“Sorry, I Didn’t Mean to Kiss at You”: A Descriptive Analysis of Tourette Syndrome in Interpersonal Interactions

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Abstract
Recent research has begun to explore the specific social challenges experienced by persons with Tourette syndrome (TS); however, it does not specifically address the challenges that often arise interpersonally as part of people’s communicative interactions and these interactions socially construct the individual and collective well-being of all involved. This study conducted semi-structured interviews with 18 adults who identified as having TS in order to investigate the ways in which others respond behaviorally to TS behaviors and the ways TS behaviors are misinterpreted within interpersonal interactions. Thematic analysis was used to identify themes common within participant responses. All participants reported receiving unwanted attention from others in response to their TS symptoms. Unwanted attention was further divided into six emergent subthemes, including verbal harassment, physical abuse, staring, general bullying, getting into trouble, and being kicked out. Three types of misunderstandings were also reported in interpersonal interactions: misunderstanding communicative intention, misunderstanding TS, and misunderstanding the cause of TS behaviors. Applying attribution theory, it is determined that it is ultimately the misattribution of communicative intent to TS behaviors that causes many misunderstandings reported by adults with TS and leads to a plethora of interpersonal, communicative challenges. Importantly, these misunderstandings are what ultimately contribute to much of the unwanted attention described by the participants in this study and documented in previous work, highlighting the value of a greater awareness of how misunderstandings take place with respect to TS.

Keywords Tourette syndrome · tic · nonverbal · misattribution · harassment

Tourette syndrome (TS) is a neuropsychiatric condition that affects an estimated 1% of the worldwide population (Robertson et al., 2009). TS is manifested through both
physical (motor) and phonic (sound) tics. A tic is as “a sudden, repetitive, nonrhythmic, stereotyped motor movement or vocalization involving discrete muscle groups” (Bloch & Leckman, 2009, p. 497). These tics generally appear early in a person’s life—typically between the ages of 4–6—though they often become more severe over time, particularly around the onset of puberty, until often waning into adulthood (Scahill et al., 2005). Tic severity can be classified into several dimensions, including “tic frequency, intensity, complexity, number of tic types and the disruption or distraction caused by premonitory urges or by actual tic expressions” (Zinner et al., 2012, pp.125-6). Common tics include eye blinking, facial twitches and grimaces, sudden bodily movements or jerks, clearing of the throat, or various verbal utterances ranging from partial words or grunts to profanity (Bruun et al., 1997). TS is oftentimes accompanied by other co-occurring disabilities, such as attention-deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), anxiety, learning interferences, behavioral disorders, and mood disorders (Bitsko, Holbrook, Visser, Mink, Zinner, Ghandour & Blumberg, 2014). Its symptoms may manifest in ways that parallel other disabilities such as stuttering, Asperger’s, and autism (Van Borsel & Vanryckeghem, 2000). The type of tics and their severity varies for each individual and fluctuates over time. Increased severity of tics has also been reported to decrease the quality of life for persons with TS (Conelea et al., 2013).

Although TS is neuropsychiatric, as a behavioral manifestation, tics can be understood as a form of nonverbal behavior, encompassing a wide range of involuntary physical movements and vocal expressions. Importantly, tics often mimic other communicative behaviors, but they are not intentionally communicative. In an interpersonal context, however, tics may be assessed inaccurately by observers as intended behaviors, often directed to them and subject to varying interpretations not related to their actual origin and responded to in real time. The potential to misattribute the intentionality—and subsequent meaning—underlying these nonverbal behaviors, and for the person to respond to the person with TS in the moment and from this basis, has implications for persons with TS and their ease with interaction. Given this, the present study examines how tics manifest in interpersonal encounters, the nature of the social consequences that may arise, and the meanings that may be given to them by others with whom people with TS are interacting. Our research questions arise from the existing scholarly literature.

**TS Research**

Most TS research has been concerned with its pathophysiology (e.g., Bitsko et al., 2014; Gilbert, 2006; Kurlan, 2005; McMahon et al., 2003). But TS can also be considered a social condition. Centering away from the social implications of TS, much of the scholarly literature reveals a limited focus on the impact of a person’s symptoms on and with the people around them.

When they do address social impacts, these studies are nearly always limited to the experiences of children (e.g., Bawden et al., 1998; Boudjouk et al., 2000; Stokes et al., 1991; Storch et al., 2007; Wadman et al., 2013; Wand et al., 1993; Zinner et al., 2012). Literature on the social relevance of TS focuses primarily on stress levels,
with the majority of the studies concentrated on the parents or caregivers of children with TS (e.g., Carroll & Robertson 2000; Einarsdóttir, 2008; Marsh, 2007; Wilkinson et al., 2008). When it has centered on the social experiences of those with TS, typically, the data collected are reported by parents or caregivers rather than by the person with TS (e.g., Conelea et al., 2011); this focus on parental perspectives is typical for research about disability in family contexts (Canary, 2008). Several studies have investigated the ways in which children and adolescents with tics are perceived by others, generally concluding that children with tics are perceived as less socially acceptable, are less-desirable playmates, and are more likely to be avoided when others seek out meaningful social relationships (Friedrich et al., 1996; Holtz & Tessman, 2007; Malli & Forrester-Jones, 2017; Woods et al., 1999).

