wasn’t freaking out too much.”

In general, Jessica was grateful for her parents’ efforts to seek professional help for her during her youth, even if they misunderstood the nature of her condition. Although the psychotherapists she saw growing up didn’t ultimately address the problem she was seeing them for, she recognized her parents’ commitment to helping her gain relief. “They tried to get me help; they thought the psychiatrist would help. That wasn’t helpful with the tics, but it was helpful in that it was a positive step. ‘Cause they figured that that couldn’t hurt.” On the other hand, Jessica found it unpleasant when her parents

noticed and commented on her tics in her younger years. “I felt much more stressed when they would point it out to me... and try to make deals with me, like ‘If you stop, we’ll do this,’ or ‘When we do this, you’ll stop.’ As if I didn’t know I was doing it, as if I were the controller. That was stressful.”

Another problematic response style for Jessica involved family members becoming distressed and overtly anxious in response to her symptoms. When her parents responded in these ways, Jessica did not feel she was able to discuss her tics and compulsions, which to her at the time, were incomprehensible. She recalled, “If I had a really bad day, or a new tic appeared, and I wanted to talk about it,... everybody went crazy. I mean my parents went hysterical! That was no good; I couldn’t really talk about it.” Jessica remembered one instance in particular as a teen when she engaged in an inexplicable behavior that was part tic, part compulsion. She experienced a strong urge to run a razor over her cheek in order to see whether this would cause her to grow hair in this area. Unable to resist this urge, she shaved her cheek. Subsequently, she told her parents, who responded with great distress. “I felt I had to tell them because I was really worried about it. But I didn’t get a good response... They got more worried... the worst things were the mumblings and the talking when they thought I couldn’t hear them. Like, ‘What’s wrong with her? We have a crazy kid!’”

As with the responses from her family, Jessica found it helpful and reassuring when her friends and peers didn’t make much of her symptoms and didn’t let it affect their relationship: “[What was helpful was] the fact that they didn’t say anything. Or maybe asked me about it, but still didn’t withdraw from me. Just remained my friend.” On the flip side, she resented some of the teasing she was subjected to by peers whom she

was not close with. “They stood in front of me and imitated me and stuff like that. That was obviously not helpful because you feel embarrassed and all that. Or imitating noises I made, or stuff like that.” Jessica noted that even adults would sometimes draw negative attention to her tics when she was growing up. “A youth group leader once, he said to me, ‘Why are you doing this?’ In front of everybody. I was so embarrassed, I ran out of the room.”

Jessica recalled several instances in her adult life when others responded to her tics in ways that would uncomfortably draw attention to her in public. She suggested, however, that she felt less bothered by others’ inappropriate comments once she had received and understood her TS diagnosis: “At least then I knew what I had.” It is likely that Jessica has become more comfortable with her condition with age and maturity, as well as through an understanding of her diagnosis.

Interventions received for TS. In addition to taking various medications that have been prescribed to her by doctors over the years, Jessica has attended counseling sessions and support groups to address her tics and associated psycho-social difficulties. After being diagnosed with TS, Jessica found it helpful to attend support groups for individuals with TS in order to receive support for what she was going through. Later on, she found it helpful and rewarding to attend these groups in order to help others who recently had been diagnosed. She explained, “For a while, people were calling me when they were newly-diagnosed, the parents [of children with TS]. So I talk to the parents; I talk to the kids. And I just like doing that, because when I was in that situation as a kid, and you don’t know what’s wrong with you, and you think you’re always going to have

these severe tics, you just never believe that you can grow up and have a job and get married and do whatever, or have any friends even, or whatever.”

In terms of treatments, Jessica has also received Botox injections to lessen a particular tic that was causing her impairing muscle pain in her arm. (Botox temporarily paralyzes a set of muscles in the region it is injected into.) She noted, however, that this only reduced the occurrence of her arm tic, but not her urge to engage in the tic: “It worked in that it deadened my arm and gave my arm a rest for a while, but the psychological torture of that was worse.” (Engaging in a tic usually relieves the urge – thus an inability to engage in a given tic while still experiencing the associated urge can be extremely frustrating.) When asked whether she might consider Botox again in the future, Jessica responded, “I think that if my pain was ever to get so, so bad, and I just needed a break, maybe I would just tell [my doctor] to do it again - just to take the pain away for a little bit.” Jessica has received physical therapy to help strengthen her arm and to reduce the pain caused by a repeated arm tic. But as with the Botox, she did not feel that this has brought her significant relief. “It was probably good, but I think I was just too lazy to work at it. It didn’t help the tics themselves, and it was just such hard work!”

What has helped in adjusting to having TS. Jessica reported feeling tremendously fortunate with regard to how accepting those around her have been of her condition. “I’ve just been lucky in that I’ve just been surrounded by people who are accepting, who understand and don’t judge me, and who can live with me. Because - this is terrible to say - but I don’t know if this was my spouse, and I had to watch all the movements all the time and listen to things, the noises, I don’t know if I could do it, if I

could live with somebody [with TS].” For Jessica, the accepting and patient stance of her husband, children, and close friends has been something she appreciates and does not take for granted. Additionally, Jessica feels that the various medical and mental health professionals she has seen have had a positive impact on her overall wellbeing in the context of living with TS. She noted that their helpfulness often took the form of expressing understanding for her as an individual and what she was going through. She pointed out that she continues to see her current medical doctor, who lives almost an hour away, not only because of his expertise with TS, but because she likes his understanding and supportive manner: “He’s just like a good friend!”

Dating experiences. Jessica has had four romantic relationships lasting three months or longer. She reported typically meeting boys/men through youth group functions, school, and friends. When asked whether she had ever avoided becoming romantically involved with men because of her TS, she responded that she didn’t believe so. “[Becoming romantically involved with someone] was always something I looked for. Not that I was always successful, but ... I don’t think I ever avoided it. It’s just a very strong need I had, to be accepted and to be liked. That outweighed my fear of embarrassment.” Jessica pointed out that in the years when she started dating, her tics were at their mildest, and she was less afraid of how she might appear to others.

When she was in college, Jessica was in a long-term relationship with a young man who was particularly supportive and accepting. After several years of having fairly mild tics and compulsions, her symptoms once again became quite severe. At this time, Jessica had been dating her boyfriend for almost two years. She recalled his role as she

went through the process of being diagnosed with TS: “He came with me and my parents to the doctor when I was diagnosed. And he just stuck by me... When the appointment was over, he gave me something that said, ‘I like you just the way you are,’ or something... It didn’t bother him.” Jessica knew her husband, Peter, in her teens, but only began dating him after she graduated from college.

When Jessica was asked to reflect on how she has typically disclosed her TS symptoms or diagnosis to romantic partners, she noted that she had only started one relationship (with her husband) with the knowledge of her diagnosis. Prior to being diagnosed with TS, she had a hard time explaining to her boyfriends what her tics were, as she herself did not know. When the opportunity arose to provide an explanation for her involuntary movements, either because someone would ask her about her symptoms, or because she felt the need to explain her tics and compulsions, she would try to address them briefly: “I just said, ‘You know, I’ve been doing these things for a long time. I don’t know why I do them.’” With her boyfriend during college, who was with her when she was diagnosed, Jessica obviously did not feel the need to actively share her diagnosis. Regarding her husband, Peter, Jessica pointed out that he had observed her tics prior to when they became romantically involved. Unbeknownst to Jessica at the time, he had asked a friend of hers about them, and her friend explained that these were movements and sounds that Jessica had been making for a long time. Because Jessica knew Peter before they started dating, she did not feel especially self-conscious with him about her symptoms. She recalled that it was not a big deal to bring up her diagnosis once they began dating when Jessica was in her 20s. “We probably just started talking about it when I started dating Peter... I don’t remember exactly the first time I told him. Or

maybe my friend told him, I don't remember. But it was never, really, like, a big deal. Whether he asked me or I told him, I don't know... So I don't remember it being a real issue, you know?"

Jessica highlighted that her husband has never made much of her tics. "My husband said that when he met me... before he knew what was going on, he thought it was a little strange, but - I said, 'Didn't my tics bother you?' And he said, 'No, I thought they were cute!'" Furthermore, she noted that he seems not to notice her tics, even when she is very aware of them. "There have been times when I have said to my husband, 'Does this bother you?' He said, 'No, I'm used to it.'"

Jessica was asked whether her romantic partners had taken steps to learn about TS and to support her. She had difficulty pinpointing ways in which they had. She suggested that her boyfriend in college certainly had learned about TS by accompanying her to the doctor when she received her diagnosis. "I was diagnosed when I was with this most serious boyfriend for the four years, and he was with me through it all." With regard to her husband, Jessica suggested, "When I asked him to come to a support group in the beginning, he did. But he didn't have any intense interest in things. I mean, he's read about it, but not any intense interest to keep going over it and all that stuff." What Jessica found most helpful in her romantic partners' attempts to support her was their general patience, understanding, and encouragement. She described an intense negative reaction she once had to a medication used for her tics and her husband's response to this: "I'm sure [my reaction to the medication] was very hard for him. But he just said, 'I'm sure it'll get better.'"

Looking back, Jessica did not feel that making disclosures about her diagnosis

and symptoms of TS to romantic partners impacted her relationships much. “I guess [TS] was just always something that was part of me... [Romantic partners] have been sympathetic to some extent. Not overly babying me... just taking it in strides.” She noted that overall, her partners have assured her that her tics don’t bother them, which she has found helpful and reassuring.

Impact of family and peers’ responses to TS on dating experiences. Jessica proposed that the generally positive responses from her immediate family and friends had helped her to go about dating without fears of being rejected or ridiculed. “[My mother] just thought everything I did was so wonderful, especially when she knew I had this diagnosis.” “I think that I was lucky that I had friends that were friends with me despite everything. It gave me reason to believe that as I got older, I would always have some friends... I guess I just thought if I had people that accepted me, that other people would accept me too.” At the same time, Jessica acknowledged some of her parents’ negative reactions when they misunderstood the involuntary nature of her tics. With regard to these, she felt that she may have become more determined to lead life as normally as possible, in spite of her symptoms. “I just kind of wanted to forget about those early days... just all the not understanding and everything. I just think the whole thing in general probably made me stronger.”

Advice for adults with TS and parents of children with TS with regard to dating. Jessica had several suggestions for parents of children with TS and adults with TS in relation to navigating dating and pursuing romantic relationships. The first

involved educating children with TS and their parents about the course of TS. “[I would tell them] that things with Tourette Syndrome could change day to day, and that things could help, medicine could help, that they’re going to experience different degrees of tics. If they think they’re really bad now, that they’re not always going to be this way. They shouldn’t ever think that they don’t have a future with anything.”

The second point Jessica made was that parents of children with TS need to encourage the latter to pursue as normal a life as possible. “Don’t ever tell them that they won’t find a relationship... not to ever try to discourage them from pursuing friends and relationships. Be supportive.” She suggested that affected children would benefit from the attitude that tics are just one example of a trait that children may dislike about themselves, and that all children have some traits they do not like about themselves. “Just go for it! Because everybody’s got something, you know? Whether it’s visible or not!”

Jessica’s third point addressed how adults with TS might go about finding treatments for their symptoms: “They should try to help themselves as much as they can, as far as trying to get good treatment and as best control as they can... I just think in general, it is a lot easier if you can have some control over your tics.” At this point, Jessica shared a story about an adult male acquaintance with severe tics who has refused all medication in order to avoid side effects. Jessica admired him for successfully navigating romantic and social relationships, but felt that his social life might have been a lot easier had he been willing to seek more treatment for his tics.

Finally, Jessica advocated for talking to romantic partners about TS. “[Adults with TS] should be open with their partners and their dates and everything... [Partners] need a certain amount of education about the fundamentals about what [TS] is.” She

added that it is important for romantic partners of people with TS to be accepting of the symptoms: “I guess you just have to find someone that’s patient and tolerant. It’s going to have to be something that they can overlook. Not overlook ignore, but overlook in a way that it’s not going to bother them being with you... I would never date anyone who would tell you, ‘I know you can help that [the tics], so stop it.’” Jessica also pointed out the importance of partners being willing to give up certain date activities that are not possible for an individual with TS. Using as an example her friend with loud vocal tics and his associated difficulties with going to movie theatres, she stated, “So [the tics] might be a barrier in things you can do together. It could be in those kinds of cases. It could just be something to ask people or make people aware of who are dating or who are looking for relationships. Like, maybe it’s not so important, something the person can give up, going to the movies.”

How the genetic nature of TS may affect dating. At the end of the interview, I asked Jessica whether she had any additional comments about TS and dating that she thought would be relevant. In response, she raised the issue of the genetic nature of TS and the impact this might have on starting a family with a spouse. None of her and Peter’s children have tics or TS, but Jessica was conscious about how this possibility could have impacted her life. “I don’t know – how would my marriage be now if [all our kids] came out with TS? ... How would I be? How would my life be? I don’t know.” She has been well aware of the possibility of her children developing symptoms during their childhood and has gone through efforts not to expose them to potential triggers, such as stimulants. With regard to the chances of children inheriting TS from a parent, she

suggested “I think it is something that is probably worth discussing [with a partner]... Maybe genetic counseling would be something that could be discussed, something that I would recommend.”

I was curious about to what extent Jessica and her husband had engaged in this kind of conversation, especially given the severe tics that Jessica had experienced during several periods in her life. While she thought this was important discussion to have, she pointed out that she and Peter never doubted wanting to have children. “I don’t even think it was ever a question that we were debating - whether to have children or not, even though I knew I had [TS], and at that time there was a possibility that it was genetic... Why we never even thought about it? ... Maybe just because I thought, ‘Hey, I’m ok now living with it.’” Furthermore, for Jessica, the possibility of her children having TS seemed far less worrying than the prospect of them having other serious genetic illnesses. “I’ve had people say to me, like, ‘Why would you even think of having kids?’ And I’m like, ‘Well, it’s not a fatal disease!’ That’s my response... I see so many horrible things, and to me, it’s just... I mean, I’d rather have [TS] than a million other things.” Jessica also pointed out that there is much more awareness of and treatment for TS nowadays, compared to when she was growing up in the 60s. “I just think that if [my children] are to get my genes, they don’t have to wait 15 years to be diagnosed.... There’s been a lot of change.”

The Case of Anne

Identifying information and relevant history. Anne is a heterosexual Caucasian woman in her mid 50's living in a suburban area. She is married with two children and works as an executive assistant. Anne first began exhibiting tics at the age of 13 years and received her TS diagnosis when she was in her mid 30's. She has no other psychiatric diagnoses and currently takes no medication to treat her tics. Anne's tics were in the moderate range at the time of the interview, according to the YGTSS. Throughout the interview, she had loud vocal tics that intermittently disrupted her speech.

Process of receiving diagnosis. At the time Anne was growing up, very little was known about TS. During her youth, she was plagued by embarrassment and shame about her tics. She vaguely remembered going to a hospital as a teenager with her parents, where some tests were performed. When asked about the nature of these evaluations, she suggested, "I don't [remember]... I just kind of blocked all of this out, I guess." She did know, however, that this medical visit did not lead to an understanding of what was wrong with her. "Back then, nobody knew what this was." It was not until her mid 30's that Anne first heard of TS. The first time she came into contact with the term was at an organized social event at which a TS organization did a presentation in order to raise funds for TS research. Anne recalled that a film was shown on TS, and that she found the symptoms being explained very familiar. "I'm sitting there, thinking, 'You know what? I bet that's what I have!' ... It was almost like self-diagnosis. I had never heard of Tourette's before - never." After the presentation, Anne visited a neurologist, who diagnosed her with the neurological condition.

I asked Anne whether it was a relief to find out that there was a known neurological cause for her symptoms once she received her diagnosis. She responded, “No, because I still hid [my tics]. Like, it wasn’t socially acceptable for me to tic... It was, like, ‘Oh, that’s what this is.’ But it didn’t make me feel happier.” As such, Anne did not feel that her life changed after she gained an understanding of her tics, and she has remained uncomfortable about her symptoms to this day. She suggested, “I was always embarrassed by [TS]. I didn’t like it; I was very ashamed. My self-esteem wasn’t great.”

Family’s response to tics. Anne described growing up in a volatile family environment. She recalled, “It was very hard growing up.” With regard to how her parents responded to her tics, she said, “I don’t even think they knew what it was.” She explained that they thought she would be able to control her tics if she made an effort and therefore chastised her for them. “I was berated for it, embarrassed, punished for it, which was, like, saying, ‘Stop, stop, I know you can stop that!’” Anne moved out of her parents’ home permanently once she started college. When she received her diagnosis as an adult, she shared it with her parents. However, she stated, “We didn’t get into what it was.” When asked whether her parents changed their stance toward her and her tics at that time, she stated, “Nobody ever brought it up. It was like nothing.”

Peers’ reactions to tics during childhood. Anne described feeling very self-conscious in grammar school with regard to her tics, as she was teased about them by her peers. She remembered crying in response. Additionally, her teachers were not very

understanding about her vocal tics and perceived them as deliberate, disruptive acts. She stated, “I was embarrassed a lot by [my tics]... It was hard. There was no support.” During high school and college, Anne’s tics subsided somewhat, and Anne was less plagued by negative attention from peers. Additionally, she developed an increased capacity to conceal her tics during her late adolescence, which she found beneficial. “I think I tried to contain a lot of them, like hide them more, until I was alone. And then it would come out.”

Helpful and problematic responses from family and peers. Anne found the responses of her parents to her tics particularly problematic. She recalled, “My family told me I could stop it, that I would be punished if I didn’t stop.” One of her alleged punishments involved being taken to a “children’s home,” where she was “dropped off.” Anne also noted that the teasing by her peers in school was unhelpful. Talking about these memories was very painful for her, and Anne chose not to elaborate further on how others’ reactions had impacted her while growing up.

As an adult, Anne has continued to encounter reactions to her vocal tics that have induced humiliation and heightened self-consciousness. She recalled an incident while shopping in a store: “This cashier said, ‘Why is she making all of these noises?’ I was mortified. And I never went back to [location] again. I still have the association with that. But I feel like people look at me... Probably people could care less when they’re doing their own thing, but I feel like, ‘Oh my God, everybody’s watching!’” As a result of her discomfort with her tics, Anne has often actively avoided social situations in which others may observe her symptoms. “I haven’t kept in touch with good friends that I would have

liked to... I've isolated myself... And I don't do things because I feel embarrassed." Anne identified no helpful reactions from family or peers.

Interventions received for TS. Upon being diagnosed with TS in her mid 30s, Anne's neurologist prescribed her an anti-psychotic medication along with some other medications, whose names she could not recall. However, the undesirable side-effects of extreme sleepiness and weight gain made Anne decide to discontinue their usage not long afterwards. She recalled, "It did work, the tics stopped, but... the side-effects were worse than the tics, I think ... I didn't like the way that they made me feel."

Besides taking medication, Anne attended an adult TS support group for a few sessions, which she described as "very helpful." She has also tried homeopathy, counseling and several other alternative treatments, including one that put physical pressure on certain meridian points on the body. She has tried to eliminate certain foods from her diet that have been hypothesized to influence the frequency of tics. Anne found that these alternative treatments alleviated her stress and improved her immune system. As for whether they reduced her tics, she stated, "Nothing worked 100%."

What has helped in adjusting to having TS. First and foremost, Anne has found the TS support groups and organized gatherings to be helpful, as these have allowed her to feel somewhat more at ease about having TS. She finds it uplifting to volunteer as a counselor at camps for children with TS. She explained, "Even though I'm older, I still hide [my tics]. I'm not comfortable saying it to people. That's something I've wanted to do more, to say, 'I have Tourette Syndrome,' and no big deal. And anyone I've spoken

to, it isn't a big deal for them. It's me. It's my feeling of low self-esteem. So I think working with the kids helps." Anne has been impressed with the comfort level of many children with TS who are able to explain their tics to others with no observable discomfort: "Oh my gosh, these little 10-year-old kids, or whatever they are – they're talking about their tics and what to do. It's amazing!" I asked her whether these observations have made her feel more at ease when she experiences her own tics. Anne suggested, "Probably. Because then I don't have to be so - that I don't want to tic in front of people."

While Anne has found it comforting to be in contact with other people who have TS, it remains hard for her to openly disclose her diagnosis and acknowledge her tics. She recalled a recent incident in her workplace when one of her colleagues brought her daughter to work. Anne was asked to spend some time with this 14-year-old girl while her mother was busy. Anne remembered feeling anxious about having noticeable tics in front of her. "I wish I could just have said, 'I have Tourette's, don't pay any attention [to the tics].' It turned out later, that the woman's daughter, the girl that was in there, has Tourette's. And I said, 'Boy, what a missed opportunity to say something!'"

On several occasions during the interview, Anne described her wish to be able to communicate more easily with others around TS, both with those who share her condition, as well as with those who don't. She tearfully recalled that she had not spent as much time with her nieces and nephews as she would have liked to while they were growing up due to her discomfort with her tics. "I don't have a relationship with them because I don't want to come out and say... I don't want to be around them and tic... I'm not open about saying what I have. I'm thinking, 'God, my whole life I haven't spent

enough time with them.’ And that’s the part now that I really regret.” She recognized that talking more openly about her TS would be helpful in her adjustment to living with the condition, but pointed out that this was hard for her: “I’d like to [be more open], and I don’t quite know how to get there yet.”

Dating experiences. Anne estimated that she has had about 20 romantic relationships in her life that have lasted at least three months. She has met romantic partners through school, friends, and work. Anne did not remember avoiding dating because of her tics. She suggested, “I don’t remember being in that situation. I think I’m more concerned with it now, but not when I was dating. I dated a lot.” When asked how she managed her tics when she was actively dating, Anne pointed out that her tics were not as severe at the time as they are presently. When she did have tics, she remembered trying to hide them as best as she could.

When I asked Anne to reflect on how she has typically talked about her tics to romantic partners, she noted that she has not typically volunteered information about her tics. She pointed out that explaining her tics to others while she was dating would have been difficult, as she really did not know what her tics were at the time. “It was a habit, it was something - we didn’t know what it was. There was nothing I would know. It was never anything that anybody knew about. Why I did those things? It was a habit... My parents would say that.” It wasn’t until she received her diagnosis that Anne had language to talk about her tics. When she did receive her diagnosis, she was in her 30s and had been married to her husband for over a decade. Receiving an explanation for her tics reportedly still did not make it easier for her to talk about them. Even with her

husband, Anne recalled, “I was still very private, very embarrassed by it all. It was very limiting.”

Anne did not remember any of her romantic partners inquiring about her tics. She attributed this in part to the fact that her tics may have been less severe when she was actively dating. She suggested, “I don’t think it was a big deal back then... I never lost a boyfriend because of it.” Later in life, after she got married and had children, her tics became more noticeable. She felt that her husband had responded well to her tics, as well as her diagnosis. “He had said it didn’t bother him...He was very accepting of it. I don’t think it ever fazed him back then.” She added, “I still don’t think it really fazes him that much that I have Tourette’s. It’s more that I scare him every once in a while,” referencing her loud vocal tics. She suggested that receiving her TS diagnosis was probably a relief to her husband, as it provided an explanation for her tics.

Anne was asked whether her romantic partners had taken steps to learn about TS and to support her. She felt that this only applied to her husband, as her previous partners had not known about the condition. Of her husband, Anne said that he has probably looked up TS on the internet. Additionally, he has accompanied her when she has attended support group meetings and other TS events. Anne noted, “I don’t know people outside of my everyday life that have Tourette’s. So I wanted my husband to see what some of them do.”

Impact of family and peers’ responses to TS on dating experiences. When Anne was asked to reflect on how the responses of her peers and family of origin to her TS have impacted her dating experiences, she suggested that others’ responses to her TS

per se had not directly influenced her romantic life. However, she felt that she had dated a large number of men “because I think that I was looking for a father figure, or somebody to like me... Probably I was looking for that love that I didn’t get.” In other words, Anne believes she compensated for the poor relationship she had with her parents by seeking out romantic relationships continuously as a young adult. She added, “And then you could say that it was the Tourette’s that probably caused the issues with my family.” She explained that she believed her father had suffered from rage problems, which may have been caused by TS. She believed that his anger issues contributed to a combative and volatile family environment.

Advice for adults with TS and parents of children with TS with regard to dating. I asked Anne how she would advise other adults with TS in the area of dating and pursuing romantic relationships. Here, she proposed that one needed to believe, “I’m perfect the way I am,” and “That’s just part of who you are.” She laughed, acknowledging that she had not yet put into practice what she was advocating: “Am I going to believe that about myself? No, but it would be the best thing.” She added that counseling would be helpful to adults like herself who need support and help to feel more comfortable in their skin. She suggested that it would be beneficial for individuals with TS to not focus excessively on their condition in order to enjoy dating and being in relationships. “I guess, being lighter, more easygoing about it. Like making it not a big deal, which I’m sure it really isn’t.”

With regard to suggestions for parents of children with TS in helping them navigate dating experiences, Anne suggested that parents need to be knowledgeable about

TS as a condition. She lamented the lack of information about TS that was available to her parents while she was growing up and pointed out that things nowadays are vastly different: “I think now there are a lot of parents educating themselves, going to these meetings, finding other children with Tourette’s, meeting with other families, going to these parent things on the weekends...” Beyond actively seeking out information about TS and understanding it, Anne believed parents need to show their children “unconditional acceptance.”

How the genetic nature of TS may affect dating. At the end of the interview Anne brought up the question of deciding whether or not to have children, given the genetic nature of TS. Anne expressed her belief that it is important for affected adults and their partners to consider the risk of their children inheriting the condition. “I’m not sure if I had known that I had [TS], that it could be passed on to my children, if I would have ever wanted to have children... That might have been a concern when we got married. Why would I want to pass this thing on?... I love the kids, but I wouldn’t want them to go through what I went through.” Her concerns in this area made it clear that Anne has undergone significant emotional suffering in her life, which she believes is related to growing up with TS. As such, she has worried about her children who are potentially at risk for having similar painful experiences. At the same time, Anne acknowledged that the increased knowledge about TS nowadays does make it easier to grow up with tics. “I think the difference between somebody my age and somebody younger is that there is so much more awareness... It’s not like you’re being embarrassed and told to stop it. Just

accepting it – it’s a different world now.” She added, “Boy, if I knew then what I know now, my whole life would have been different.”

The Case of Nancy

Identifying information. Nancy is a heterosexual Caucasian woman in her mid-twenties who lives in a large town. She is unmarried, but is currently in a long-term relationship with her boyfriend, Bill. She works for an advertising agency and has no children. Nancy first began experiencing tics at the age of 5 years and was diagnosed with TS at 9 years. She has no comorbid psychiatric diagnoses, but does experience some mild OCD symptoms, including needing to do certain things in a ritualized fashion. While Nancy has taken medication for her tics in the past, she currently takes none. At the time of the interview, Nancy rated her tics to be in the moderate range, as per the YGTSS.

Process of receiving diagnosis and living with diagnosis. Nancy’s tics emerged when she was 5 years old. Sometime after observing her first tics, her parents began what turned out to be a lengthy and frustrating process of seeking a diagnosis and treatment for their daughter. Nancy explained, “Growing up, they were throwing doctors at me. And [the doctors] just didn’t know [about TS].” She remembered undergoing numerous tests with specialists to determine a cause for her tics, including an electrocardiogram and magnetic resonance imaging. “They put all this crap on my head with the little wires and round things... They were just doing all these tons of tests. I guess they didn’t know. No one really knew what it was.” After getting an MRI from a specialist, she was sent to a

psychiatrist from whom she ultimately received a diagnosis of TS. At the time, 9-year-old Nancy was confused about the sessions with her psychiatrist. “He would play games with me. ... He was asking me questions about my friends. I mean, I understood it, but I’m like, ‘How is this all related to [my tics]?’ He just gave me medicine.”

Upon being diagnosed with TS, Nancy was placed on an antihypertensive medication by her psychiatrist in order to reduce her tics. While the medication did have its intended effect, it also had the undesirable side-effect of extreme drowsiness. Nancy explained, “It made me fall asleep, all the time. I’d fall asleep in class!” To counteract the drowsiness, her psychiatrist prescribed a stimulant for Nancy. However, Nancy remembers that she still had trouble staying awake. For several years she received an accommodation at school that allowed her to excuse herself from class and rest in the nurse’s office when she felt tired or when her tics acted up. About two years after receiving her diagnosis, Nancy was encouraged by her guidance counselor to explain TS and her tics to the students in each of her classrooms, which she did. “I wanted them to know that... ‘The reason you see [me] doing all these things is because [I] have Tourette’s, and this is what it means. And I don’t want you guys to think I’m a weirdo, and I’m not a freak, and there’s nothing wrong with me... It’s just something I can’t control.’”

Nancy stopped taking her the antihypertensive medication about two years later, as she no longer wanted to deal with the drowsiness it caused. Additionally, she reported, “I just was sick of the schedule. Like, that if I was going out for long periods of time, I’d have to pack medicine. ... And I just wanted to be normal.” Coincidentally, the severity of Nancy’s tics decreased notably when she was in high school. It was only when she was

in college that they came back in a dramatically more forceful manner. “With finals, I was getting so stressed out. I couldn’t sleep, and I was twitching all the time - from the time I woke up to the time I went to sleep. It was exhausting, and it was hurting me. I was really sore.” She decided that the possible side-effects of medication were at least temporarily worth tolerating in exchange for some relief from her tics. “I was like, ‘I think I want to go back to the doctor and get some medication. I know it’s going to knock me out, but I can’t do this all day. I really need to not think about this for a while.’ So I went to a doctor.” Unfortunately for Nancy, the side effects of the medications she was prescribed at that time once again led to unbearable drowsiness. “I could not do anything. I took the pills, and I would be out for hours.” Just a few weeks later, she decided to discontinue her medical regimen. Since then, Nancy has dealt with the waxing and waning of her tics without medication.

Family’s response to tics. When asked how her family of origin responded to her tics, Nancy recalled her parents’ very different responses. Her father tended not to acknowledge her tics and did not appear to become upset by them. “He didn’t criticize me, or make fun of me, or anything.” Her mother, on the other hand, dealt with Nancy’s symptoms quite differently. In Nancy’s words, “She could not handle it. She just found it uncomfortable... She would kind of imitate what I’m doing to show me and say, ‘This is what you’re doing.’” Nancy believed that before she received her diagnosis, her mother thought that Nancy had conscious control over her tics.

Even once Nancy had been diagnosed with TS, she suggested her mother responded to her tics in a way that highlighted her own discomfort and implied that

Nancy might be able to suppress her tics if she tried: “She would still show me, like, try and help me, I guess, by saying, ‘This is what you’re doing. Stop it. Do you know you’re doing this?’” Nancy experienced her mother’s imitations of her tics as hurtful. “At the time, I thought, ‘Why would you do that, you’re so mean!’” Nevertheless, she expressed some empathy for how her mother might have felt, recognizing her intention to help Nancy: “She was really uncomfortable... I think she just kind of wanted to control [the tics] herself for me, and she couldn’t.” Following Nancy’s diagnosis, her mother took steps to learn more about the disorder, acquiring literature on the subject, for example. However, Nancy continued to perceive that her mother was extremely bothered by her tics throughout her life and has been unable to fully accept them.

Peers’ reactions to tics during childhood. When Nancy was growing up, she remembers trying hard to conceal her tics in order to avoid potential embarrassment or simply in order not to draw attention to herself. “It would be horrible, sitting in class and just making these weird noises. Because I don’t want to distract people. I’d just go to the bathroom and let it all out, and hope that no one notices.” Nancy reported that the boys in her school would tease her and imitate her tics. “It was the boys. I would come home crying. I would be so sad all of the time.” Nancy’s female peers, on the other hand, tended to be kinder: “I can’t really remember having problems with girls over that. Or them making fun of me, or anything.” She also noted that the children she was friends with responded to her tics in more tactful ways than those she was merely acquainted with. “Obviously [my friends] knew there was something wrong, but they could ignore it a little better than the kids who didn’t know me at all, which is understandable.”

Things got better for Nancy socially once she presented and discussed her TS diagnosis in her various classes. “It changed things a lot – I mean a lot. There are still kids that are going to be kids and do stupid things, but it got so much better. They weren’t imitating me.” Nancy recalled the reaction of one boy who had been imitated her immediately following her presentation: “One kid cried. He’s like, ‘I’m so sorry, Nancy.’ And I’m like, ‘It’s ok, you don’t need to cry.’” For Nancy, talking about her diagnosis publicly appears to have been an important turning point in how others responded to her, and in turn, how she responded to others’ reactions to her tics.

Helpful and problematic responses from family and peers. Looking back, Nancy felt that her mother’s reactions to her tics have helped her to become less bothered by what others thought of her. “She was so much more attacking on the subject, that I’ve learned to just have a tough skin about it, I think.” She felt that by learning to deal with her mother’s persistent pointing out of her tics, as well as the teasing by her peers, she also learned how to deal with others who might notice her tics and give her strange looks. “I will say now, Oh, I have Tourette Syndrome. Most of the time I could care less. It makes me not embarrassed, because I’ve had to deal with all this already. I’m like, ‘What more can come?’”

With regard to her friends growing up, Nancy felt that their unconditional acceptance of her – with or without tics – helped her to feel more comfortable with herself and her diagnosis. “My girlfriends – I remember them saying, ‘We don’t care, its ok, we ignore [your tics]. You’re not a different person.’ ... And they would defend me if someone said I was a freak or weird, or retarded, or something.” Furthermore, Nancy

found it helpful when those around her would not draw attention to, or make a big deal of her symptoms.

Nancy recalled that there was another boy in her high school who had TS whom she learned of. While she felt bad for him because his tics were especially severe, she received some comfort in knowing she was not alone with the disorder, and that her tics were fairly manageable in comparison. “I felt bad for him because I knew people were making fun of him... In a way, I was kind of happy that, ‘Oh, there’s someone else, and it’s worse than me!’ ... I’m happy that this is all I have.” On several occasions during the interview, Nancy pointed out how lucky she felt for not having severe and persistent tics.

Interventions received for TS. Nancy’s treatment for her TS has primarily been medication. When visiting the psychiatrist who prescribed her medication as a child, she received some psychotherapy sessions. At the time, Nancy was unsure about the purpose of these sessions. “I didn’t really ask a lot of questions. Like, I knew I was going to this doctor. I knew I wasn’t crazy; that that’s not why I was going to see a psychiatrist. I knew it was for the Tourette’s, but I didn’t know everything, like the whole purpose.” After receiving her diagnosis at age 9, she also got accommodations at school in order to handle her tics more manageably. These included being able to leave her classroom when she experienced bouts of embarrassing or painful tics and being able to nap in the nurse’s office when she felt sleepy due to the medication she was taking.

What has helped in adjusting to having TS. For Nancy, paying as little attention to her tics as possible has enabled her to adapt to living with TS. “The more I

can not think about it, the more I can just be normal and do normal things. Just not thinking about it ... I think that's the best way, not to dwell on it." She also discussed a mentality she has adopted that has been helpful to her. This involves trying not to worry about what others might think of her if they see her ticcing and not to let such worries stop her from engaging in activities she might normally do. "It would kill me as a person to stay in all the time and be afraid that people are going to see me do these weird things. I'm not going to see 98% of these people ever again. And if I do, I wouldn't even know that I saw them to begin with. So I don't care."

Dating experiences. Nancy has had five romantic relationships lasting three months or longer. She has typically met her boyfriends through social events and school. When asked whether she ever avoided becoming romantically involved with men because of her TS, she initially stated that she had not. By and large, she could not recall staying away from situations involving dating and meeting potential boyfriends. After discussing the issue further, however, she suggested that she has on occasion limited her social interactions during specific periods when her tics were more severe. "I guess when I know that I'm in a bad time with [my tics] I would probably not go out as much ... When I was having a bad time and somebody asked me, 'Do you want to go out?' I'd be like, 'Oh no, not tonight.' I could know it was going to be bad." As such, while Nancy has not avoided dating in general, she has felt weary of exposing her symptoms to dates and potential boyfriends during discrete periods of tic flare-ups.

What Nancy was more immediately aware of were her efforts to hide her tics from dates and boyfriends in the beginning of her relationships. "When I've gone on a

first date or something, or first few dates, I've consciously thought about it and tried so hard to control [the tics]. Or I've had to excuse myself because I've felt it coming, and felt, 'Oh my God, I can't do this – this is a restaurant!'" As Nancy thought more about her reluctance to openly exhibit her tics in front of dates, she suggested that she has felt unsure and nervous about how romantic interests might respond to her symptoms. "With dating, you don't know. You don't know if they're going to look at you differently. As much as you think they're not, you don't know. So I guess I've [held back] a little bit when it's brand new."