A few studies have sought to address the social impact of TS on adults and highlight their lived experiences. One neurobiologist with TS notes that TS “differs from other neuropsychiatric disorders in one simple way: It is largely a disease of the onlooker…the discomfort, annoyance, and intervention of onlookers are what make me a Tourette sufferer” (Hollenbeck, 2003, p. 51). Hollenbeck’s insight—that one cannot understand the lived experience of a person with TS without examining its social and interpersonal implication—is echoed by others. Buckser (2008), for instance, notes that “the primary burden of the syndrome is a social one” (p. 170). In other work (Buckser, 2006), he calls TS an “illness of the observer,” such that “the burden of the disease comes primarily from the need to make sense of the tics, from the confusion and misunderstanding that they evoke in people who observe them” (p. 270). This confusion and misunderstanding on the part of the observer often places a burden on persons with TS, as they become tasked with the responsibility of holding awareness of how their tics might appear to others and must “manage the confusing and misleading impressions that tics make on other people” (p. 256).

The social burden of TS is evidenced by the feelings of stigma reported by adults with TS who face specific social challenges, including the misinterpretation of tics by others, ridicule, and uncomfortable stares (Buckser, 2008). In a study designed to measure the various impacts of TS on adults, Conelea et al., (2013) surveyed 672 people with tic disorders and found that 68% reported being treated differently than others and had experienced discrimination to such a degree that they scored lower-than-average on the Quality of Life scale compared to both people with other chronic illnesses and terminal cancer (pp. 115–116).

In his autoethnographic investigation of his own diagnosis of TS, Congdon (2014) described the negative impact on TS on his academic performance resulting from peer bullying, as well as from misunderstandings and a lack of empathy from his teacher. Lemelson & Tucker (2017) also employed an ethnographic method in case studies of two Balinese adults with TS. Notably, one of the adult’s tics were misinterpreted by some family, neighbors, and peers as being caused by insanity or possession by an evil spirit. These attributions led to her ostracization and to the stigmatization of her family to the point where she and her siblings were determined to be undesirable marriage partners.

In two additional studies, one that involved interviewing 16 adults with TS (Malli et al., 2019) and the other performing a mixed-methods approach including a survey
of 199 adults and interviews with 20 (Malli & Forrester-Jones, 2021), researchers examined the “social and personal cost of living with TS during adulthood” (Malli et al., 2019, p. 819). Their participants reported several social challenges including rejection, marginalization, victimization, the trivialization of TS through humor, prolonged and intrusive staring, and being asked to leave public places (Malli et al., 2019; Malli & Forrester-Jones, 2021). Malli and colleagues specified 21 domains of “enacted discrimination,” including in educational settings (75.4% of participants), in social life (71.4%), on public transport (60.8%) and with respect to employment (54.3%) (Malli & Forrester-Jones, 2021, p. 10). Many of these findings align with a meta-synthesis of qualitative studies examining the experiences of individuals with TS and other tic disorders (Smith et al., 2015).

**TS in Interpersonal Encounters**

This body of research provides awareness of many common social challenges experienced by persons with TS. In so doing, it suggests, though does not address specifically, that the challenges often arise interpersonally as part of people’s communicative interactions. Specifically, when tics occur during interaction, people can respond to them immediately and directly. Paying closer attention to the interpersonal nature of these challenges allows for a more complete understanding of the experiences of persons with TS, because it elucidates the specific means by which many social difficulties occur. Therefore, this study’s first research question is as follows:

RQ1: How do others respond behaviorally in response to TS behaviors that occur in interaction?

Buckser (2006) noted, the central, social (particularly interpersonal) burden of TS stems from others’ misunderstandings of tics. Verbal, phonic tics provide a salient example of how misunderstandings might occur. One of the most well-known symptoms of TS is coprolalia: the “involuntary outburst of obscene words or socially inappropriate and derogatory remarks” (Tourette Association of America, n.d.). Though affecting around only 10% of individuals with TS (McNaught, 2019), this type of tic has the potential to confuse, offend, and even provoke those who overhear the outbursts. Coprolalia has been documented as a cause of employment termination, likely due to interpersonal misunderstandings and ignorance regarding the condition (Carroll & Robertson, 2000).