When Nancy was asked to reflect on how she has typically made disclosures about her TS to romantic partners, she pointed out that there have been some occasions on which she has avoided the topic entirely. About a previous boyfriend of a few months, she recalled, "I never told him at all, and he never brought it up. I mean, I'm sure he's probably noticed; I'm sure he's probably heard of [TS]... But it was never brought up – not once, ever. I was like, 'I'm going to see how long I can do this for!'" On the occasions when Nancy has decided to bring up her diagnosis, she has approached the conversation in either a serious or a more light-hearted way. "With [Bill], I tried to be so serious: 'I have to tell you something, and I hope this doesn't change things. I swear, I'm not a freak, I'm not a weirdo.'" In other situations, Nancy noted that she has tried to casually mention her diagnosis and not linger on the topic. Looking back, she suggested, "I guess I've found the more nonchalant way is probably the best way to go."

Nancy was asked whether any of her romantic partners ever initiated questions about her tics before she made the decision to disclose her diagnosis. She suggested that while this had not occurred as far as she remembered, most of her boyfriends had already

known about her condition by the time she brought it up, usually through a third party.

“Someone always beats me to it because I wait too long! It kind of annoys me, but it’s a relief in a way. If I say, ‘Oh there’s something I want to tell you: I have Tourette’s,’ and then they’re like, ‘I already know,’ it’s like, ‘Oh, we don’t have to talk about this then.’”

The decision if and when to disclose her TS diagnosis has clearly been important to Nancy when dating. “I guess I think of the future a little bit. Like, ‘Oh, I’ve got to tell him. I don’t feel like it. Is it worth it? Do I feel like it’s going to go anywhere?’” For her, the decision to explain her TS symptoms to men she has dated is one that she has not taken lightly, and one that has involved a lot of emotional energy. “I mean I wasn’t embarrassed; I know I wasn’t embarrassed about it. It was just going to be mentally draining to explain... And I just didn’t feel like doing it.” Evidently, it has not always been easy for Nancy to discuss her diagnosis in the context of dating. She has needed to feel a certain degree of trust and closeness to potential partners before feeling comfortable enough to raise the topic. In past dating situations, Nancy has thought about whether a romantic relationship had potential in the long-run, and accordingly decided whether or not to disclose her TS diagnosis. “Sometimes I guess I would just stop talking to [guys] because I think, ‘I know this isn’t going to go anywhere,’ and I don’t want to go into this whole big thing about how I have [TS] and then them treating me differently...” Put simply, Nancy has taken the initiative to bring up her TS with romantic interests “when it’s necessary.” She jokingly added, “I don’t want to say, ‘Hi my name is Nancy, do you want to date me? I have Tourette’s.’”

Nancy reported that her partners have typically responded very well to her symptoms and to her talking about her TS. “They never made me feel less of a person for

the fact that I had [TS]. They never used it against me... I've been really lucky because I'm sure there are people who are in relationships, and the other person will use it against them in times of anger." Nancy pointed out that her current boyfriend often tries to support her when her symptoms become worse. "He'll try to console me, like, 'It's ok, just do it, I don't mind.' And then I say, 'No, I understand that it's ok that I do it, I just don't want to!' But he is supportive."

As much as making disclosures about her TS to romantic partners has been stressful and anxiety-inducing for Nancy, it appears that she has also felt relieved after the fact: "It made me feel easier, and maybe made the relationship a little bit easier... I'm much more relaxed. I'm not afraid if I have to twitch or something. I just do it; I don't care. I'm not embarrassed or trying to hide it." In this way, Nancy has felt more at ease in her relationships once her partners have known about her condition, as she has needed to invest less energy in concealing her tics or anticipating discomfort from her boyfriends.

Impact of family and peers' responses to TS on dating experiences. When Nancy was asked to reflect on how the responses of her family of origin and peers to her TS have impacted her dating experiences, she initially recalled her mother's reactions to her tics. Because her mother often tended to draw negative attention to them, Nancy feels she may be more prone to becoming defensive when romantic interests notice her tics: "I guess sometimes when [guys] ask, 'Are you ok? What are you doing?' I would automatically get all defensive, because that's how my mother said to me." At the same time, she suggested that her mother's reactions could have had a far worse impact on her dating experiences. She contemplated that she may have worried incessantly about how

romantic interests were perceiving her. “I would have been so nervous, like, are they going to do this to me too? Are they going to say these things, like, ‘Stop it, what are you doing?’” and imitate me?”

Nancy’s father’s responses to her TS seem to have had a buffering effect for her. “I guess, he being a guy, if he had had a reaction like my mom had, I’m sure that would have made some psychological damage... Unconsciously, him being calm, it didn’t make me weary about stepping out into [dating]. So I think it was a pretty positive impact.” Similarly, Nancy felt that her close friends’ responses have helped her feel relatively confident to seek out romantic relationships. “My friends, they always just ignored [my tics]. They never brought it up. And I think it makes me feel more comfortable, that I don’t need to be nervous. And I don’t need to be worried that if I go somewhere, and there are boys.”

Advice for adults with TS and parents of children with TS with regard to dating. When asked about advice Nancy had for other adults with TS in dating and navigating relationships, she stated, “I would say, ‘Think about seeking a relationship before you think about the Tourette’s... If you like someone, don’t think about the Tourette’s and that you have to tell them. Talk to them first, and they’ll react to you. And if you see them reacting negatively, then you’ll know that’s not the person you should date.’” She recommended bringing up the topic of one’s tics when it becomes clear that the other person has noticed them and an explanation may be helpful. “When you feel the discomfort and the tension level is rising, that’s when you say something.” She recalled her own tendency to avoid bringing up her condition in dating situations, and the negative

impact this may have had: “I guess, me waiting too long sometimes could have damaged the relationship.”

Nancy’s advice for parents in helping their children with TS to navigate dating and romantic relationships in the future was for them not make a big deal about their child’s tics. She reflected upon her own experiences in her youth and suggested, “[Parents’] reactions will make a difference in [their children’s] relationships... The way you react now is going to affect them later.” Nancy felt that if both her parents had drawn negative attention to her tics frequently, she may have been very reluctant to go out on dates. “I probably would have been so scared, like, ‘What are [guys] going to do to me? If [my dad] is acting like this, what is the other guy going to do to me?’” As such, Nancy saw a clear relationship between parents’ reactions to their child’s tics and the child’s future dating experiences. In her opinion, parents need to model tolerance and acceptance of their child’s condition without drawing much attention to the tics. In this way, their child is likely to anticipate that future dating partners will do the same.

In terms of how parents might advise their children to discuss their TS with romantic partners, Nancy believes parents should encourage children to feel comfortable with making disclosures. “I would tell them to tell their kids, ‘Don’t be nervous or embarrassed to tell someone that this is what you have, because it will make the relationship a lot easier. It will make you feel a lot less tense.’” She noted that this would be particularly important for children with severe tics, whose involuntary movements and sounds are likely to be quite obvious to others. At the same time, Nancy recommended that parents should not make their children feel obliged to disclose their diagnosis to dates if they are not comfortable with doing so. She found this might be particularly true

for children with mild to moderate tics. “Maybe say, ‘You should tell [dates] right away if you feel like you should. But don’t feel obligated to tell anyone something about that if you don’t want to.’” In sum, Nancy advocated for parents to support their children with how and when they would like to disclose their diagnosis in the context of dating, while helping them to find a way to do so comfortably.

How the genetic nature of TS may affect dating. I asked Nancy whether she had considered how the genetic nature of TS might impact relationships for individuals like herself. In response, she said that she had thought about this matter a lot. She has, for example, considered the possibility that her children may inherit TS from her and has ultimately decided that this would not deter her from having children in the future. “I absolutely want to have kids – I really do. That’s very exciting to me. And I have thought about the fact that there’s a 50-50 chance that they could get it. I’ve thought about it, and I think I’m willing to take that risk.” With regard to how this risk might come into play in romantic relationships, Nancy suggested that she would respect a long-term partner’s potential concerns about having children with TS. “I would fully accept and want to discuss with the person if that’s a concern of theirs. I mean, that’s totally understandable. It would be good to talk about that if it came to that: ‘What could happen? How would we handle that?’ Being prepared is probably the best idea, just in case.”

The Case of Beth

Identifying information and relevant history. Beth is a heterosexual Caucasian woman in her mid-20’s who lives in a large suburb. A school teacher, Beth is unmarried

and has no children. Currently, she is in a long-term relationship with her boyfriend, Sam. Beth's first tics began when she was about 5 years old, and she was diagnosed with TS within months after she first exhibited symptoms. She also received diagnoses of OCD and Attention Deficit Disorder (ADD) during her early childhood. Her symptoms for these include needing to complete tasks in a perfectionist way (OCD) and having difficulty paying attention (ADD). Beth takes a low dosage of an antihypertensive drug to treat her tics. As per the YGTSS, her tics were in the mild range at the time of the interview.

Process of receiving diagnosis. It was not long after Beth first started exhibiting tics that she was diagnosed with TS. At the time, her parents were already well informed about the nature of tics and TS in general, as their first child (Beth's older brother) was also diagnosed with the neurological condition. Beth suggested, "In my immediate family, [TS] is very common. It didn't really cause any problems." When she was first diagnosed with TS, Beth also received diagnoses of OCD and ADD.

Family's response to tics. When thinking about how her family of origin had responded to her tics when she was growing up, Beth considered that her situation was somewhat unique, as her parents had had two children who developed TS. She suggested that her parents knew what to expect, to some degree, when she started having symptoms similar to those of her older brother. At the same time, Beth noted that while her parents were knowledgeable about TS, they also had to adjust to the way in which her symptoms were distinct from her brother's. "I think they were expecting one thing, because my

older brother is...much more severe. They might have been expecting the same thing from me, but then were surprised because it is so different from person to person, from boys to girls.”

Overall, Beth felt her family had been tolerant and supportive: “My parents are really good... Our extended family knows, and everyone’s been really accepting.” She did recall some isolated incidents in which her parents may not have understood the nature of her symptoms as well as she would have liked them to. For instance, she remembered times when she had difficulty doing her homework as a child because of problems with concentration due to ADD, and because her tics were bothering her. “You’re going to say, ‘I can’t do it, I’m having trouble because of my TS.’ And [parents] will say, ‘No, you’re just using that as an excuse.’ You’re like, ‘No, I’m really not – this is a real medical problem!’ So that might have caused a couple of problems.” She added, “I think when we were younger, maybe with my dad, it was just hard [for him] to accept that things just are the way they are... He’d say, ‘Oh, I don’t want to hear that. You just don’t want to do your work.’ But he learned.”

Peers’ reactions to tics during childhood. When asked how her peers responded to her tics while she was growing up, Beth once again felt that those around her had, by and large, been supportive. “For the most part, peers and friends were really accepting.” She only recalled one incident as a child when someone mimicked one of her motor tics in class. “I was doing it, and they thought it was funny to do it back. Every time they did it back, it made it worse for me. I don’t know why that memory sticks out, but other than that, it really wasn’t an issue.”

Beth pointed out that when growing up, she has been selective about whom to disclose her diagnosis to and that she has had the choice to do so because her tics have never been especially severe. “A lot of people with TS, they’re so vocal or obvious, that they’re forced – whether or not they want to keep it private – they have to explain to people what’s going on with them, so [others] don’t get scared or ridicule them. But for me it wasn’t that bad. So I could get away with not explaining to people.” When Beth did decide to tell her friends about her TS, as well as her OCD and ADD, they did not seem to make much of it. “Those friends I did choose to tell were, ‘Oh, ok, that’s cool.’”

Helpful and problematic responses from family and peers. As Beth thought about how the reactions from family and peers over the years have impacted her, she came to the following conclusion: “For the most part, I haven’t had any experience with really negative reactions. So all the reactions have been positive, and in that way it’s been really helpful and reassuring to me.” When asked in what ways others’ reactions to her tics and TS have been helpful, she suggested, “I think that they’ve shown: ‘This is not something to be afraid of; this is who you are; you don’t have to be ashamed and not tell people about this part of yourself.’”

Beth noted that she did not share her TS diagnosis with many friends while she was growing up. On several occasions, however, friends have jokingly asked her whether she had TS after she exhibited noticeable tics. She has typically used these opportunities to explain her condition to her friends: “This has actually happened in every situation when I’ve told someone, because they’ve made a joke. Like, ‘Oh, you have Tourette Syndrome!’ And you’re like, ‘Ha ha, I actually do!’” While she did not identify these

jokes from her peers as problematic, she suggested, “[It] is kind of weird, that catalyst for telling someone.”

The only problematic reactions from people that Beth identified involved the situation of job interviews. She briefly explained that after disclosing her TS diagnoses in such situations, others might say, “You can’t do this because you have this” and proceed to make assumptions about the difficulties caused by TS in the job setting. When this has occurred, Beth has explained the nature of TS in order to educate others. She suggested that this has come rather naturally to her: “For me, I’m not the kind of person who would pose a threat to someone who doesn’t understand what TS is.”

Interventions received for TS. Since childhood, Beth has taken medications continuously to treat her tics. These have typically been effective. When seeing her psychiatrist to renew her prescriptions, she has received brief therapy sessions, which she typically finds awkward. “It’s strange, because the therapy - if you want to call it that - it’s like, ‘if you want your prescription, you have to do this.’” However, Beth has accepted that the occasional therapy sessions are necessary in order for her to receive the medication that she needs. With regard to any additional forms of treatment, Beth noted, “I haven’t gone through any types of alternative treatment or anything. I’m interested in not taking medication. So then in the future I might be exploring different types of treatment that are more holistic, so that I can replace the medicine in some way.”

Beth has also attended a support group for individuals with TS during a short period of time, primarily to support a friend of hers with TS. “I didn’t really have anything to share because I wasn’t particularly having a hard time with anything. But just

to be there to listen to other people, that was, like, mind-blowing. Very intense. You hear crazy stories of all this crap people have had to put up with. So I guess it is therapeutic in a way, just to listen to their experiences.”

What has helped in adjusting to having TS. Beth acknowledged that the support she has received for her TS both inside and outside of her family has helped her tremendously in her adjustment. She also feels that her positive relationships with others have enabled her to feel confident and comfortable with herself as an individual with TS. “Having that support has given me that confidence.” Beth suggested that she has an attitude that embodies the idea “You’re not going to stop me from what I’m going to do.” She added, “I think it’s more my state of mind that’s helped me deal with [TS]... I don’t really see it as a problem for me.” Again, Beth acknowledged that she was probably able to “let things roll off [her] shoulders” more than someone with tics more severe than hers, as her tics have not caused significant impairment in her life.

Dating experiences. Beth has had three romantic relationships that have lasted three months or longer. She has met partners through school and her network of friends, noting, “I’ve never done any online dating or been picked up at a bar or something.” Beth reported never having avoided dating situations because of her tics, suggesting that she has not worried about her partners rejecting her because of her symptoms. She admitted, “I guess you could say sometimes you approach things with a sense of caution. But for me, I’ve never let [TS] define me enough to stop me from wanting to get to know a person.” Additionally, Beth explained that she has typically dated people whom she has

known previously for some time, which has reduced her anxiety about having tics in front of them. “These are just people I was kind of friends with before. I’ve never really met someone who has said, ‘I don’t really know you, let’s go on a date and then see if we want to be together’... Because these were relationships that had been developing and nurtured for a long time... it was never a problem.”

While she has felt relatively comfortable with her tics around romantic partners, Beth has made a point to hold off talking about her diagnosis with men until she feels the time is right. “I would definitely withhold that information until the right time... It’s more the anxiety around telling them that’s worse than the symptoms for me.” In brief romantic relationships, she has typically never addressed her tics and her TS diagnosis, at times suppressing her tics in order to avoid a conversation about them. In longer relationships that were of greater significance to her, Beth described her process of disclosing her diagnosis as follows: “In my mind, I’m deciding when I should tell this person, and then you’ll be in a group of friends, or a social setting, just hanging out with that person, and then you’ll do something abrupt, or loud, or you’ll curse unexpectedly, and the person will say, ‘Oh, what’s the matter with you? Do you have Tourette’s or something?’ And I’m, like, ‘Alright. Well, I guess this is the moment.’”

For Beth, the opportunity to explain her symptoms has often occurred in such situations, where others have made benign, but uninformed jokes about her tics. She explained, “And it sucks because it doesn’t put it on your terms anymore – it puts it on their terms. Because if you don’t address it then and there, what are you going to do? Ignore it, and then three months later, be, like, ‘By the way, I have this’? And that just makes your significant other feel terrible, that they’ve been joking about it with you for

so long.” As such, Beth has often felt forced to disclose her TS diagnosis prematurely, or on others’ terms, rather than her own.

Although Beth has found it somewhat unpleasant not have control over when to address her tics with partners, she also acknowledged that when others ask about her tics, it provides a natural opening to talk about and explain TS. “Actually making the decision and following through with the decision to tell someone is very stressful. So if the choice is taken away from you and you’re presented with this opportunity, you go for it... It is easier, in a way.” She remembered that when she first started dating, talking about her diagnosis with partners was nerve-racking. With her first boyfriend, Beth recalled, “I don’t even think I could say it. I think I had to write it down in a note or something and present it. Because I was a lot younger, and I was still nervous, I didn’t know what the reaction was going to be.” With her current boyfriend Sam, on the other hand, Beth remembered the moment in which she shared her diagnosis as “very non-stressful.” During an intimate conversation they had while their relationship was developing, Beth said to him, “I think this is something you should know about me...” She described Sam’s reaction as follows: “I think he was just, like, ‘Beth, you’ve told me before!’ ... It was so not a big deal.”

Beth described a common initial reaction of guilt on behalf of her romantic partners when they were informed of her TS diagnosis after previously having joked about her symptoms. In situations in which a boyfriend has jokingly asked whether she had TS after she had a burst of tics, Beth described his apparent remorse once she confirmed her diagnosis: “In those situations, there is a very intense period of guilt on their part, because they feel really bad that they were joking about it. They’re just like,

‘I’m so sorry, I’m so sorry, I’m so sorry!’” While Beth admitted to feeling bothered by others’ jokes initially, she suggested, “I’m just used to hearing those types of comments ... I’m like, ‘You don’t need to apologize, it’s not a big deal.’” She explained that her partners in the past have typically felt bad about joking about her tics for a few months and then have become very understanding about her symptoms.