Speech dysfluency, “delayed speech, poor diction, poor language expression… talking too fast and too loud” (Van Borsel & Vanryckeghem, 2000, p. 229), “repetitions, hesitations, and false starts” (O’Quinn & Thompson, 1980), “stutter-like behavior” (Singer et al., 1978), and echolalia – the involuntary repetition of the spoken words of another person – have all been identified as symptoms of TS that might impact the communication process. Motor tics also have the potential for a significant impact on the communication process and subsequent misunderstandings. This type of tic “may be ‘simple,’ involving individual muscle groups and producing an instantaneous eye blink, eye jerk, head twitch, or shoulder shrug; or it may comprise
a more ‘complex’ coordinated pattern of movements such as ocular deviation, facial movement, touching, jumping, smelling, or copropraxia (obscene gesture)” (Singer & Walkup, 1991, p. 15).

Whatever their form and frequency, these tics have the potential to be interpreted as intentional communicative messages by an observer or communication partner, especially when the person is unaware that they occur unintentionally. That is, others may interpret the tics, not as tics, but as communicative behavior directed toward them. Given that nonverbal behavior can be a reflection of some internal state or condition or it can be seen as a social, communicative cue (Burgoon et al., 2009), how people interpret what is behind the tics matters. In these ways and more, the symptoms of TS may contribute to others’ misunderstandings of the person with TS and their intentions. Our second research question aims to explore these misunderstandings:

RQ2: In what ways are TS behaviors misinterpreted within interpersonal interactions?

These research questions are answered through the voices and reported experiences of our adult participants and therefore reflect their subjective perceptions and post hoc recollections of these interpersonal encounters.

Method

Research Design Overview

In this study, we adopted a social constructivist approach, seeking to examine the process of meaning creation as it takes place in interpersonal communication (Creswell, 2013). To do so, we conducted in-depth interviews with adults with TS in order to explore their perceptions of TS-related social difficulties. We analyzed our data using thematic analysis (Braun & Clarke, 2006).

Researcher Description

The first author’s personal experience with TS and participation in the Tourette community helped to frame the research questions and overall design and conduct of this study. The first author was diagnosed with TS at the age of 10 and has significant personal experience with many of the social difficulties described in this research. In addition, the first author has co-led a support group for parents of children with TS, given lectures on the impact of TS on interpersonal communication, and participated in TS conferences, including those sponsored by the Tourette Association of American (TAA). This degree of membership in the Tourette community enabled access to TS support groups that were exclusively for persons with TS (Ellingson, 1998). Familiarity with similar experiential complexities as those discussed in this study enhanced the authors’ ability to recognize specific communication patterns, practices, and features in ways that may elude someone with no personal experience with TS (Dollar, 1995).
Recruitment Process

Following IRB approval at a large research institution in the U.S. Pacific Northwest, participants were recruited primarily from an online Facebook support group for adults with TS. A call for participants was posted that described the study aims, estimated time required, and general information that would be solicited. The study also employed snowball sampling within the TS community. Potential research participants were provided with a full consent form for review and consent. Participants received a $10 gift card for completing the interview in gratitude for their contribution to the research.

Participant Selection

Data for this study were collected in 2017 via recorded Skype calls. We used purposive sampling, as it is particularly useful when working with specific groups or when investigating unique experiences that are not common in the general population (Devers & Frankel, 2000). Snowball sampling within the TS community was also employed in order to obtain as many participants as possible. There were three specific criteria for participant eligibility: (a) they must be a person with TS (formal diagnosis was not required, but most participants reported that they had been formally diagnosed with TS); (b) they must be at least 18 years of age; and (c) they must be fluent in English. Participants were not asked directly about co-morbidities and thus all adults attesting to meeting the above selection criteria were included in this study.

Data Collection

This study used semi-structured interviewing. Interview length ranged from 30 to 60 min, consisting of primarily open-ended questions. These questions evolved over the course of the study, as initial participants’ responses led to more diverse paths of inquiry (Strauss & Corbin, 1998). Sample questions were as follows “Can you think of a time when your TS/tics/symptoms impacted how you communicated with someone?” and “How do you think your tics/symptoms have affected how others communicate with you?” Participants were asked to answer as they felt comfortable and could choose not to answer any question that they preferred not to. In three instances, participants said they felt more comfortable providing their responses in written format and, in order to encourage maximum inclusivity in this study, participants were supplied the questions via email to be completed and returned to the researchers.