Generally, Beth’s boyfriends have become quite accustomed to her tics. “Once they know, it just kind of blends into the background of ‘sounds that Beth makes,’ or something.” She added, “Sam will tell me that he doesn’t even notice anymore.” At times, her boyfriends have even found her tics endearing. She explained, “My current boyfriend thinks my tics are really cute, and it bugs the hell out of me. Because I’m like, ‘They’re not cute, they’re annoying!’ He says, ‘No, they’re just really cute!’” As such, Beth has usually been more bothered by her tics than her boyfriends have been.

Furthermore, she has often anticipated that the interference of her tics in daily activities would bother her partners more than it actually has. She described such instances with her current boyfriend, Sam: “Sometimes if I’m leaning on him, or something, and I have some of my motor tics in that particular week, like a tensing, or a shoulder jerk or something, I’m assuming it’s not comfortable for me to be touching him and doing all these movements while he’s just trying to relax. So I always have to ask, ‘Hey, am I bothering you or making you uncomfortable?’ And he’s like, ‘I don’t even know that you’re doing them.’ So I guess that’s good.”

Beth’s boyfriends have made active efforts to learn more about TS in order to support her. She explained, “In the past, I have had people want to learn more and go out of their way to ask me questions. ... My ex-boyfriend... actually came to that support

group with me because he wanted to support me." Otherwise, partners have shown support by listening to her and expressing curiosity about the condition, occasionally asking questions about TS, for instance.

Beth felt that while it has often been stressful to disclose her TS diagnosis to her partners, the process of doing so has had a positive impact on her romantic relationships in the big picture. "The makeup of the relationship, the foundation of our relationship, I think it's gotten stronger, if anything." She jokingly added, "[My TS] hasn't sent people running for the hills." Beth believed that once her partners have understood the nature of her tics, she felt more at ease about ticcing in front of them, and that they, in turn, have been able to support her when her symptoms became bothersome: "And it's good, because I feel like it takes the stress off me, ... if I'm having a bad day, they'll say, 'Oh, what's wrong?' I'll say, 'My tics are really bad today, I'm just having a rough time.' And they really have been very compassionate about that. And they may not understand what it's like for me, but they understand that I'm just really stressed and just need someone to calm me down and be there for me."

Beth noted that it has been a relief for her not to have to hide her tics with boyfriends: "There are so many periods where you're hiding, or you're passing it off as something else. I know [my tic] sounds like a hiccup because so many people have said to me, 'Beth, you have the hiccups!' And I'm like, 'No, but yes.' So you're in so many of those situations all the time. So you just want to come home and let loose and not have to worry about being with someone." In this sense, Beth has felt much more relaxed in her relationships once she has shared her diagnosis with partners.

Impact of family and peers' responses to TS on dating experiences. Beth conveyed that she has generally felt very comfortable with who she is, and that her tics have not held her back from her desire to pursue romantic relationships. "It's just like, whatever. It's just a part of who I am." She suggested, "I would think the people who would have the most influence would be my family. And my family has always been really cool about it... I try to not have a fear of not being accepted, but that's part of the way I was nurtured and raised." In addition to believing that her parents have instilled in her a sense that others would accept her in spite of her tics, she indicated that her mother has also taken an interest in how she has navigated her dating experiences in the context of having TS. "My mom would ask, when I first started with someone, 'Are you going to tell them?' Or 'How are you going to handle this?'" As such, it appears that Beth has continuously perceived a great deal of support, as well as interest from her parents with regard to dating with TS. This perceived support appears to have contributed significantly to her comfort in this area.

At this stage in the interview, Beth once again acknowledged that the manageability of her symptoms and her ability to disguise her tics has significantly contributed to her comfort in social and dating situations. "I guess I can blend in enough so that my tics aren't really noticeable... I've just been lucky enough that my genetic make-up was in such a way that my tics weren't bad enough so that it was a big deal." She recognized that for others with more severe and disturbing tics, like her older brother, more complications may arise in dating situations.

Advice for adults with TS and parents of children with TS with regard to dating. Beth advised not to let TS define oneself as a person, not to let the condition interfere with getting to know others, and to believe that others will see one for who one is, not one's tics. "It is not who you are, it's just something you happen to have," she suggested. Beth acknowledged, however, that maintaining such an attitude is difficult for individuals with TS who have had negative social experiences growing up. Such people, she suggested, may have gotten the message that others are likely to focus more on their tics than on them as individuals. "So by the time they're ready to start dating, their social experiences could have been bad enough that they're already scarred. And it's hard to tell someone at that point, 'Don't be afraid, just have the confidence to go out and meet people that interest you.'" While Beth felt that her own experiences have been quite different, she showed a great deal of compassion for those whose tics have interfered this markedly with their social lives.

Beth suggested that parents of children with TS should convey acceptance of their children and communicate to them something like, "You should not be ashamed of who you are and just have faith that the right person will not care. [Your partner] should care and want to support you and help you through it, but it shouldn't matter to them that you have it or not." In other words, she recommended for parents to assure their children that they will be successful in their dating experiences. She also felt that parents need to encourage their children to feel comfortable with when and how they want to disclose their diagnosis to dates. She emphasized that individuals with TS may have different preferences regarding when they would like to openly discuss their tics with others.

While Beth believes parents need to be honest and communicative with their children about their TS and the potential social implications of living with tics, she also feels that parents should not draw unnecessary attention to the neurological condition. “I think that maybe it’s good to treat it sometimes like it’s not a big deal.” She added, “Because if it’s not a big deal to your family and your parents, then you’re going to grow up thinking it’s not a big deal. And then I think maybe when you start to approach other people, like friends, or guys or girls, depending on the situation, you’re going to say to yourself in your head, ‘it’s not a big deal.’”

How the genetic nature of TS may affect dating. When Beth was asked how the genetic nature of TS might affect the dating experiences of people with TS, she acknowledged that she and her boyfriend had discussed this topic. She reported that because she and Sam plan to marry and have a family in the future, they have explored the possibility of having children who may be affected by TS. Beth has found her partner very supportive in this regard. “It’s really not been a big deal for him.” She noted that at times, she has had concerns about having children with tics significantly more severe than hers and who may be bullied or teased as a result. On these occasions, she has felt reassured by Sam’s attitude that they will be able to address such challenges when the time comes. Despite her occasional concerns, Beth emphasized that the possibility of having children with TS has not caused her and Sam to consider to forgo having children, and that she undoubtedly wants to have children in the future, regardless of whether they have tics or not.

The Case of Shannon

Identifying information. Shannon is a Caucasian heterosexual woman in her mid-20's who lives in a suburban area. She is unmarried, without children, and is currently in a long-term relationship with her boyfriend, Alex. Shannon works a research assistant. Her first tics began when she was 7 years old, and she was officially diagnosed with TS in her early 20's. Around that time, she was also diagnosed with ADHD, as well as depression. Shannon currently takes a benzodiazepine to control her tics and an antidepressant for her depression. While she has not been diagnosed with OCD, Shannon feels she has some of its symptoms. These include having to perform several daily routines in a rigid, ritualistic manner. Her symptoms of ADHD include difficulty staying focused and paying attention. According to the YGTSS, Shannon's tics were in the moderate range at the time of the interview.

Process of receiving diagnosis. When Shannon's tics started at the age of 7, her parents did not consider them to be something that warranted medical or psychiatric attention. Shannon stated, "I think when it started, [my parents] thought it was a bad habit, an allergy, I don't know." She herself was also unsure of what her tics were: "In my head, I just called them my plagues or my curses that I did. I didn't even know they were tics." Shannon's tics were at their worst when she was in high school. She had an obvious facial tic she experienced at that time, which was also extremely difficult to suppress. When Shannon was in her early 20's, she went to a neurologist, who diagnosed her with TS.

Family's response to tics. Shannon's early tics included throat clearing, snorting, and sniffing, which her parents interpreted as symptoms of allergies or congestion. As such, they did not make much of them and believed Shannon would be able to suppress them with some effort. Often, they would ask her to stop: "It would just come to a point where my dad would just be like, 'Oh, stop clearing your throat already!'" "She added, "I think they thought I could control it. And that it was something like a bad habit, something I could just stop doing if I really wanted to try." For many years, Shannon thought her parents must be right.

By the time she was in her late teens, Shannon had heard about TS through the media and had done some research on the topic on her own. After looking up some information on TS on the internet, she approached her mother with the idea that she may be affected by this condition. Shannon described her mother's disappointing reaction: "She pretty much just dismissed the idea ... She basically had a reason for all the tics that I had. Like, I was clearing my throat because there was bad ventilation... She said, basically, 'You don't have Tourette's. You'd be doing a lot more wild, major tics if you did.'" I asked Shannon about her father's reactions to her hypothesis at the time. She recalled, "He didn't really say anything. He just kind of was quiet, and kind of confused." When Shannon finally received an official diagnosis for TS from a neurologist, she was hesitant to share the news with her family. She remembered that even then, her mother was not convinced that her daughter really had TS. She decided not to discuss her diagnosis with the rest of her family.

Peers' reactions to tics during childhood. While growing up, Shannon's peers and friends generally did not draw negative attention to her tics, and she could not recall instances of teasing or mimicking. Rather, on occasion, people in school would inquire about her tics. "I remember sometimes people asking me why I was doing something. But I would just respond, 'I don't know.' Or I would just kind of shrug it off, or try to change topics because I didn't really know what to say." As such, when her peers did bring up her tics, it was with curiosity rather than malice. Regardless, Shannon found it very difficult to respond to their questions. "I would just basically, inside, just freeze up... I really didn't have a good answer." Even once she received her diagnosis in her 20's, she was hesitant to share it with friends. "I just figured that no one would believe me and think I was just making it up."

Looking back on her childhood and adolescence, Shannon expressed a desire to have known more about the cause of her tics at the time, noting that this might have made it significantly easier for her to respond to her peers' inquiries. "Maybe if I knew when I was in middle school or high school, like, I knew what it was called, I could [have just told] people. Like, tell my friends at school, 'I have these tics that I can't help doing.' At least that much. Not just, 'I do weird things, and I don't know why.'" Shannon felt that others would have been less likely to perceive her as "kind of weird," had they known that there was a neurological cause for her tics, and that these were not voluntary.

Helpful and problematic responses from family and peers. For Shannon, her mother's response to her initial suggestion that she had TS was very disappointing: "I guess my mom's responses have made me angry, that she's not really understanding, or

thinks it's, just, like, ridiculous, and made up." She added, "When I initially told my mom, I really expected her to be, like, 'Oh wow, this really makes sense!'" Because Shannon received no affirmation from her parents that her tics were anything unusual or worthy of further evaluation, Shannon described feeling "like there was this thing about me that I just couldn't have the willpower to stop, and that other people could have the willpower."

In terms of problematic responses from peers, Shannon pointed out that while people in high school did not draw negative attention to her tics, she was aware of them perceiving her as oddly different. "I have a suspicion that they probably thought I was kind of weird, a weirdo doing these things. And they probably didn't tell me to my face or anything, but maybe they made fun of me behind my back." Shannon felt that her social life as a teenager was adversely affected by the obvious tics she had. "My tics just made people uncomfortable to come up and talk to me, or talk to me for long. Because I could see why that would happen. Like, if you're talking to somebody, and they just keep on doing a tic or something, that makes you uncomfortable. You might start to feel weird talking to them." Shannon reflected on the fact that, unlike many students in her class, she did not stay in contact with her peers from high school since graduating. She suggested that this was likely related to others' image of her as "the weird girl." For Shannon, her tics were a factor that heavily contributed to how she felt she was - and continues to be - perceived by her peers from adolescence.

Shannon identified some helpful reactions from select friends while growing up that countered the experiences described above: "I did have really good close friends who didn't seem to care and never said anything about it. And I truly think that even if they

did notice, they didn't care. So I think that it wasn't everybody [who perceived me as the weird girl]." Post-diagnosis, Shannon pointed out a particularly supportive reaction from a friend after she disclosed her diagnosis for the first time. "He was, like, 'Oh, well, I had a friend growing up who had tics, the guy next door.' And he was, like, 'Well, if it makes you feel any better, I haven't noticed anything.' But he wasn't, like, 'Oh, that's ridiculous!' He wasn't very negative about it. He was pretty supportive, which I was surprised [about]."

Interventions received for TS. Since receiving her TS diagnosis, Shannon has been taking medication for her tics (a benzodiazepine), as well as for depression (an antidepressant). Shannon has received some psychotherapy as part of her treatment for both conditions since receiving her diagnoses. One of the therapists she has seen recently specializes in the assessment and treatment of TS. Shannon recently also attended a support group for individuals diagnosed with TS, which she has found helpful. She noted that she has also tried taking an antihistamine to reduce the tickling sensation in her nose that often leads to a nose tic.

What has helped in adjusting to having TS. Shannon pointed out that seeing a therapist who specializes in TS and who is familiar with its course, presentation, and implications has been extremely helpful. "I've told other therapists about it, but they didn't really seem to take an interest or be really understanding about it... It's nice to talk about it with someone who really knew what they were talking about." Shannon also appreciated the TS support group she attended for providing a safe space in which she

could share her experiences of living with TS. “I thought it was helpful just to talk to them... At that point it was the only other people I told besides my mom.” Shannon was encouraged by the role played by parents of the children with TS in the group: “It was nice to see the parents being so proactive and caring about kids and taking steps and things like that.” When reflecting upon this, she also noted that attending the group brought up a sense of regret that her parents had not been more supportive of her. In terms of social supports, Shannon suggested that her boyfriend Alex plays an important role for her when it comes to her TS. “I can just randomly talk to him about things... and not have to go on this whole explanation about things. It’s nice.”

Dating experiences. Shannon has had four romantic relationships lasting three months or longer. Typically, she has met partners through work, school, or mutual friends. When asked whether she ever avoided becoming romantically involved with men because of her TS, Shannon stated that it had not held back from dating per se. She suggested, “[TS] was there and I just didn’t care, I guess. It didn’t bother me in that realm, like to try to talk to guys and things like that.” At the same time, she felt that her tics did have an impact on how she interacted with boys in high school. “I think [TS] might have made me talk to the cool, really handsome guys less and go more for the geeky guys... It probably affected my self-confidence, which probably affected that.” Looking back, she felt that her tics may have made her appear “strange” to her peers, thereby negatively impacting her attractiveness to potential romantic partners. She suggested that had she not had noticeable tics during her adolescence, “maybe in high

school there were guys that maybe would have talked to me, and they just [felt uncomfortable].”

Prior to receiving her TS diagnosis, only one of Shannon’s boyfriends expressed curiosity about her tics. She recalled an incident with him in which he asked her why she scrunched her face, imitating the tic in detail in order to demonstrate what he meant. Shannon described the mortification this induced in her at the time, as well as not knowing how to respond appropriately: “I just froze, didn’t know what to say, and was, like, in my head for half a second, I thought about how to try to explain it. At that time I still didn’t know about Tourette’s. So I thought in my mind, ‘Well, I have these things that I do, starting when I was little, and I do this and that.’ But then I thought ‘I don’t want to go through all that,’ so I was just, like, ‘I don’t know!’ And then I guess the talk just dropped.” Shannon did not address her tics with the other boyfriends she had prior to being diagnosed.

Once Shannon had received her diagnosis in her early 20’s, the idea of addressing her tics with a boyfriend became somewhat less humiliating and slightly more straightforward. With her current boyfriend, Alex, she decided to take the initiative to broach the topic, as the opportunity to do so arose naturally. She recalled having just attended her first TS support group session at the time and feeling more confident to discuss her symptoms with others. “After the group I felt pretty good about it and figured that I’d tell people. And you know, that was the first time I was really around other people who had [TS] and who were talking to me about it. So I felt pretty good.” After leaving this first group session and seeing Alex, Shannon decided to share with him where she had been and then shared with him her diagnosis. “I was, like, ‘I have Tourette Syndrome,’ and I

kind of explained it a little bit. And that's pretty much how I brought it up. I felt like I wanted to tell him because I felt like I could trust him with these things. 'Cause I had previously told him about my depression. So he was ok with that."

Shannon was asked how Alex responded to her disclosure, and how the disclosure affected her romantic relationship with him in general. She noted that he had responded well to the news, expressing interest in how the disorder affected her. "He responded at first [by] just being curious about it, just asking me questions. And I guess he's been pretty supportive. When I talk about it, he doesn't seem to be uncomfortable or upset about it." Shannon felt that overall, the act of sharing her TS diagnosis with Alex and his consequent positive response had solidified her trust in him and in their relationship. "I feel good that I can talk to him about it. So I feel that I trust him more, and it's making me like him more... He just seems very understanding about these weird things about me, I guess." She added, "It just makes me feel better about dating him." Shannon pointed out that Alex has taken some steps to learn about TS and to support her in living comfortably with her disorder. He has accompanied her on an organized walk to promote awareness about TS, for instance. On another occasion, he brought up a TV show he had seen about TS and subsequently discussed with Shannon the common misperceptions about TS that people typically have. As a result, Shannon has felt comfortable talking with him about how others have responded in unhelpful ways to her tics in the past, and how this has made her feel. "I could tell him things my mom said, or other things [people] say to me about it, or I hear people saying about it. It's been helpful that way."

While Shannon has developed a level of comfort with Alex that allows her to freely talk about her tics, it is apparent that this comfort has not generalized to all dating

situations for her. She noted, “I’d probably be really scared to tell a guy about it. Like, if I broke up with [Alex], and I was going out with someone else, I’d probably still be really scared.” Shannon suggested that she remains somewhat uncomfortable with others knowing about her diagnosis, especially people she is not close with. “The idea of them thinking about me makes me uncomfortable, even though it’s probably kind of irrational... I just don’t want people to really know.”

Impact of family and peers’ responses to TS on dating experiences. When Shannon was asked to reflect on how the responses of her peers and family of origin to her TS have impacted her dating experiences, she suggested that she may have anticipated that dating partners would respond similarly to how her mother had responded to her tics. “It was kind of, like, well, if my mom didn’t think it was true [that I had TS], why would this person who didn’t grow up with me and see me doing all these things think it was true, just by me saying it?” As such, Shannon expected that romantic partners might not take seriously that she suffered from a legitimate neurological disorder, just as her mother had not. At the same time, her mother’s rather invalidating response made Shannon determined to find romantic partners who would respond differently. She noted her inner sense that “I have to go out with a guy who is really going to be understanding. And not be shocked, or make fun of me, or do anything like that.”