Data Analysis

The audio data from the online interviews were transcribed verbatim by the first author in Microsoft Word, then all data were coded and analyzed using Atlas.ti software. We employed Braun and Clarke’s (2006) six phase approach for inductive thematic analysis. This approach emphasizes close reading and re-reading of the data, and the generation of codes that become the building blocks of themes. The developed themes were reviewed with respect to all coded interviews to ensure coherency,
and named and defined after repeated analysis. An inductive approach was useful in allowing participant responses to shape the nature of the research, allowing the interview questions and thematic focus to evolve throughout the course of participant interviews. Researcher reflexivity and member checking helped ensure confirmability of the research findings (Lincoln & Guba, 1985; Lindlof, 1995; Strauss & Corbin 1998). The first author kept a researcher journal from initial interview through data analysis stages, noting participant responses that might benefit from follow-up, documenting the development of potential codes, and recording the process of thematic organization. Member checks were performed with several key research participants after transcription and during data analysis and interpretation.

**Results**

**Participants**

Eighteen adult participants with TS were interviewed for this study. Ten identified as female, and eight identified as male. Their ages ranged from 19 to 54 ($M = 32.4$) and the mean age of diagnosis was 16.1 (two participants were unsure and did not provide an answer to this question). All of the participants identified as white. Seven of the participants reported having mild TS symptoms, eight had moderate symptoms, and two reported severe symptoms at the time of the interview. One participant did not report the intensity of their symptoms.

**Research Question One: Interpersonal Responses to TS Behaviors**

In their interviews, participants described the nature and impact of others’ behavior on their daily lived experience. From these data, we identified a superordinate theme of interpersonal responses to TS behaviors: unwanted attention. Unwanted attention developed from consistently reported experiences of discomfort with respect to the attention directed at persons with TS. It encompasses the communicative behaviors by which observers paid unwanted attention to persons with TS. Every single participant reported experiencing some form of unwanted attention from others, with respect to their tics. Within this theme, we noted six subthemes of communicative behaviors as identified by participants: verbal harassment, physical abuse, staring, general bullying, getting into trouble, and being kicked out.

**Verbal Harassment**

Verbal harassment was by far the most common form of unwanted attention that was reported by participants. Reported experiences were categorized under this subtheme only if they were directly stated by the participant or it seemed clear from the context that the participant was distressed by or uncomfortable with the communication they described. Given the volume of detail provided by participants, this subtheme was further subdivided into five categories, which provide deeper insight into how verbal
harassment takes place communicatively and contributes to the overall experience of unwanted attention.

**Laughter.** Seven participants provided descriptions of being laughed at because of their tics. P2 provides a detailed narrative of growing up with a grunting tic. He describes the tic as “sound[ing] like a hard exhale” and relates an experience during junior high school when the music in his headphones prevented him from realizing the noises he was making while ticcing, which were apparent to others: “I put on the headphones, cranked up the music, and... everyone stared at me. Everyone. Then they started to laugh. My grunting tic, quiet up to that point, got headphone voice... I never really lived that down.”

Other participants describe their discomfort at being the target of belittling laughter from peers, strangers, and family members. P9 relates a situation that occurred in a college cafeteria: “One time in college I was sitting and eating at the student centre. Someone across the table from me was mimicking me with their friend and they were all laughing about it.”

**Telling Them to Stop.** Four participants described situations in which others told them directly to stop their tics. P16 shared a poignant example of this category from her experience in a doctor’s office:

I must’ve been like sucking like *makes sound* and clicking my teeth. So I think he probably thought I was like cracking my gum you know. Which is really quite annoying, like some people really hate the sound. So he turns to me and he touches me on the knee and says “Oh yeah you’re going to have to stop doing that, that’s making me crazy.” So I said, “Hey how ‘bout this you should try having Tourette’s and trying to stop doing it. Now that would make you fucking crazy.”

Others recalled situations in which strangers approached them to ask or demand that they stop ticcing. One participant noted that others likely felt motivated to ask her to stop because they found her tics to be a distraction.

**Asking if They are Okay.** Six participants provided narratives in which they described being asked if they were okay. In these situations, others may have been concerned about the well-being of the person with TS and were inquiring, but they were nonetheless seen as a challenge. P3 is clear about her frustration with these types of encounters. She notes that some people believe she is having a seizure and consider calling an ambulance:

Or people asking me if I’m okay...that sucks. I don’t like that at all. It happens all the time. ....I’ve had people ask, when I was with my mom, if I was having a seizure, if I needed an ambulance. And it’s just like, because I couldn’t really talk, but I was sitting right there, I’m fully aware, and it’s just like “Can they just stop?” I’m fine, I always have to tell these people that I’m fine. And even after you wave them off, they think “Well I need to save this girl from herself.”

It is evident that P3 feels frustrated by being asked frequently about her tics. Part of this frustration appears to be due to infringement on her sense of agency, as she feels
that others are unable to understand what she is experiencing, and act without her consent.