Advice for adults with TS and parents of children with TS with regard to dating. In terms of advice for other adults with TS in the area of dating, Shannon strongly recommended attending a support group for TS. She suggested that this would

be helpful to them “because they can talk to other people. They’re not the only one. I think it would make them feel like they’re not alone. So it would make them feel more confident.” Shannon related this advice to her own positive experiences with attending a support group. Shannon also advocated for adults not to over-focus on their tics when going on dates. “Just try to ignore [the tic]... I mean, even if you’re actively doing it, just try to not think about it, just try to focus on talking to somebody... If you’re ticking, or saying something, or having a vocal tic, just do it and then go back to talking.”

I asked Shannon how she would advise adults with regard to making disclosures to romantic partners about their TS. Here she suggested that it is probably only worth discussing one’s diagnosis once one knows the relationship has potential for the future. “Probably not right away. Definitely wait until it’s at the point where you know you want to be with them for a while, you’re probably going to be with them for at least a year or so, and things are going well. I think that may be a good time.”

Shannon drew on her own childhood experiences with her parents in order to come up with suggestions for parents of children with TS in helping them to navigate romantic relationships. She suggested that first and foremost, parents should demonstrate to their children their commitment to helping them with their tics, whether through medication, therapy, or books on TS. “Help them try to minimize doing their tics. Just to show that you care... Because they probably want the help to try to stop doing it.” She added that this should be done in an educated and supportive manner that conveys an understanding of tics as involuntary, rather than purposeful. Secondly, Shannon suggested parents should reassure their children that they will find a romantic partner who will care about them, despite their tics. “I would say, ‘You’re probably going to find

someone to date who's going to like you and not care about that stuff.'" For Shannon, it was clear that these were approaches she would have liked her parents to have had with her.

How the genetic nature of TS may affect dating. Shannon was asked how she feels the genetic nature of TS might impact romantic relationships. Here, she pointed out that this conversation has not come up with her and her boyfriend Alex. She noted, however, "I think that if we had a kid that had some tics, or Tourette's, then I think that we both know about it. And I guess we can help – we can just address it from the start." While Shannon did not have much else to say on the subject, it appeared that she did not see the chances of passing on TS to one's offspring as a reason not to have children. Rather, Shannon conveyed a need for parents of children with TS to be educated in order to optimally support their children.

Results - Part 2

This section identifies and discusses core themes that run across the five cases. The first of these themes concerns whether, why, when, how, and what the women with TS have chosen to disclose to partners about their disorder. These questions were previously identified by Klitzman and Sweeney (2011) as central dilemmas faced by adults with genetic illnesses in dating situations. The second theme involves the common challenges that the subjects of this study have faced in explaining TS to partners. Next, the notion of concealing tics in the context of dating is explored as a theme, and the subjects' reasons for concealing tics are examined. The fourth theme concerns the impact

that making disclosures about TS to partners has had on subjects and their relationships. Next, the responses of subjects' family and peers to their tics are conceptualized as providing an internal model for how subjects expect romantic partners to respond. The responses of subjects' family and peers to their tics are then understood as providing motivation to subjects for receiving better responses from partners. Finally, the different ways in which the genetic nature of TS affects the romantic relationships of the five women is discussed as a theme.

Considerations when Disclosing to Partners: Whether, Why, When, How, and What?

When faced with situations in which the idea of talking to dates or romantic partners about TS arises, the women in this study encounter challenges relating to whether, why, when, how, and what do share. For some, the question of whether to share their TS diagnosis at all tends to arise first. To help guide her in this area, Nancy asks herself, ““Is it worth it? Do I feel like it’s going to go anywhere?”” Her decision whether to disclose is therefore largely informed by how much potential she feels a relationship is likely to have in the long-run. Shannon’s recommendation for adults with TS mirrors this idea: “Definitely wait [to disclose] until it’s at the point where you know you want to be with them for a while, you’re probably going to be with them for at least a year or so, and things are going well.” Nancy recalls a relationship during which she didn’t mention her tics even once because she did not feel it would last. Similarly, Beth has avoided the topic in romantic relationships that were relatively brief, opting instead to conceal her tics as well as she could. As such, Nancy, Beth, and Shannon have all considered how viable a

romantic relationship appears when considering whether or not to talk about their TS and tics to romantic interests.

With regard to why to disclose, Beth notes a sense of obligation to share her condition with partners when the topic arises in order to educate partners and prevent them from making misinformed comments. She says, “Because if you don’t address it then and there, what are you going to do? Ignore it, and then three months later, be, like, ‘By the way, I have this’?” For Nancy, a related reason why to disclose relates to the impact that not disclosing may have on the quality of a romantic relationship. She notes, “Me waiting too long [to disclose] sometimes could have damaged the relationship.” For Beth and Nancy, the decision to disclose relates to a sense of a duty to be honest with their partners about their condition for the sake of their relationship, especially once they feel it has long-term potential.

Reasons for which the subjects have chosen not to disclose their diagnosis include the perception of little long-term potential for a romantic relationship, as discussed for Nancy, Beth, and Shannon. For Anne and Shannon, an implicit fear of rejection or humiliation may be involved when deciding not to disclose. While Anne cannot pinpoint what she is afraid might happen if she talks with others about her TS, she states, “I was always embarrassed by it... I was very ashamed. My self-esteem wasn’t great.” As a result, she has avoided disclosing her diagnosis to most people, including romantic partners. She outwardly recognizes, “Probably people could care less.” At the same time, an underlying sense of shame at the thought of others noticing and knowing about her symptoms is apparent. This avoidance of potential shame may also play a role for Shannon. She says, “The idea of [others] thinking about me makes me uncomfortable.

Even though it's probably kind of irrational... I just don't want people to really know."

This general discomfort with others knowing about their condition appears to be a major reason for not making disclosures about TS to romantic partners for Anne and Shannon.

Tic severity also appears to play a role in deciding whether, why, and when to disclose. Nancy suggests that when her tics are barely noticeable, she is likely not to bring up the subject of TS: "I didn't feel the need to bring up an issue that wasn't too defined right now." On the other hand, if her symptoms are more apparent while getting to know someone, the need to explain her tics becomes more urgent: "If I'm meeting someone and I am in a bad spot, I sometimes have to, sort of, 'So, by the way!' just nonchalantly throw it in there." Beth, who has had fairly mild tics throughout her life, also notes that tic severity impacts pressure to disclose: "I don't tell many people because I feel like I'm not noticeable enough for them to need to know." She points out that for those individuals whose tics are more obvious, the need to address their symptoms might be greater: "They have to explain to people what's going on with them, so they don't get scared or ridicule them."

Nancy, Beth, and Shannon all express a preference to hold off on disclosing their diagnosis to a romantic partner until they feel a certain degree of trust and closeness in the relationship. Nancy says, "I guess I've [held back] a little bit when it's new, when it's brand new." Beth echoes this sentiment when she says, "I would definitely withhold that information until the right time." Shannon recommends making disclosures to partners "probably not right away." With her current boyfriend, she recalls the point at which she finally decided to share her diagnosis with him: "I felt like I could trust him with these things."

When “the right time” is to share one’s diagnosis is something these three women consider subjective. Nancy recommends, “You should tell [dates] right away if you feel like you should. But don’t feel obligated to tell anyone something about that if you don’t want to.” Beth suggests, “The person needs to make their own decision about how they want to address that. Do they want to wait until someone brings it up, or do they want to go for it right away?” As such, while these women all express an instinct not to share their diagnosis with partners until a certain level of intimacy has been attained, they recognize that what feels like the right time to disclose one’s TS diagnosis is likely to vary from person to person.

With regard to how to disclose one’s diagnosis, several possibilities and preferences have been identified by the subjects. On some occasions, the women have used natural openings as an opportunity to explain their condition to dates and partners. These include situations in which others have explicitly noticed or asked about their symptoms. Beth recalls several incidents in which, upon noticing a tic, others have joked, ““Oh, what’s the matter with you? Do you have Tourette’s or something?”” She has often used such moments in order to initiate a conversation about her neurological condition, noting, “... if the choice is taken away from you and you’re presented with this opportunity, you go for it.” She notes that these natural openings have made it somewhat easier for her to bring up her TS than when she has had to take the initiative to disclose. Jessica first openly talked about her diagnosis with her husband-to-be when she needed a ride back from an appointment with her neurologist, and the reason for her visit naturally arose with him. With Jessica’s previous boyfriend who was present when she first

received her diagnosis, the subject of TS inevitably came up naturally as well, as he had been present as her symptoms become worse and she ultimately consulted a neurologist.

On other occasions, the women have taken the initiative to purposely bring up their diagnosis with partners. For instance, Nancy said to her current boyfriend, “I have to tell you something, and I hope this doesn’t change things.” Shannon describes her very similar approach with Alex: “I was, like, ‘I have Tourette Syndrome,’ and I kind of explained it a little bit.” Beth said to her current boyfriend, “I think this is something you should know about me...” In one of her earlier relationships, Beth chose to share her diagnosis by “writing it down in a note.” Nancy suggests it is important to initiate the topic when a partner’s uneasiness in response to one’s tics is apparent. “When you feel the discomfort and the tension level is rising, that’s when you say something.”

Finally, some of the women in this study have relied on third party disclosures to make their partners aware of their condition. Jessica notes that her husband had asked a mutual friend about her tics, and that her friend then explained the condition to the best of her knowledge at the time. Similarly, Nancy often finds that her boyfriends already know about her TS from friends by the time she is ready to bring up the subject: “Someone always beats me to it because I wait too long!” She describes these occurrences as a sort of relief, as she feels less pressure to discuss TS with a partner when he has already received this information from someone else.

When looking at what the women in this study have chosen to disclose regarding their TS, what stands out is an important distinction between disclosures made before, versus after a diagnosis has been received. Nancy and Beth, who were both knowledgeable about TS by the time they started dating, have had different experiences

from Jessica, Anne, and to some extent, Shannon. When Nancy and Beth chose to talk about their diagnosis with partners, they were able to explain the nature or the disorder to at least some extent. Jessica, Anne, and Shannon, on the other hand, all dated prior to having received an official diagnosis of TS. During this period of their lives, they had little understanding of their symptoms and struggled with how to address them. Jessica for instance, would say, “I’ve been doing these things for a long time. I don’t know why I do them.” Similarly, Shannon considered saying something like, “I have these things that I do, starting when I was little, and I do this and that...” Furthermore, Jessica and Anne grew up in an era when very little was understood about TS in general. One can imagine that not having the language to explain their symptoms posed great challenges to making disclosures about their condition, especially given the often bizarre and intrusive nature of tics. Anne explains her lack of understanding of her condition: “Back then, I never knew anyone with Tourette’s before. I’d never heard of it, even.”

Having noted the difference between disclosures made pre- and post-diagnosis, it is clear that explaining TS to romantic partners is a process that presents its unique challenges regardless. These are examined in the following section.

Challenges of Sharing TS Diagnosis with Romantic Partners

All five women have encountered obstacles when addressing their neurological condition with dates and partners, and several types of challenges have been identified among the subjects. These include the difficulty involved in explaining the nature of TS, the emotional energy involved in doing so, the anticipation of discomfort in a partner, and simply not knowing exactly how a partner will respond to disclosure.

Jessica, who was faced with the task of explaining her tics to dates before receiving her diagnosis, recalls struggling in light of not having a proper explanation for why she made odd movements and sounds. She found it hard to explain her tics even after her diagnosis: “Even afterwards, because you don’t know why, still.” Shannon describes her embarrassed response to being asked about a tic by her boyfriend, pre-diagnosis: “I just froze, didn’t know what to say... so I was just, like, ‘I don’t know!’” Anne suggests her explanation was something like “Why I did those things? It was a habit.” Even for Nancy and Beth, who dated with a better understanding of their condition, finding the right way to explain TS has not been straightforward. The women’s experiences all point toward a general difficulty in explaining tics and TS to romantic partners, presumably because of how peculiar the disorder can appear those unfamiliar with the neurological condition.

Furthermore, the emotional energy involved in sharing their diagnosis with a partner is apparent among several of the women. Nancy and Beth describe this experience in similar words. Nancy says, “I know I wasn’t embarrassed about it. It was just going to be mentally draining to explain.” Beth says, “Actually making the decision and following through with the decision to tell someone is very stressful.” Anne describes her anxiety with regard to disclosing, saying “I’m not comfortable saying it to people. That’s something I’ve wanted to do more, to say, ‘I have Tourette Syndrome,’ and no big deal.” As such, making disclosures about their TS is challenging for the subjects in that it requires a great deal of emotional effort.

An additional challenge involved in making disclosures about TS to partners appears to involve the anticipation of discomfort in a partner, or a broader uncertainty

about how a partner will respond. When discussing the reactions of their dates and partners to their diagnosis and symptoms, the subjects touch on a sense that partners may be uneasy with their condition. Even when their partners have ultimately been supportive, understanding and comfortable with their symptoms, the subjects have expressed the belief that partners would be significantly bothered by them. Shannon proposes, "... if you're talking to somebody, and they just keep on doing a tic or something, that makes you uncomfortable. You might start to feel weird talking to them." Beth describes times with her boyfriend when she expects him to be bothered: "I'm assuming it's not comfortable for me to be touching him and doing all these movements while he's just trying to relax. So I always have to ask, 'Hey, am I bothering you or making you uncomfortable?'" Anne suggests that her vocal tics bother her husband now that they are more severe than previously: "I think it bothers him more now, honestly. Because I scare him." Jessica is even surprised with her husband's patience and tolerance for her tics. She notes, "I don't know if this was my spouse, and I had to watch all the movements all the time and listen to things, the noises, I don't know if I could do it - if I could live with somebody [with TS]."

For Nancy, the anticipation of partners' discomfort has taken the form of an uncertainty as to how partners may respond to her sharing her diagnosis: "With dating, you don't know. You don't know if they're going to look at you differently." She has been concerned about being perceived as odd by her partner, once prefacing her disclosure with, "I swear, I'm not a freak, I'm not a weirdo..." Beth had a similar experience with her first boyfriend, suggesting, "...I was still nervous, I didn't know what the reaction was going to be." One can imagine that this uncertainty of the other's

reaction invokes a fair amount of anxiety for the subjects, making the act of addressing their condition with partners challenging.

Reasons for Concealing Tics

When looking at reasons for why women have chosen to hide or disguise their tics, several themes emerge. One has been the desire not to draw undue attention to oneself through one's symptoms, with romantic interests and with others in general. Jessica describes her response after an exercise instructor innocently commented on one of her motor tics: "It was fine, because it wasn't really anything I had to be embarrassed about. But afterwards I went up to her so that she wouldn't say that again. Because I felt that it would draw attention to me in the class." Nancy remembers trying to suppress her tics in class at school for similar reasons: "I don't want to distract people." The thought of getting peoples' attention with loud vocal tics while on a date was also extremely off-putting for Nancy: "I've consciously thought about it and tried so hard to control this. Or I've had to excuse myself because I've felt it coming, and felt, 'Oh my God, I can't do this – this is a restaurant!'"

Often, drawing undue attention to oneself goes hand in hand with feeling embarrassed by one's tics. Nancy's efforts to conceal loud vocal tics while on a rendezvous therefore probably also prevent embarrassment in front of her date and the other people present. Similarly, Anne has made efforts to hide her tics in order to avoid embarrassment. She says, "I don't do things because I feel embarrassed... I don't think I ever had that openness in my life. I was always hiding it."

Additionally, by concealing their tics, some of the subjects have been able to avoid going through the often anxiety-inducing process of explaining their diagnosis to romantic interests. Nancy recalls times she would postpone a date because her tics were particularly bad on a given day. She explains that on these occasions, she did not have the energy to talk about her symptoms and diagnosis: “I just didn’t feel like doing it. I didn’t feel like brushing over that topic whatsoever.” By keeping her distance temporarily, thereby hiding her tics, she has consequently avoided self-disclosure about TS. Similarly, Beth describes situations in which disguising her tics has been easier than having to disclose and explain her diagnosis: “I would just hide it well enough until I had decided whether or not to tell them.”

Finally, concealing tics can serve the function of avoiding a potential negative response from a romantic partner to one’s tics and diagnosis. As described earlier, subjects have often anticipated negative reactions by dates following disclosures, or more generally, have felt unsure and nervous about how partners may respond. Nancy explains about a previous boyfriend: “I didn’t even want to say. I tried so hard to conceal it. Like, ‘I don’t want to tell him; I don’t know how to tell him.’ I really liked him, and I didn’t know how he’d react.” Anne suggests she hid her tics even after receiving her diagnosis because “it wasn’t socially acceptable for me to tic.” By hiding their tics, the women in this study may therefore at least temporarily avoid the possibility of unpleasant reactions from dates and romantic partners.

Impact of making Disclosures to Romantic Partners

While making disclosures about TS to romantic partners has required significant emotional energy for the majority of the subjects, it appears that the effort involved in concealing their tics has also been draining. Thus, sharing their diagnosis has often ultimately led to relief, which Nancy, Beth, and Shannon describe in their interviews. One can imagine the freedom these subjects experienced once they no longer felt the need to hide their tics for a fear of embarrassment or attracting negative attention. As Beth says, “You just want to come home and let loose and not have to worry about being with someone... And you can’t be hiding in your free time, as well as in your working life, so it’s a big weight off your shoulders, for sure.” Nancy suggests that after disclosing her diagnosis in a relationship, “I’m much more relaxed. I’m not afraid if I have to twitch or something... I’m not embarrassed or trying to hide it.” Anticipating rejection or discomfort in one’s partner is also an uncomfortable state to be in, and no longer worrying about such possibilities is likely to be liberating as well. Nancy recalls how she felt after sharing her diagnosis with her boyfriend: “It made me feel easier, and maybe made the relationship a little bit easier.”

Another positive outcome for these women after disclosing their diagnosis is a perceived strengthening of the relationship, as well as increased comfort in the relationship. Beth says, “The makeup of the relationship, the foundation of our relationship, I think it’s gotten stronger...” Shannon describes her boyfriend’s supportive stance post-disclosure, suggesting, “I feel good that I can talk to him about it. So I feel I can trust him more, and it’s making me like him more... It just makes me feel better about dating him.” This solidifying of the relationship has also taken the form of

increased support from partners around TS and its symptoms. Beth says, “And [boyfriends] may not understand what it’s like for me, but they understand that I’m just really stressed and just need someone to calm me down and be there for me.” Nancy describes her boyfriend’s support after she shared her diagnosis with him: “He’ll try to console me, like, ‘It’s ok, just do it.’” Shannon notes the multiple ways in which her boyfriend has educated himself about TS and supported her with her condition post-disclosure.

Jessica and Anne, who happen to be significantly older than the other subjects, do not report that making disclosures about TS has impacted their romantic relationships in any major ways. This is perhaps not surprising, given that their life partners came to know about her symptoms before the women had been diagnosed or had a name for their condition. Both women’s husbands learned about their symptoms over longer periods of time, such that the act of disclosing their diagnosis may not have felt especially momentous for Jessica and Anne. It is also possible that these women remember making disclosures to their partners in a less salient manner than Nancy, Beth, and Sharon because the former are remembering a time in the more distant past.

Family and Peers’ Responses as a Model for how Romantic Partners may Respond

Among all five subjects, there is support for the notion that how they perceived their parents and friends as responding to their tics serves as a template for how they believe others, including potential romantic partners, might respond to their tics and TS diagnosis. Jessica feels that the supportive and positive responses from her family and peers while growing up helped her to feel confident in her later relationships: “I was

lucky that I had friends that were friends with me despite everything. It gave me reason to believe that as I got older, I would always have some friends... I guess I just thought if I had people that accepted me, that other people would accept me too.” Like Jessica, Beth believes that the support from her family has enabled her to feel comfortable and confident in dating situations: “I try to not have a fear of not being accepted, but that’s part of the way I was nurtured and raised.”

For Nancy, her mother’s reactions to her tics made her feel attacked, and as though she needed to defend herself. She notes that this defensiveness has reappeared in situations in which potential romantic partners inquire about her tics: “I guess sometimes when they ask, ‘Are you ok? What are you doing?’ I would automatically get all defensive, because that’s how my mother said to me.” Nancy also sees a connection between her father’s relative acceptance of her symptoms and her later level of comfort when dating: “Unconsciously, him being calm, it didn’t make me weary about stepping out into [dating].” She recognizes the similar impact of her friends’ ease with her tics growing up: “My friends, they always just ignored [my tics]. They never brought it up. And I think it makes me feel more comfortable, that I don’t need to be nervous... if I go somewhere, and there are boys.” Shannon similarly makes a direct link between how her mother responded to her tics and TS diagnosis and how she has expected potential dates to react to her disclosure that she has TS. She states, “It was kind of, like, ‘Well, if my mom didn’t think it was true, why would this person who didn’t grow up with me and see me doing all these things think it was true, just by me saying it?’” Shannon has anticipated that romantic partners might not take her symptoms and diagnosis seriously, in a way that would mirror her mother’s responses.

Unlike the other women, Anne does not explicitly propose a connection between her early experiences with family and friends and her later expectations of how dates might respond to her symptoms. However, one can infer that her parents' negative reactions to her tics contributed strongly to her impairing and enduring self-consciousness. The degree of her current avoidance of social situations in which her tics might be noticed parallels the severity of her parents' punitive and shaming responses to her symptoms as an adolescent: "I was berated for it, embarrassed, punished for it ... My family told me I could stop it, that I would be punished if I didn't stop." As an adult, she has panicked at the thought of others noticing her tics: "I feel like, 'Oh my God, everybody's watching!' ... I've isolated myself... And I don't do things because I feel embarrassed." While Anne's self-consciousness did not limit her while she was actively dating, probably due to reduced tic severity at the time, one can imagine her fear of humiliation in dating situations, were she actively dating while her tics were more severe.

This observed relationship between subjects' experiences with important others in childhood/adolescence and their expectations from others in dating situations is noteworthy. All subjects in the current study, with the exception of Anne, consciously recognize and make note of the relationship between their early experiences and how they have expected romantic partners to react to their TS. As Nancy says, "[Parents'] reactions will make a difference in [their children's] relationships... The way you react now is going to affect them later." Beth elaborates on this idea: "...if [TS] is not a big deal to your family and your parents, then you're going to grow up thinking it's not a big deal. And then I think maybe when you start to approach other people, ... you're going to say to yourself in your head, 'it's not a big deal.'" This supports the need for individuals

with TS to have early experiences that will instill self-confidence and comfort with their condition that is likely to translate into dating and other social experiences.

Family and Peers' Responses as a Motivation for getting Better Responses from Romantic Partners

While responses from important others in the earlier years may serve as internalized models for how potential romantic partners are likely to respond to TS, there also seems to be another process at work for most of the women in this study. Namely, their family and peers' negative responses also appear to have provided them with a motivation to seek out relationships in which others would respond more favorably to their tics. Shannon acknowledges that her mother's invalidating reactions to her tics and diagnosis made her determined "to go out with a guy who is really going to be understanding. And not be shocked, or make fun of me, or do anything like that." Jessica emphasizes, "I would never date anyone who would tell you, 'I know you can help that [the tics], so stop it,'" which is what her parents had told her during her early years. Anne believes that the lack of emotional support from her parents has caused her to seek out many romantic partners who are likely to provide warmth: "Probably I was looking for that love that I didn't get."

For Jessica and Nancy, the unpleasantness of their early experiences has also created a determination to lead as normal a life as possible, despite the reactions they may encounter from others to their condition. Jessica says: "I just kind of wanted to forget about those early days... just all the not understanding and everything. I just think the whole thing in general probably made me stronger." Nancy has developed a similar sense

of toughness in light of her mother's persistent negative reactions to her symptoms: "[My mother] was so much more attacking on the subject that I've learned to just have a tough skin about it." She has made conscious efforts not to let negative experiences with others prevent her from exploring romantic possibilities: "I could have totally said 'I don't want to attempt anything.' But what kind of a life is that? I'm very proud of myself for [putting myself out there]."

Beth does not connect her resilience in the context of living with TS to negative reactions from others while growing up. In fact, she minimizes the negative responses she has received from others. However, she does reference her older brother's "really bad, bad experiences" with others' reactions, noting, "I feel if I've had bad experiences, it's because of going through it with him." It is therefore likely that Beth's attitude of "you're not going to stop me from what I'm going to do" is related at least in part to having vicariously experienced her brother's difficulties and subsequently being determined not to let TS interfere with her dating or other social experiences.

Considering Genetics and Children

While the impact of having a genetic disorder on romantic relationships was not an original focus of this study, both Jessica and Anne made note of it during their interviews. Subsequently, it was decided that this topic should be addressed in the other interviews as well, which is consistent with a grounded theory approach. Subjects have expressed overlapping and distinct thoughts about the subject. For all but Anne, the fact that TS is a genetic disorder has had no reported impact on their or their partners' decision to have children. Jessica says, "I don't even think it was ever a question that we

were debating ... even though I knew I had [TS], and at that time there was a possibility that it was genetic.” Similarly, Nancy suggests, “I’ve thought about it, and I think I’m willing to take that risk.” Beth notes her boyfriend’s acceptance of the possibility of having children who are affected by TS: “It’s really not been a big deal for him ... it has not been a factor in deciding, in our talks about it.”

The women provide various reasons for why the possibility of having children with TS has not been a deterrent to having children. Jessica points out that TS is not a fatal disease, and that the consequences of having children who develop the disorder are much less grave than for other genetic illnesses in question. She says, “I mean, I’d rather have [TS] than a million other things ... It’s not like some other fatal genetic thing that you might have to grapple with and decide what to do, as far as having kids.”

Another reason why the genetic nature of TS has not been a deterrent to having children for the five women is that there is growing awareness about the neurological disorder, as well as treatments that might lessen symptoms. Awareness about the socio-emotional difficulties that children with TS face now and in the future is also growing. Jessica suggests about her children, “I just think that if they are to get my genes, they don’t have to wait 15 years to be diagnosed ... there’s been a lot of change.” While Anne proposes that she may not have had children had she known about the genetic nature of her condition at the time, she acknowledges that children growing up with TS nowadays have it easier than she did: “I think the difference between somebody my age and somebody younger is that there is so much more awareness.” Jessica and Anne grew up during a period when knowledge about TS among professionals and society at large was

extremely limited. Anne's words, "It's a different world now" are certainly true when it comes to living with the disorder.

Shannon suggests that if her future children have TS, she will be knowledgeable about the condition and associated challenges as a parent. In her view, she and her partner would be prepared to help their children through the difficulties related to having TS. She says, "I think that if we had a kid that had some tics, or Tourette's, then I think that we both know about it. And I guess we can help – we can just address it from the start." The genetic nature of TS has therefore not deterred Shannon from having children in any way.

Chapter IV

Discussion

At the outset of this study, it was proposed that adults with TS might be hesitant to date. Dating entails exposing one's symptoms to potential romantic partners, which is likely to arouse fears of rejection rooted in the common negative socio-emotional experiences of growing up with TS. Interestingly, none of the women interviewed in this study report having avoided dating or seeking out romantic relationships as a result of having TS. Rather, their stories illustrate the nuanced ways in which growing up and living with TS is likely to affect dating experiences. In light of the public, noticeable, and often intrusive nature of tics, the subjects have faced several challenges regarding how to manage their symptoms in front of romantic interests, as well as how to talk about them with partners. The data suggest that the women's dating experiences have been impacted by their experiences with family and peers growing up. And, despite the challenges faced, the women have found ways to date without letting their symptoms and diagnosis pose significant barriers.

When reflecting on the first two guiding research questions of how adults with the neurological condition navigate dating and romantic relationships and what challenges and limitations they face in the process, several findings are relevant. One way in which the women in this study have managed their symptoms in the context of dating is by attempting to conceal them to the extent possible. Hiding one's tics can serve as a mechanism whereby individuals with TS can titrate how much they expose or reveal to romantic interests about their condition. For instance, by hiding their symptoms while

dating, the women have avoided unwanted attention and embarrassment that tics often elicit. They have also avoided potential rejection by a partner that is related to not knowing how a partner may respond to tics or disclosure of TS as a diagnosis. Furthermore, the women have avoided, or at least delayed, the need to explain their symptoms and diagnosis to dates. Because the process of explaining TS to a significant other is emotionally involving and can feel rather exposing, it is understandable that adults with the condition would want to have the option of waiting until a certain point in the relationship to do so. Thus, the ability to conceal one's tics appears to play an important role in navigating romantic relationships. At the same time, it is clearly not a solution for the long-run, nor is it one that is guaranteed to be effective at all times. The desire to conceal tics, but not always being able to, therefore appears to be one of the challenges that adults face when dating.

When it comes to making disclosures to dates and romantic partners about their TS, the women have navigated relationships by taking into consideration several important questions, including whether, why, when, how and what to disclose. The need to consider these questions when dating can also be thought of as a challenge/limitation in dating among adults with TS. Furthermore, these considerations address the third research question of how adults with TS go about explaining TS to partners. In considering whether, why, and when to disclose, several parallels exist between the findings of the current study and those of Klitzman and Sweeney (2011).

For instance, one reason for why some of the women in this study have chosen to share their diagnosis with a romantic partner involves a sense of obligation to be honest about their condition. This perceived responsibility to disclose is similar to the one

described by Klitzman and Sweeney (2011) among adults with genetic diseases or at risk for a genetic disease. At the same time, the non-fatal nature of TS puts it in a different category from the genetic illnesses involved in Klitzman and Sweeney's study (2011), which are potentially fatal. It would make sense that adults with TS may not feel quite the same level of moral obligation to disclose their diagnosis to partners as adults with potentially fatal conditions that can be passed on to children.

Another reason why the women with TS have decided to disclose their diagnosis in dating situations is simply because their tics have been severe and/or observable, and therefore not possible to conceal. This trend parallels Klitzman and Sweeney's finding (2011) that adults who choose to make disclosures to partners about their genetic conditions often do so because their diagnosis is hard to hide. The need to disclose one's diagnosis - often without wanting to - because one's symptoms are obvious to others, can certainly be seen as a central challenge faced by adults with TS. Perhaps this is one of the challenges the subjects in Champion et al.'s 1988 study were referring to, when they reported problems with dating as a result of having TS.

While all five women in this study have been in relationships in which their partners have reportedly responded positively to their neurological condition, some have at times chosen not to disclose their diagnosis because of an implicit fear of rejection. Similarly, Klitzman and Sweeney (2011) note that among their sample of individuals with a genetic illness or a risk for one, the fear of rejection is a deterrent to making disclosures to partners about this genetic illness. Newth and Rachman (2001) also point out the fear of rejection among patients with OCD when sharing the nature of their symptoms with others. For adults with TS, concerns that others may respond unfavorably

to their condition are understandable, given some of their likely earlier negative social experiences. After all, some research among children suggests that even when information about TS is provided to children, they are likely to rate a peer with TS less positively than a peer without TS (Friedrich et al., 1996). Common sense might suggest that peers are likely to become more tolerant and accepting of an individual with TS in adulthood. However, there are no known studies that examine adults' attitudes toward adults with TS. Support groups may be a good venue for individuals with TS to address their concerns about the anticipated reactions from other adults, particularly romantic interests.

With regard to when the women have chosen to disclose their TS diagnosis to partners, the tendency not to disclose unless one feels a relationship has long-term potential and delaying disclosure until one feels comfortable enough in the relationship appear to play important roles. Klitzman and Sweeney (2011) note the same themes among their subjects. The authors also emphasize the subjectivity involved in deciding whether and when to share one's diagnosis or genetic risk for a disease. They identify a conflict faced by many of their subjects: "...balancing one's own desires for, and right to, privacy vs. one's sense of implicit responsibility to others." (p. 106). Adults with TS likely face a similar dilemma. They are likely to feel exposed and/or vulnerable when making a romantic interest aware of their condition. For many, sharing their diagnosis entails making public a rather private part of their experience. Often, they may be forced to publicize this information before they feel ready, as when others ask about their tics. They may be put in a situation in which they have disclosed more personal information than their partner, creating a sense of disequilibrium in the relationship. Freeman (1998)

proposes that intimacy is “a reciprocal dyadic interaction between two equals.” (p. 161).

When a disclosure feels premature and one-sided, rather than reciprocal, the development of intimacy may therefore be skewed in a relationship. The questions of if and when to share one’s diagnosis can therefore be a noteworthy challenge faced by adults with TS.

Another important challenge entails the difficulty of explaining TS as a neurological condition to a partner who is likely to be unfamiliar with it. As some of the women describe, it is not easy to explain things like why one engages in tics, what they feel like, why one has the tics one has, why they wax and wane, and why one often cannot suppress them. For individuals who do not have an awareness of their condition, answering such questions is even harder. By comparison, the implications and manifestations of other genetic medical conditions and illnesses tend to be fairly straightforward for the lay person to understand: Affected persons are seen as unwell and possibly at risk of dying if their condition progresses. As such, one can presume that the individuals in Klitzman and Sweeney’s study (2011) did not face the same challenges as the women in this study with regard to how to describe their condition. Explaining TS to others appears to involve difficulties that are rather unique, in light of the nature of this condition.

The consideration of the genetic implications of having TS in the context of romantic relationships was not thought of as a significant challenge or limitation by all but one of the women in this study. Furthermore, the women’s romantic partners were seemingly not fazed by the possibility of having children with TS or tics with them. While all women noted that it might be important to talk about the genetic piece of TS when in a serious romantic relationship, only one felt that it might have ultimately

influenced her decision to have children. It is noteworthy that the women in this sample do not suffer from extremely severe tics. It would be interesting to see whether individuals with more impairing symptoms would be more impacted by the genetic component of TS in the context of dating.

Indirectly related to the third guiding research question of how adults with TS go about explaining their symptoms to romantic partners is the impact that making disclosures about TS has on romantic relationships. For three of the five women, sharing their diagnosis with romantic partners has had a significant positive effect on their relationships. They describe the relief associated with no longer needing to conceal their tics and no longer worrying about how their partners may respond. Furthermore, they have perceived their romantic relationships as becoming stronger as a result of the disclosure. It is worth noting that none of the women remember a disclosure about TS impacting their romantic relationships in a negative way.

In addressing the fourth guiding research question of how the socio-emotional experiences of adults with TS with family and peers influence their dating experiences, two trends were identified. On the one hand, the women appear to have expected responses from romantic interests and partners that are similar to the responses they received from family and/or peers growing up. This finding that family and peers' responses during childhood may serve as an internalized model for how romantic partners may respond broadly supports Edell and Motta's finding (1989) that parents' reactions to their children's TS predicted their children's emotional adjustment.

At the same time, when the women in this study have received unfavorable responses from their family and friends, it seems to have inspired or motivated them to

find partners who would respond in a better manner. All five women describe some experiences in which family members, peers, or strangers, have made them feel embarrassed, ridiculed, or at the very least, self-conscious with regard to their tics. It is reasonable to assume that even individuals with mild tics, like Beth, will encounter situations like these during various stages in their lives. One would hope that for most people with TS, such experiences will serve as an incentive to seek out relationships, romantic and otherwise, in which others are accepting of them as individuals and tolerant of their symptoms. However, for some, like Anne, the emotional damage of others' negative reactions may prevent them from feeling comfortable even with close acquaintances. As such, negative reactions from others may facilitate and/or hinder the development of a social hardiness that is observable in Jessica, Nancy, and Beth. Evidently, other personality and environmental factors are likely to play a role in determining to what extent individuals will develop resilience.

This leads into the fifth guiding research question of the study, namely: What factors are helpful for adults with TS in navigating romantic relationships? Here, the subjects' advice for adults with TS and parents of children with TS in the area of dating appears particularly relevant. The women's responses suggest that it is helpful for parents to be educated about TS and what to expect from the condition, so that they can best help their children to feel comfortable living and dating with TS. Parents' support and encouragement for their children to be able to date successfully, despite their tics, was also identified as helpful. This includes an overall acceptance of parents for their children. For several women, the support and acceptance of their peers was also perceived as facilitating a comfort in dating situations. Being able to manage one's tics

with the help of medical and/or psychological treatment was seen as beneficial for dating, as was taking part in a support group for TS with other affected individuals. When actually involved with someone romantically, some of the subjects have pointed out the value of being able to accept oneself despite one's tics, without letting one's symptoms take over one's identity. Finally, most of the women have advocated for being honest with others about one's condition in the context of dating, while still relying on one's inner sense of when it feels comfortable to disclose one's diagnosis.