**Asking What They are Doing.** Another form of reported verbal harassment, reported by seven participants, occurs when others – usually strangers or peers – ask them what they are doing, prompted by some clearly evident tics. P11 talks about her anxiety regarding others’ responses to her tics in a college classroom:

In college during exam taking time. Oh my god that was the worst sitting in a silent room with like 50 students taking a statistics exam. And people would hear me and they would ask me you know “What are you doing?” It got so embarrassing for me I had to talk to my professor and take my exams in a room by myself.

In this example, other students’ inquiries about her tics felt burdensome enough that she felt the need to extricate herself from the situation and future similar situations. Other participants report being asked “What was that?” (P7), “What’s wrong with [you]?” (P9), and “What is that sound?” (P11) when they hear the person with TS making noises while ticcing.

**Pointing out That They are Ticcing.** Other participants report specific circumstances in which someone would point out that they are ticcing, or note that their tics are particularly severe at a given moment. P14 communicates her frustration with having her tics pointed out directly by others:

“Are you having a bad day? Your ticks are really bad.” And it’s like yeah, I know that. I live in my own body. So yeah, I guess in that sense sometimes I wish people wouldn’t point them out so much because it’s like, “dude like I know, hello! Just keep talking, you know, just pretend like they’re nothing”… I don’t want to have to listen to someone tell me they’re bad today, you know?

**Physical Abuse**

Another subtheme of unwanted attention, the one with the most serious implications for persons with TS, was physical abuse. Experiences coded in this subtheme were only those that contained explicit descriptions of physical contact and abuse, as opposed to those which might allude to it, but did not provide tangible portrayals. In this way, examples in this category are distinct from those categorized under what is described below as “general bullying.”

P1 provides two detailed narratives of times when he was traveling abroad and experienced physical abuse. In the first, he was physically harassed by a teenager on a bus, and in the second he was assaulted by a stranger on shared public transportation:

Within a couple minutes he pokes me, and he’s like “Stop.” And I tried to explain to him like, “If you let me sleep, then I’ll stop.” And I would keep on trying to sleep and he would poke me again and be like, “No stop, you should stop moving.” And I’m like “I’m trying buddy, but you gotta let me go.” …
Every time I’m nearly asleep he would poke me and be like “You know you have stop.” And I’m like, “Just let me sleep!”

In a second excerpt, P1 describes what he believes to be a stranger’s reaction to a tic where he turns his head to the side, which might appear as if he is looking behind him:

Twice while I was in Turkey, I got hit by someone. Like a guy punched me. Never very hard. But once I was on this shared taxi, shared bus thing. And there was a guy, like a couple behind me, and I kept on kinda turning, and I think the guy thought I was checking out his girlfriend. And he just like hit me in the back of the head at some point. And it like shocked me, and I didn’t have very much Turkish so I just turned around and kind of like held up my hands and said, “Sorry I don’t know.” I think I said “Why? What was that?” And I didn’t understand and he didn’t understand me, so I was just like “Okay.”

This particular tic has presented ongoing challenges for P1, especially when paired with a “pinch of the lips in a kissing motion” tic, also described by the participant. He notes trying to avoid this particular tic in specific situations, such as at a biker bar, where he believes a misunderstanding could lead to physical violence. He reports trying to diffuse potential negative outcomes by telling observers directly, “Sorry, that wasn’t intentional… I didn’t mean to kiss at you.”

Other participants also provided explicit descriptions of physical abuse, mostly by peers. P10 indicates that she experienced physical abuse at the hands of other students in school: “I did not have many friends in middle school, and every day the kids bullied me. One kid even saw me twitching on the stairs and then pushed me down the flight of stairs.” P18 describes being beaten up on the bus, attributing it to the thought that “kids didn’t know what Tourette’s was.” In each of these cases, the participants report explicit descriptions of physical abuse. They all also attribute these instances of abuse to others’ reactions to their observable tics. These experiences align with broader data regarding the prevalence of physical abuse directed at persons with disabilities (e.g., Equality & Human Rights Commission, 2011).

Staring

A third subtheme that became apparent during data analysis was the experience of being stared at and the discomfort it caused for persons with TS. Staring was considered present when a participant gave an account of being “stared at” explicitly, or described being looked at in uncomfortable ways on account of their tics. In their own documentation of interpersonal stigma faced by persons with TS, Malli & Forrester-Jones (2021) point out that the form of staring reported often reflects what Garland-Thomson (2009) terms the “baroque stare,” which “is flagrantly stimulus driven, the rogue looking that refuses to be corralled into acceptable attention” (p. 50). The act of staring in this way functions to otherize the person with TS. As Garland-Thomson (2009) writes, “[t]he manifestation of stigma in the social world is being stared at, for it is then that people register another’s status and reflect it back to them” (p. 131).
P1’s examples of TS and nonverbal communication interactions often center around his experiences in different cultures. He mentions being stared at in both Turkey and India, and the discomfort that causes him:

“Strangers asking me or looking at me or staring at me…that would probably be like my biggest problem.” … “I travel a lot and I’ll notice, like, different cultures have different reactions. Like, I lived in Turkey for a year and it was very difficult for me in Turkey, cause people were very open about kind of staring at me. I was in India also and it was very similar, like, a lot of people were… a lot less shy about openly like giggling or anything like that.