Limitations of this Study

This study uses a qualitative approach, and the themes identified are descriptive and exploratory in nature. They neither confirm nor refute other research examining the dating experiences of adults with TS. Several factors limit the extent to which the findings can be generalized to adults with TS. Perhaps most importantly, only women were interviewed. As stated previously, this was done for clinical reasons, with the hope that richer data would be obtained through a gender-matched interview process. However, it is possible that the dating experiences of men and women with TS differ, and caution should be taken when applying findings from this study to men with TS.

Additionally, generalizability is limited because all subjects are from New Jersey or New York, states in which there is a good amount of advocacy for TS. Because most of the women who participated in this study are directly or indirectly linked to a TS advocacy group, they are likely to have participated in such an organization to some extent and be fairly knowledgeable about and comfortable with TS. Women from other

states and regions in which there are no formal TS advocacy groups are likely to have different experiences from those of the women in this study.

It should also be noted that a small sample size was used, and all subjects are either in their 20s or their 50s. While comparisons were made between the women in these age groups, women in their 30s, 40s, and 60s and beyond are not represented in the sample. It is possible that the experiences of individuals in these age groups are distinct. Finally, all subjects are Caucasian. Women other races may have somewhat different experiences of living with TS.

Investigator bias may be a limitation of this study. The researcher designed the interview used for data collection and conducted the interviews and qualitative data analysis single-handedly. Inter-rater reliability was not ensured during the process of data collection or analysis. When interpreting the findings of this study, these forms of possible bias should be taken into account.

Concluding Recommendations

For adults with TS. In order to maximize their comfort level in dating with TS, adults with the disorder should consider different treatment options and pursue treatment that is most likely to work for them. This is not to say that treatment is necessary for everyone, and naturally, the decision to seek it relates to tic severity and impairment caused by TS. Potential adverse side-effects also need to be considered in the case of medical treatment. Nevertheless, individuals with TS need not feel unnecessarily burdened or limited by their symptoms when effective relief is available. Keeping their tics at a manageable level is likely to enhance their comfort level in dating situations.

Along the same lines, individuals with TS are likely to benefit tremendously from educating themselves about the causes, course, and nature of the neurological disorder. Having a good understanding about one's condition will reduce the potential confusion, embarrassment, and shame that can be associated with having tics in dating situations. It may reduce the need to conceal one's tics. Understanding and having the language to describe one's condition also makes the process of explaining tics and TS to romantic partners less anxiety-inducing and more straight-forward. Given the finding that individuals have often felt relieved and more at ease in their romantic relationships once they have shared their diagnosis with their partners, it is important for people with TS to feel as though they have the knowledge and language to accurately explain TS. Furthermore, being able to comfortably explain one's symptoms is likely to lead to increased support from partners. Many of the challenges faced by individuals with TS when dating can therefore be reduced significantly through increasing one's knowledge about the disorder. Organizations like the National Tourette Syndrome Association and the New Jersey New Jersey Center for Tourette Syndrome and Associated Disorders are examples of resources for detailed information about TS.

There are several benefits to making disclosures about TS to romantic partners, and overall, affected individuals are encouraged to educate and talk to partners about their disorder. At the same time, the experiences of the participants in this study highlight that questions like when and whom to disclose to play an important role. As several participants point out, individuals are likely to have different preferences and needs as to when they would like to disclose their diagnosis to romantic interests. It is important that adults with TS trust their own sense of comfort with regard to when and whom they

would like to share their condition with, while not feeling they are incapable of addressing their TS. When considering these questions, they might take into account factors like the long-term potential of a relationship, to what extent they feel a partner should know about their condition, their current tic severity, and the degree of closeness and trust in the relationship. Needless to say, adults with TS should find partners who are accepting, supportive, and flexible with regard to sacrificing activities that may be rendered difficult due to tics.

Finally, because adults with TS may face significant socio-emotional challenges in their lives and understandably have concerns about how their symptoms interfere with dating, they should seek out organized sources of support focused on living with TS. These can take the form of individual counseling or support groups, the latter of which most of the subjects in this study have found very helpful. Support groups provide exposure to other individuals with TS who may have similar concerns and experiences in the area of dating. Regular interactions with others within these groups can provide emotional relief and normalization, which is likely to enhance people's comfort level and wellbeing with regard to dating with TS.

For caregivers of children/adolescents with TS. Just as adults with TS should seek out and explore treatment options, parents of children, adolescents, and even young adults, should pursue treatment for them to help reduce symptoms to a manageable level. In the process, they should educate themselves, their children with TS, as well as other family members on the causes, course, and nature of TS and associated disorders. At the same time, it is advisable for parents not to focus on a child's tics excessively, modeling

an ability to look past his or her tics and live with them comfortably. Creating an atmosphere of understanding, acceptance, and support in the home is likely to enhance an affected child's emotional wellbeing and comfort with his or her disorder. Consequently, he or she is more likely to feel at ease with peers, which is then likely to translate into future dating experiences.

Parents also do well by helping their children with TS to make sense of and explain their disorder to others. Making disclosures about TS, especially at a young age, can be quite challenging, and caregivers can help by providing children with the language needed to explain their condition to those around them. This will make children more comfortable in discussing their diagnosis with dates and romantic partners in the future. It may be helpful for caregivers to discuss with their children and adolescents how and when they might explain TS in dating situations specifically. Parents should also normalize the concerns that their children have about dating, while providing encouragement. At the same time, they should respect their child's personal preferences surrounding when, to whom, and how to share their condition.

For mental health professionals. Mental health professionals who work with individuals with TS should take into account the major themes of this study in order to recognize and appreciate the socio-emotional experiences of such persons. Those professionals specializing in TS may already be fairly familiar with the themes explored here. Regardless, an in-depth look at the experiences of the five cases is likely to make mental health workers more attuned to the nuances of the challenges and strengths that affected adults may encounter in the area of dating and pursuing romantic relationships.

Attention might be paid to how a client's early experiences with others impact her expectations of how romantic partner will respond to her tics and her disclosure of her diagnosis. Additionally, how early or late in life a patient has come to learn about TS is likely to play a role in the degree of comfort he has around others with his symptoms. Mental health professionals should assess how much a client understands about TS and its associated symptoms, and if necessary, provide sufficient psychoeducation or appropriate resources on the topic. As noted earlier, a good understanding of the neurological condition is likely to enhance an individual's psycho-social wellbeing. It is also likely to make it easier to communicate with romantic partners about TS. Thus, it is imperative for mental health workers to facilitate a good understanding of TS in their patients. They may also choose to educate and support family members, especially when working with children and adolescents.

While professionals should assist patients in comfortably making disclosures about TS to others, particularly romantic interests, they should also be sensitive to the varying degrees of comfort that individuals have with their disorder. Furthermore, they should be mindful of the factors discussed that may determine whether, why, when, how and what individuals with TS choose to share with others. It is important to encourage and facilitate making disclosures, while being attuned to and normalizing concerns that patients may have about disclosing. Referrals to support groups may be helpful in this regard as well. Finally, mental health professionals should be aware of the ways in which individuals with TS have developed a sense of resilience and determination to lead a normal life, despite their diagnosis. These strengths should be noticed and built upon in any therapeutic setting.

References

- Abbey, R. D., Clopton, J. R., & Humphreys, J. D. (2007). Obsessive-compulsive disorder and romantic functioning. *Journal of Clinical Psychology, 63*(12), 1181-1192.
- Abwender, D. A., Como, P. G., Kurlan, R., Parry, K., Fett, K., Cui, et al. (1996). School problems in Tourette's syndrome. *Archives of Neurology, 53*, 509-511.
- American Psychological Association (2000). *Diagnostic and statistical manual of mental disorders (4th ed. text revision)*. Washington, DC: Author.
- Auerbach, C. F. & Silverstein, L. B. (2003). *Qualitative data: An introduction to coding and analysis*. New York: New York University Press.
- Azrin, N. H. & Nunn, R. G. (1973). Habit-reversal: A method of eliminating nervous habits and tics. *Behaviour Research and Therapy, 11*(4), 619-628.
- Azrin, N. H., Nunn, R. G., & Franz, S. E. (1980). Habit reversal versus negative practice treatment of nervous tics. *Behavior Therapy, 11*(2), 169-178.
- Azrin, N. H. & Peterson, A. L. (1990). Treatment of Tourette syndrome by habit reversal: A waiting-list control group comparison. *Behavior Therapy, 21*(3), 305-318.
- Bawden, H. N., Stokes, A., Camfield, C. S., Camfield, P. R., & Salisbury, S. (1998). Peer relationship problems in children with Tourette's disorder or diabetes mellitus. *Journal of Child Psychology and Psychiatry, 39*(5), 663-668.
- Burd, L., Kerbeshian, J., Cook, J., Bornhoeft, D. M., & Fisher, W. (1988). Tourette disorder in North Dakota. *Neuroscience & Biobehavioral Reviews, 12*, 223-228.
- Carter, A. S., O'Donnell, D. A., Schultz, R. T., Scahill, L., Leckman, J. F., & Pauls, D. L. (2000). Social and emotional adjustment in children affected with Gilles de la Tourette's syndrome: Associations with ADHD and family functioning. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 41*(2), 215-223.
- Champion, L. M., Fulton, W. A., & Shady, G. A. (1988). Tourette syndrome and social functioning in a Canadian population. *Neuroscience and Biobehavioral Review, 12*, 255-257.
- Coffey, B. J., Miguel, E. C., Biederman, J., Baer, L., Rauch, S. L., & O'Sullivan, R. L., et al. (1998). Tourette's disorder with and without obsessive-compulsive disorder in adults: Are they different? *Journal of Nervous and Mental Disease, 186*, 201-206.
- Coffey, B. J. & Park, K. S. (1997). Behavioral and emotional aspects of Tourette syndrome. *Neurological Clinics of North America, 15*, 277-289.

- Cohen, D. J., Bruun, R. D., & Leckman, J. F. (Eds.), (1988). *Tourette's syndrome and tic disorders: Clinical understanding and treatment*. New York: Wiley.
- Comings, D. E. & Conings, B. G. (1985). Tourette syndrome: Clinical and psychological aspects of 250 cases. *American Journal of Human Genetics*, 37, 435-450.
- Corbin, J. & Strauss, A. (2008). *Basisc of qualitative research*. Thousand Oaks, CA: Sage Publications.
- Dykens, E., Leckman, J., Riddle, M., Hardin, M., Schwartz, S., & Cohen, D. (1990). Intellectual, academic, and adaptive functioning of Tourette syndrome children with and without Attention Deficit disorder. *Journal of Abnormal Child Psychology*, 18(6), 607-615.
- Edell, B. H. & Motta, R. W. (1989). The emotional adjustment of children with Tourette's syndrome. *Journal of Psychology*, 123(1), 51-57.
- Ercan-Sencicek, A. G., Stillman, A. A., Ghosh, A. K., Bilgavur, K., O'Roak, B. J., King, R. A., et al. (2010) L-histidine decarboxylase and Tourette's syndrome. *New England Journal of Medicine*, 362(20), 1901-1908.
- Freeman, A. (1998). The intimacy styles approach: A cognitive-behavioral model for understanding and treating problems of intimacy. In J. Carlson & L. Sperry (Eds.), *The Intimate Couple* (pp. 158-184). Ann Arbor, MI: Edwards Brothers.
- Freeman, R. D., Fast, D. K., Burd, L., Kerbeshian, J., Robertson, M. M., & Sandor, P. (2000). An international perspective on Tourette syndrome: Selected findings from 3500 individuals in 22 countries. *Developmental Medicine and Child Neurology*, 42, 436-447.
- Friedrich, S., Morgan, S. B., & Devine, C. (1996). Children's attitudes and behavioral intentions toward peer with Tourette syndrome. *Journal of Pediatric Psychology*, 21(3), 307-319.
- Holtz, K. D. (2000). The psychosocial implications of Tourette syndrome in Children: Evaluation of an intervention (Doctoral dissertation, George Washington University, (2000). *Dissertation Abstracts International*, 61/04.
- Jagger, J., Prusoff, B., Cohen, D. J., Kidd, K. K., Carbonari, C. M., & John, K. (1982). The epidemiology of Tourette's syndrome: A pilot study. *Schizophrenia Bulletin*, 8, 267-277.
- Klitzman, R. L. & Sweeney, M. M. (2011). "In sickness and in health"? Disclosures of genetic risks in dating. *Journal of Genetic Counseling*, 20, 98-112.

- Kurlan, R. (Ed.), (2005). *Handbook of Tourette's syndrome and related tic and behavioral disorders*. New York: Marcel Dekker.
- Lambert, S. & Christie, D. (1998). A social skills group for boys with Tourette's syndrome. *Clinical Child Psychology and Psychiatry*, 3(2), 267-277.
- Leckman, J. F. & Cohen, D. J. (Eds.), (1999). *Tourette syndrome – tics, obsessions, compulsions: Developmental psychopathology and clinical care*. New York: Wiley.
- Leckman, J. F., Cohen, D. J., Goetz, C.G., & Jankovic, J. (2001). Tourette syndrome: Pieces of the puzzle. In D. J. Cohen, J. Jankovic, & D. G. Goetz (Eds.), *Advances in Neurology: Vol. 85. Tourette Syndrome* (pp. 369-390). Philadelphia: Lippincott Williams & Williams.
- Leckman, J. F., Riddle, M. A., Hardin, M. T., Ort, S. I., Swartz, K. L., Stevenson, J., et al., (1989). The Yale Global Tic Severity Scale: Initial testing of a clinician-related scale of tic severity. *Journal of the American Academy of Child and Adolescent Psychiatry*, 28, 566-573.
- Leckman, J. F., Zhang, H., Vitale, A., Lahrin, F., Lynch, K., Bondi, et al., (1998). Course of tic severity in Tourette syndrome: the first two decades. *Pediatrics*, 102, 14-19.
- Lerer, R. J. (1987). Motor tics, Tourette syndrome, and learning disabilities. *Journal of Learning Disabilities*, 20(5), 266-267.
- McCracken, G.D. (1988). *The Long Interview*. Newbury Park, California: SAGE Publications.
- Murray, J. B. (1997). Psychophysiological aspects of Tourette's syndrome. *Journal of Psychology*, 131(6), 615-626.
- Neimat, J. S., Patil, P. G., & Lozano, A. M. (2006). Novel surgical therapies for Tourette Syndrome. *Journal of Child Neurology*, 21(8), 715-718.
- Newth, S. & Rachman, S. (2001). The concealment of obsessions. *Behaviour Research and Therapy*, 39, 457-464.
- Nomura, Y., Kita, M., & Segawa, M. (1992). Social adaptation of Tourette syndrome families in Japan. In T. N. Chase, A. J. Friedhoff, & D. J. Cohen (Eds.), *Advances in Neurology: Vol. 58. Tourette Syndrome: Genetics, Neurobiology and Treatment* (pp. 323-332). New York: Raven Press.

- O'Connor, K. P., Brault, M., Robillard, S., Loiselle, J., Borgeat., F., & Stip, E. (2001). Evaluation of a cognitive-behavioural program for the management of chronic tic and habit disorders. *Behaviour Research and Therapy*, *39*(6), 667-681.
- Papert, E. J., Goetz, C. G., Louis, E. D., Blasucci, L., & Leurgans, S. (2003). Objective assessments of longitudinal outcome in Gilles de la Tourette's syndrome. *Neurology*, *61*, 936-940.
- Piacentini, J. C., Woods, D. W., Scahill, L., Wilhelm, S., Peterson, A. L., Chang, S., Ginsburg, G. S., Deckersbach, T., Dziura, J., Levi-Pearl, S., Walkup, J. T. (2010). Behavior therapy for children with tourette disorder: A randomized controlled trial. *Journal of the American Medical Association*, *303*(19), 1929-1937.
- Price, R. A., Kidd, K. K., Cohen, D. L., Pauls, D. L., & Leckman, J. F. (1985). A twin study of Tourette syndrome. *Archives of General Psychiatry*, *42*, 815-820.
- Riddle, M. A. & Carlson, J. (2001). Clinical psychopharmacology for Tourette syndrome and associated disorders. In D. J. Cohen, J. Jankovic, & D. G. Goetz (Eds.), *Advances in Neurology: Vol. 85. Tourette Syndrome* (pp. 343-354). Philadelphia: Lippincott Williams & Williams.
- Sheppard, D. M., Bradshaw, J. L., Purcell, R., & Pantelis, C. (1999). Tourette's and comorbid syndromes: Obsessive compulsive and attention deficit hyperactivity disorder – A common etiology? *Clinical Psychology Review*, *19*(5), 531-552.
- Silva, R. R., Munoz, Dinohra, M., Barickman, J., Friedhoff, A. J. (1995). Environmental factors and related fluctuation of symptoms in children and adolescents with Tourette's disorder. *Journal of Child Psychology and Psychiatry*, *36*(2), 305-312.
- Singer, H. S. (2005). Tourette's syndrome: from behaviour to biology. *The Lancet Neurology*, *4*, 149-159.
- Spencer, T., Biederman, J., Harding, M., O'Donnell, D., Wilens, T., Faraone, S., et al. (1998). Disentangling the overlap between Tourette's disorder and ADHD. *Journal of Child Psychology and Psychiatry*, *39*(7), 1037-1044.
- Stokes, A., Bawden, H. N., Camfield, P. R., Backman, J. E., & Dooley, J. M. (1991). Peer problems in Tourette's disorder. *Pediatrics*, *87*(6), 936-942.
- Storch, E. A., Murphy, T. K., Chase, R. M., Keeley, M., Goodman, W. K., Murray, M., et al. (2007). Peer victimization in youth with Tourette's syndrome and chronic tic disorder: Relations with tic severity and internalizing symptoms. *Journal of Psychopathology and Behavioral Assessment*, *29*(4), 211-219.
- Strauss, A. & Corbin, J. (1990). *Basics of qualitative research*. Newbury Park, CA: Sage Publications.

- Thibert A. L., Day, H. I., Sandor, P. (1995). Self-concept and self-consciousness in adults with Tourette syndrome. *Canadian Journal of Psychiatry*, 40, 35-39.
- Walkup, J. T. (2001). Epigenetic and environmental risk factors in Tourette syndrome. In D. J. Cohen, J. Jankovic, & D. G. Goetz (Eds.), *Advances in Neurology: Vol. 85. Tourette Syndrome* (pp. 273-279). Philadelphia: Lippincott Williams & Williams.
- Walkup, J. T., Khan, S., Schuerholz, L., Paik, Y., Leckman, J. F., & Schultz, R. (1999). Phenomenology and natural history of tic-related ADHD and learning disabilities. In J. F. Leckman & D. J. Cohen (Eds.), *Tourette's Syndrome – Tics, Obsessions, Compulsions: Developmental Pathology and Clinical Care* (pp. 63-79) New York: Wiley.
- Wigley, K., Mason, A., Lambert, S., Collins, J., Lask, B., & Christie, D. (2000). A specialist service for children and adolescents with Tourette's syndrome: Problems and attempted solutions. *Clinical Child Psychology and Psychiatry*, 5(2), 247-257.
- Wilhelm, S., Deckersbach, T., Coffey, B. J., Bohne, A., Peterson, A. L., & Baer, L. (2003). Habit reversal versus supportive psychotherapy for Tourette's Disorder: A randomized controlled trial. *American Journal of Psychiatry*, 160(6), 1175-1177.
- Woods, D. W. & Himle, M. B. (2004). Creating tic suppression: Comparing the effects of verbal instruction to differential reinforcement. *Journal of Applied Behavioral Analysis*, 37(3), 417-420.
- Woods, D. W., Piacentini, J. C., Chang, S., Deckersbach, T., Ginsburg, G., Peterson, A., et al. (2008). *Managing Tourette Syndrome: A Behavioral Intervention for Children and Adults Therapist Guide*. NY: Oxford Press.
- Woods, D. W., Piacentini, J. C., & Walkup, J. T. (Eds.) (2007). *Treating Tourette syndrome and tic disorders: A guide for practitioners*. New York: Guilford Press.
- Yin, R. K. (2003). *Case study research design and methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Zohar, A. H., Ratzoni, G., Pauls, D. L., Apter, A., Bleich, A., Kron, S., et al. (1992). An epidemiological study of obsessive-compulsive disorder and related disorders in Israeli adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 31(6), 1057-1061.

Appendix A

Advertisement

Are you a woman with Tourette's Syndrome?

Participate in a new study on TS and dating!

Women with TS aged 18 years and above are being recruited for a doctoral dissertation study at the Graduate School of Applied and Professional Psychology (GSAPP) of Rutgers University. Participants will be interviewed about their experiences with dating and pursuing romantic relationships. If you are interested, please contact Nadia Lemp, M.A. at (732) 445-6111 ext. 887 or at nlemp@eden.rutgers.edu for more information.

Participants should not have a serious psychiatric disorder (e.g. bipolar disorder, psychosis) or developmental disabilities. Interviews will last approximately 90 minutes and will be audio taped. Confidentiality will be ensured. There is no compensation for participating in this study.

Study on TS and Dating
Nadia Lemp, M.A.
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Rutgers University
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Appendix B

Demographics Questionnaire

- 1) Age: _____
- 2) Ethnicity: _____
- 3) Occupation: _____
- 4) Relationship status
 - a. single/currently not in a romantic relationship
 - b. married/in domestic partnership
 - c. currently in a romantic relationship
 - d. divorced/separated
- 5) Do you have children?
Yes If yes, how many? _____
No
- 6) Number of romantic relationships you have had lasting 3 months or longer: _____
- 7) Age of onset of tics: _____
- 8) Age at which TS diagnosis was received: _____
- 9) Other psychiatric diagnoses received (specify diagnoses below):
 - a. OCD
 - b. ADHD
 - c. Learning Disorder (specify): _____
 - d. Depressive Disorder (specify): _____
 - e. Other (specify): _____
- 10) Do you have symptoms of OCD or ADHD? If so, briefly describe them:

- 11) Are you currently on any medication for your TS or related conditions? If so, which ones?

Appendix C

Yale Global Tic Severity Scale (YGTSS)

PATIENT ID #:	TODAY'S DATE :	/	/
RATER:			

MOTOR TIC SYMPTOM CHECKLIST

Description of Motor Tic Symptoms. Motor tics usually begin in childhood and are characterized by sudden jerks or movements, such as forceful eye blinking or a rapid head jerk to one side or the other. The same tics seem to recur in bouts during the day and are worse during periods of fatigue and/or stress. Many tics occur without warning and may not even be noticed by the person doing them. Others are preceded by a subtle urge that is difficult to describe (some liken it to the urge to scratch an itch). In many cases it is possible to voluntarily hold back the tics for brief periods of time. Although any part of the body may be affected, the face, head, neck, and shoulders are the most common areas involved. Over periods of weeks to months, motor tics wax and wane and old tics may be replaced by totally new ones.

Simple motor tics can be described as a sudden, brief, "meaningless" movement that recurs in bouts (such as excessive eye blinking or squinting). Complex motor tics are sudden, stereotyped (i.e., always done in the same manner) semi-purposeful (i.e., the movement may resemble a meaningful act, but is usually involuntary and not related to what is occurring at the time) movements that involve more than one muscle group. There may often be a constellation of movements such as facial grimacing together with body movements. Some complex tics may be misunderstood by other people (i.e., as if you were shrugging to say "I don't know"). Complex tics can be difficult to distinguish from compulsions; however, it is unusual to see complex tics in the absence of simple ones. Often there is a tendency to explain away the tics with elaborate explanations (e.g., "I have hay fever that has persisted" even though it is not the right time of year). Tics are usually at their worst in childhood and may virtually disappear by early adulthood, so if you are completing this form for yourself, it may be helpful to talk to your parents, an older sibling, or a relative, as you answer the following questions.

- Age of **first** motor tics? _____ years old
- Describe **first** motor tic: _____
- Was tic onset sudden or gradual? _____
- Age of **worst** motor tics? _____ years old

Motor Tic Symptom Checklist

In the boxes on the left below, please check with a mark (x) the tics the patient

- 1) has **EVER** experienced
- 2) is **CURRENTLY** experiencing (during the past week)

State **AGE OF ONSET** (in years) if patient has had that behavior.

Also, in the tic descriptions below, please circle or underline the specific tics that the patient has experienced (circle or underline the words that apply).

Ever	Cur- rent	Age of onset	The patient has experienced, or others have noticed, involuntary and apparently purposeless bouts of:	Ver
-eye movements.				
			eye blinking, squinting, a quick turning of the eyes, rolling of the eyes to one side, or opening eyes wide very briefly.	
			eye gestures such as looking surprised or quizzical, or looking to one side for a brief period of time, as if s/he heard a noise.	
-nose, mouth, tongue movements, or facial grimacing.				
			nose twitching, biting the tongue, chewing on the lip or licking the lip, lip pouting, teeth baring, or teeth grinding.	
			broadening the nostrils as if smelling something, smiling, or other gestures involving the mouth, holding funny expressions, or sticking out the tongue.	
-head jerks/movements.				
			touching the shoulder with the chin or lifting the chin up.	
			throwing the head back, as if to get hair out of the eyes.	
-shoulder jerks/movements.				
			jerking a shoulder.	
			shrugging the shoulder as if to say "I don't know."	
-arm or hand movements.				
			quickly flexing the arms or extending them, nail biting, poking with fingers, or popping knuckles.	
			passing hand through the hair in a combing like fashion, or touching objects or others, pinching, or counting with fingers for no purpose, or writing tics, such as writing over and over the same letter or word, or pulling back on the pencil while writing.	
-leg, foot or toe movements.				
			kicking, skipping, knee-bending, flexing or extension of the ankles; shaking, stomping or tapping the foot.	

Ever	Current	Age of onset	taking a step forward and two steps backward, squatting, or deep knee-bending.	Ver
			The patient has experienced, or others have noticed, involuntary and apparently purposeless bouts of:	

-abdominal/trunk/pelvis movements.

			tensing the abdomen, tensing the buttocks.	
--	--	--	--	--

-other simple motor tics.

			Please write example(s): _____	
--	--	--	-----------------------------------	--

-other complex motor tics.

			Touching	
			Tapping	
			Picking	
			evening-up	
			reckless behaviors	
			stimulus-dependent tics (a tic which follows, for example, hearing a particular word or phrase, seeing a specific object, smelling a particular odor). Please write example(s): _____	
			rude/obscene gestures; obscene finger/hand gestures.	
			unusual postures.	
			bending or gyrating, such as bending over.	
			rotating or spinning on one foot.	
			copying the action of another (echopraxia)	
			sudden tic-like impulsive behaviors. Please describe: _____	
			tic-like behaviors that could injure/mutilate others. Please describe: _____	
			self-injurious tic-like behavior(s). Please describe: _____	

-other involuntary and apparently purposeless motor tics (that do not fit in any previous categories).

			Please describe any other patterns or sequences of motor tic behaviors: <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	
--	--	--	--	--

Phonic (Vocal) Tics

Description of Phonic (or Vocal) Tic Symptoms Phonic tics usually begin in childhood, typically after motor tics have already started, but they can be the first tic symptoms. They are characterized by a sudden utterance of sounds such as throat clearing or sniffing. The same tics seem to recur in bouts during the day and are worse during periods of fatigue and/or stress. Many tics occur without warning and may not even be noticed by the person doing them. Others are preceded by a subtle urge that is difficult to describe (some liken it to the urge to scratch an itch). In many cases it is possible to voluntarily hold back the tics for brief periods of time. Over periods of weeks to months, phonic tics wax and wane and old tics may be replaced by totally new ones. Simple phonic tics are utterances of fast, meaningless sounds whereas complex phonic tics are involuntary, repetitive, purposeless utterances of words, phrases or statements that are out of context, such as uttering obscenities (i.e., coprolalia), or repeating over and over again what other people have said (i.e., echolalia). Complex tics can be difficult to distinguish from compulsions; however, it is unusual to see complex tics in the absence of simple ones. Often there is a tendency to explain away the tics with elaborate explanations (e.g., “I have hay fever that has persisted” even though it is not the right time of year). Tics are usually at their worst in childhood and may virtually disappear by early adulthood, so if you are completing this form for yourself, it may be helpful to talk to your parents, an older brother or sister, or older relative, as you answer the following questions.

- Age of **first** vocal tics? _____ years old.
- Describe **first** vocal tic: _____
- Was tic onset sudden or gradual? _____
- Age of **worst** vocal tics? _____ years old.

Phonic Tic Symptom Checklist

In the boxes on the left below, please check with a mark (x) the tics the patient

- 1) has **EVER** experienced
- 2) is **CURRENTLY** experiencing (during the past week)

State **AGE OF ONSET** (in years) if patient has had that behavior.

Also, in the tic descriptions below, please **circle** or **underline** the specific tics that the patient has experienced (circle or underline the words that apply).

Ever	Current	Age of onset	The patient has experienced, or others have noticed, bouts of involuntary and apparently purposeless utterance of:	Ver
			-coughing.	
			-throat clearing.	
			-sniffing.	
			-whistling.	
			-animal or bird noises.	
			-Other simple phonic tics. Please list: _____	
			-syllables. Please list: _____	
			-words. Please list: _____	
			-rude or obscene words or phrases. Please list: _____	
			-repeating what someone else said, either sounds, single words or sentences. Perhaps repeating what's said on TV (echolalia).	
			-repeating something the patient said over and over again (palilalia).	
			-other tic-like speech problems, such as sudden changes in volume or pitch. Please describe: _____	
			Describe any other patterns or sequences of phonic tic behaviors: _____ _____ _____	

SEVERITY RATINGS

NUMBER	Motor	Phonic	
None	o	o	0
Single tic	o	o	1
Multiple discrete tics (2-5)	o	o	2
Multiple discrete tics (>5)	o	o	3
Multiple discrete tics plus as least one orchestrated pattern of multiple simultaneous or sequential tics where it is difficult to distinguish discrete tics	o	o	4
Multiple discrete tics plus several (>2) orchestrated paroxysms of multiple simultaneous or sequential tics that where it is difficult to distinguish discrete tics	o	o	5

FREQUENCY	Motor	Phonic	
NONE No evidence of specific tic behaviors	o	o	0
RARELY Specific tic behaviors have been present during previous week. These behaviors occur infrequently, often not on a daily basis. If bouts of tics occur, they are brief and uncommon.	o	o	1
OCCASIONALLY Specific tic behaviors are usually present on a daily basis, but there are long tic-free intervals during the day. Bouts of tics may occur on occasion and are not sustained for more than a few minutes at a time.	o	o	2
FREQUENTLY Specific tic behaviors are present on a daily basis. tic free intervals as long as 3 hours are not uncommon. Bouts of tics occur regularly but may be limited to a single setting.	o	o	3
ALMOST ALWAYS Specific tic behaviors are present virtually every waking hour of every day, and periods of sustained tic behaviors occur regularly. Bouts of tics are common and are not limited to a single setting.	o	o	4
ALWAYS Specific tic behaviors are present virtually all the time. Tic free intervals are difficult to identify and do not last more than 5 to 10 minutes at most.	o	o	5

INTENSITY	Motor	Phonic	
ABSENT	o	o	0
MINIMAL INTENSITY Tics not visible or audible (based solely on patient's private experience) or tics are less forceful than comparable voluntary actions and are typically not noticed because of their intensity.	o	o	1
MILD INTENSITY Tics are not more forceful than comparable voluntary actions or utterances and are typically not noticed because of their intensity.	o	o	2
MODERATE INTENSITY Tics are more forceful than comparable voluntary actions but are not outside the range of normal expression for comparable voluntary actions or utterances. They may call attention to the individual because of their forceful character.	o	o	3
MARKED INTENSITY Tics are more forceful than comparable voluntary actions or utterances and typically have an "exaggerated" character. Such tics frequently call attention to the individual because of their forceful and exaggerated character.	o	o	4

SEVERE INTENSITY Tics are extremely forceful and exaggerated in expression. These tics call attention to the individual and may result in risk of physical injury (accidental, provoked, or self-inflicted) because of their forceful expression.	0	0	5
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COMPLEXITY

	Motor	Phonic	
NONE If present, all tics are clearly "simple" (sudden, brief, purposeless) in character.	0	0	0
BORDERLINE Some tics are not clearly "simple" in character.	0	0	1
MILD Some tics are clearly "complex" (purposive in appearance) and mimic brief "automatic" behaviors, such as grooming, syllables, or brief meaningful utterances such as "ah huh," "hi" that could be readily camouflaged.	0	0	2
MODERATE Some tics are more "complex" (more purposive and sustained in appearance) and may occur in orchestrated bouts that would be difficult to camouflage but could be rationalized or "explained" as normal behavior or speech (picking, tapping, saying "you bet" or "honey", brief echolalia).	0	0	3
MARKED Some tics are very "complex" in character and tend to occur in sustained orchestrated bouts that would be difficult to camouflage and could not be easily rationalized as normal behavior or speech because of their duration and/or their unusual, inappropriate, bizarre or obscene character (a lengthy facial contortion, touching genitals, echolalia, speech atypicalities, longer bouts of saying "what do you mean" repeatedly, or saying "fu" or "sh").	0	0	4
SEVERE Some tics involve lengthy bouts of orchestrated behavior or speech that would be impossible to camouflage or successfully rationalize as normal because of their duration and/or extremely unusual, inappropriate, bizarre or obscene character (lengthy displays or utterances often involving copropraxia, self-abusive behavior, or coprolalia).	0	0	5

INTERFERENCE

	Motor	Phonic	
NONE	0	0	0
MINIMAL When tics are present, they do not interrupt the flow of behavior or speech.	0	0	1
MILD When tics are present, they occasionally interrupt the flow of behavior or speech.	0	0	2
MODERATE When tics are present, they frequently interrupt the flow of behavior or speech.	0	0	3
MARKED When tics are present, they frequently interrupt the flow of behavior or speech, and they occasionally disrupt intended action or communication.	0	0	4
SEVERE When tics are present, they frequently disrupt intended action or communication.	0	0	5

IMPAIRMENT			
NONE		o	0
MINIMAL Tics associated with subtle difficulties in self-esteem, family life, social acceptance, or school or job functioning (infrequent upset or concern about tics vis a vis the future, periodic, slight increase in family tensions because of tics, friends or acquaintances may occasionally notice or comment about tics in an upsetting way).		o	10
MILD Tics associated with minor difficulties in self-esteem, family life, social acceptance, or school or job functioning.		o	20
MODERATE Tics associated with some clear problems in self-esteem family life, social acceptance, or school or job functioning (episodes of dysphoria, periodic distress and upheaval in the family, frequent teasing by peers or episodic social avoidance, periodic interference in school or job performance because of tics).		o	30
MARKED Tics associated with major difficulties in self-esteem, family life, social acceptance, or school or job functioning.		o	40
SEVERE Tics associated with extreme difficulties in self-esteem, family life, social acceptance, or school or job functioning (severe depression with suicidal ideation, disruption of the family (separation/divorce, residential placement), disruption of social ties - severely restricted life because of social stigma and social avoidance, removal from school or loss of job).		o	50

SCORING

	Number (0-5)	Frequency (0-5)	Intensity (0-5)	Complexity (0-5)	Interference (0-5)	Total (0-25)
Motor Tic Severity						
Vocal Tic Severity						

<i>Total Tic Severity Score = Motor Tic Severity + Vocal Tic Severity (0-50)</i>	
<i>Total Yale Global Tic Severity Scale Score (Total Tic Severity Score + Impairment) (0-100)</i>	

APPENDIX D

Semi-Structured Interview

- 1) How has your family of origin responded to your tics?
- 2) How did your peers respond to your tics and TS diagnosis during your childhood?
- 3) In what ways did you find the responses of your family and peers helpful and in what ways were they problematic?
- 4) What types of treatment or psychological and medical interventions have you received for TS?
- 5) What has helped you in adjusting to having TS?
- 6) Have there been times that you avoided becoming romantically involved with others because of your TS? If so, how and why?
- 7) How have you met romantic partners? What attracted you to each other?
- 8) Have you disclosed your TS diagnosis to romantic partners? If so, how have you talked about it?
- 9) How has making disclosures about your TS to partners affected your romantic relationships?
- 10) How have your romantic partners responded to your tics and TS diagnosis?
- 11) Have your romantic partners taken steps to learn about TS and support you? If so, what have they done?
- 12) How do you feel the responses of your peers and family members to your TS have impacted your dating relationships and experiences?
- 13) What advice would you give parents in helping their children and adolescents with TS in navigating dating and romantic relationships in the future?

- 14) What advice would you give to other adults with TS in dating and navigating romantic relationships?
- 15) Is there anything I didn't ask that you think would be important for me to know?