His discomfort with others’ stares is echoed by P10, who expresses anxiety about this phenomenon. She describes a situation that arose with multiple professors in college:

In college, professors have been affected on how they communicate with me. As a mathematic/engineer major I often must talk to my professors in their offices where I cannot be eccentric in my body language and in my speaking. I tend to tic a little bit and they take notice and then they spend too much time staring or trying to figure out why I am doing these repetitive movements. Then I get these worried concerns. I now tell my professors I have Tourette’s to avoid any future problems if I notice them staring.

P10 noticed that her tics provoke inquisitive stares and affect how her professors communicate with her more generally. She reports using these stares as an indicator that she needs to be direct with her professors about the nature of her tics.

P1 provides another example in which he describes his anxiety of being stared at because of his tics, this time on an online communication platform:

At [company name] a lot we’ll do these remote meetings with Hangouts. And if you’re in Hangouts, the default tends to be to like turn on the camera, and so you’re all kind of seeing each other, which is great. But sometimes we’ll have like an hour-long meeting, like I know these things get projected up on the wall, and it’s just your face… And I’ll turn off my camera a lot if I’m just sitting there. Because I don’t want people to be just like staring at me ticcing.

General Bullying

The experience of being bullied for having TS is reported commonly in extant literature (e.g., Malli et al., 2021; Smith et al., 2015). Our findings parallel past studies, as participants reported experiencing bullying primarily in childhood, with an occasional mention of its presence in adulthood. In coding this subtheme, we distinguish what we term “general bullying” from the reported accounts of verbal abuse, physical abuse, and staring. Although these other forms of unwanted attention might certainly be classified under the “bullying” umbrella, this category contains other instances of bullying that do not fit in any of the other subthemes.
General bullying was recounted by nearly half of our participants. They reported peers, teachers, family members, coworkers, and strangers as engaging in the bullying. Three participants described how teachers would ridicule them in front of the class, embarrass them, and sometimes do so in ways that were reported as intentional. P9 talks about one such time when a teacher, aware of her disability, would intentionally provoke her tics:

> There was one teacher in high school. I sat in the back row in alphabetical order and he would purposely stand behind me during tests because he knew it would make me nervous and make me tic more that way. He thought it was funny. That made it difficult for me in that class. I really didn’t want to be there because I knew he found it amusing; that he’d purposely stand there to make me uncomfortable and watch me tic more.

Others reported the general experience of being bullied in school, sometimes over the course of many years. P18 describes being bullied so badly that she switched schools: “[s]chool was difficult, Junior High especially, I was bullied so badly in Junior High for my weight (from medication), and my TS that my parents moved across town so that I would switch schools.” Multiple participants describe being called names, such as “freak,” on account of their tics: “Why are you spazzing out, you freak?” (P6). Ultimately, it is clear that bullying is one of the most salient experiences for persons with TS, most notably during childhood.

### Getting into Trouble

Another subtheme identified within the category of unwanted attention is what we term “getting into trouble.” Experiences coded into this subtheme were those in which a person with TS faced some form of reprimand or disciplinary action from an authority figure, as a result of their tics. Oftentimes, participants used some variation of the phrase “get into trouble” in their descriptions. P5 relates his own experiences of getting into trouble on account of ignorance regarding the cause of his behaviors: “Nobody knew what this was. So I just got in trouble. I didn’t try to explain anything I didn’t know what it was and there was certainly no adult who was helping me understand what it was.” Similarly, P4 describes his challenges with his father and his annoyance with a particular tic:

> I can remember I used to get in trouble all the time for having non-stop sniffing even though I wasn’t stuffed up and now I know that’s like super common and everything but at the time my dad just thought I was wicked annoying... and I can actually remember I used to get in trouble for it all the time for sniffing annoyingly.

This type of unwanted attention has significant implications for persons with TS. Depending on the type of “trouble” one gets into, it could mean an impact, for example, on one’s education or employment status (Malli & Forrester-Jones, 2021). This can occur without provocation, or when a person with TS “stands up for themselves” (Congdon, 2014).
Being Kicked Out

A final subtheme reported by participants involved descriptions of being kicked out or removed from various locations or situations in response to their tics. Though some of the responses coded in this category overlap with those in the “getting into trouble” subtheme, what distinguishes instances assigned to this category is the reported forced removal of the person with TS from a location on account of their tics. Three participants recalled being kicked out of school classrooms for their tics. P5 notes that this happened to him on multiple occasions: “I was 10, my tics were very frequent. Extremely disruptive and just very vexing to me and others, you know, I used to get kicked out of class and such.”

P6 cited a similar experience, noting being sent to the principal’s office by a substitute teacher who was not aware of the nature of his tics:

My most memorable one was when I had that kind of tic in music class and we had a substitute. My parents were really big on making sure my educators knew I had Tourette’s and treated me right but the substitute hadn’t been notified. The substitute became convinced that I was just messing with her. So, I got sent to the principal’s office and I was seething and upset… I was really annoyed. The other kids were vouching for me but she said “you need to leave.”

Another participant (P2) discusses being kicked out of a company car by a coworker, on account of his coworker attributing his tics to mental instability:

A co-worker at a different job who locked me out of our company vehicles so I wouldn’t get in with them. It stung each time it happened, and I ran a very real risk of being stranded on more than one occasion as a result….Their read on my tics was that I was crazy and couldn’t be reasoned with.

The impact of forcible removal from social situations, especially educational or workplace situations, can have significant implications for the lives of persons with TS. It can negatively impact general well-being, sabotage social connection and relationships, can lead to or exacerbate educational disadvantages, and could threaten one’s livelihood and economic security.

Participants unanimously reported experiences of unwanted attention on account of their tics. Within this broader theme, we identified six ways in which this unwanted attention showed up in the lives of persons with TS. In our last example, P2 described being kicked out of a company car by a coworker and noted that it was because his coworker saw his tics as evidence of him being “crazy” and incapable of reason. This misunderstanding of the nature of tics and TS showed up often in participant responses and exemplifies the answer to our second research question: interpersonal misunderstandings.

Research Question Two: Interpersonal Misunderstandings

Our second concern we call “misunderstandings,” and includes the ways in which tics are misinterpreted within interpersonal interaction. Perhaps the most commonly discussed misunderstanding in the extant literature on TS and social challenges is the public perception that TS is a “swearing disease” (Calder-Sprackman et al., 2014; Fat et al., 2012). This inaccurate perception causes society to overlook “ordinary tics,”
which make up a great deal more of the experience for persons with TS (Buckser, 2008). Based on participant responses, we divided this theme of misunderstandings into three subthemes.

**Misunderstanding Communicative Intention**

The most commonly reported type of misunderstanding that occurred for persons with TS took place during interpersonal conversations. Described by at least 13 participants, this type of misunderstanding occurs when a conversational partner or observer misinterprets a tic as a communicative signal. Five participants reported that their tics had been misinterpreted by others as romantic signals or gestures. This may take the form of a winking tic, a pursed-lips facial movement, a grimace, or a turning of the head towards someone multiple times. P11 recalls a situation in which she believes her winking tic led to a customer misinterpreting the tic as a romantic gesture, leading him to approach her:

> When I was a teenager, I was a waitress at a restaurant and I had a customer once think that I was winking at him. And he like started coming on to me and I didn’t know why and then I was like “Ah, shit that tic was acting up again.” It was so embarrassing.

Others described how their tics sometimes cause them to pause mid-sentence or mid-thought. This pause may be misinterpreted by the conversational partner, thinking the person with TS is finished talking. As P1 reported, “I think I’ve had where I break and people interrupt. It’s not. It’s just me pausing to tic rather than finishing my thought.”

Participants provided an abundance of other examples of tics that are misinterpreted as communicative signals. P17 notes how her “eye-strain” tics have led to others asking if she is rolling her eyes at them. P18, who has a similar tic, mentions that she is afraid of how that tic, as well as a “frowning” tic, might be misinterpreted by others. P9 describes a time during class when a teacher assumed she was agreeing with him because of her “head-nodding” tic. P14 reports how a “shoulder-shrug” tic leads people to think she is saying “I don’t know.”

Several participants report specifically how others misinterpreted their tics as communicative signals and then responded as if they felt personally attacked. For example, P13 remembers being kicked out of a childhood Dungeons and Dragons group because the host mom believed his “sticking out his tongue” tic was directed at her. Similarly, in a previously cited example, P6 recalled being sent to the principal’s office by a substitute teacher who saw her tics and “became convinced that I was just messing with her.”

**Misunderstanding TS**

A second type of misunderstanding reported by persons with TS is a general misunderstanding of TS as a condition. Participants note that others may not know what TS is, but may believe they do, and may further believe that the person with TS is lying about having the condition. P10 provides one example: “I had one person tell
me that I did not have Tourette’s because I don’t show symptoms of someone having Tourette’s and my tics that I had are just nasty habits.”

This kind of interaction was reported by several study participants. Strangers or peers may only be familiar with the common societal misunderstanding of TS as a swearing disorder, and less familiar with the motor tics or other forms of verbal tics that make up the majority of its symptoms. As P3 puts it: “It’s just very upsetting and depressing… Most people think of Tourette’s as swearing; they don’t know about vocal tics or motor tics.” P4 recalls a situation in which a co-worker thought he was lying about having TS and making fun of people with the condition:

And she’s like, ‘Hey jerk, I have a cousin who has Tourette’s and that’s not very funny. You’re being an asshole.’ … [P]eople just think I’m trying to make a bad joke or trying to be a punchline like you know. And so many people have nothing but the, you know, what’s in like an Adam Sandler movie as an idea of what Tourette’s is.

Misunderstanding Cause

A third form of misunderstanding, reported by 12 participants, was based in the nature of the causal attributions people gave for tics that they observed, assuming the behavior to be based in something other than TS. One of the most common types of misattributions reported was others assuming that the person with TS has some other form of medical or mental issue. This was reported by eight participants. Several specifically note that others believe them to be “crazy” or “mentally handicapped” on account of their symptoms:

I feel very self-conscious that these things don’t necessarily make me look professional or don’t make me look like I don’t know what I am doing. Many people think that I’m handicapped or something.

Participants also provided examples of times when strangers misattributed tics as other medical issues. Five participants related that their tics led others, including in two cases a doctor and nurse, to believe that they might be having a seizure. P13 describes a time when this happened to him:

I used to go jogging around the neighbourhood in my teens. One of the neighbors stopped me to ask if I was okay because I was doing a vigorous neck tic and thought I was having a seizure or something. I didn’t even realize I was doing that.

P8 recalled multiple situations in which people thought she was having an asthma attack. P3 shared a memory of a woman who wanted to call 911 because she was concerned about her tics. Two participants reported others asking if they have a cold or have allergies as the cause of their tics.

Participants also cited several examples of others misattributing their tics to various circumstantial physical conditions. P9 reported how a “shoulder shrug” tic has led others to ask if she is cold. Working in a nursing home, P11 mentioned how her tics have caused her patients to ask if she has the hiccups. Tics were misattributed to having slept on one’s neck wrong or to bad contact lenses. In one case, a participant described situations in which others, including police officers and guards, believe he is high or on drugs:
I hate museums because a lot of people think I’m wigging out… In museums there will be guards following me around if they’re nervous about what I’m doing… I had this one guard following me through several rooms literally right next to me. “Dude, you’re not doing this to anyone else.” I’ve had a couple of police officers think I was high. There was someone who thought I was on cocaine. I’ve had that happen twice, I think. Epilepsy, drugs.

This last example, in particular, shows how misunderstanding the cause can have significant implications for persons with TS. Research demonstrates that, when uncontrollable mental-behavioral conditions are misattributed to controllable behaviors, observers are more likely to experience anger towards the person, less likely to feel pity, and be less willing to be helpful (Weiner et al., 1988). When dealing with law enforcement, particularly in the United States, this type of misattribution may also have the potential to lead to abuse.

**Discussion**

Research has begun to explore the social challenges reported by adults with TS. It is clear that these individuals face many nuanced social difficulties. This study builds upon prior studies by confirming the reported experiences of TS manifesting in interpersonal contexts. Our aims were to investigate the ways in which others respond behaviorally to TS behaviors and the ways TS behaviors are misinterpreted within interpersonal interactions. We identified several behavioral responses that other interactants had following their observation of tics. Further, we identified three different types of misunderstandings that occurred regarding the nature of the tics. Our findings reinforce the claims of prior studies that persons with TS experience a variety of social challenges on account of others’ perceptions and reactions to their tics. The present study focuses specifically on the micro, interpersonal impacts of TS; that is, on how social difficulties and stigmatization occur in communicative contexts.

Echoing Buckser’s (2008) assertion that “the primary burden of the syndrome is a social one” (p. 170), all of our participants reported experiencing and being distressed by unwanted attention from communicative partners or interaction observers. This unwanted attention took several forms in our data, which we categorized into six subthemes: verbal harassment, physical abuse, staring, general bullying, getting into trouble, and being kicked out. Each of these forms of unwanted attention has been reported by participants in prior studies on the impact of TS for adults. Despite its prevalence as the primary vehicle through which persons with TS experience unwanted attention or stigma, however, existing research has not conducted a deeper exploration into the interpersonal nature of verbal harassment in this context. Doing so is important because unwanted attention as experienced by persons with TS might manifest in unique ways that distinguish it from verbal harassment in other contexts and give us more nuanced insight into the experience of living with TS.

We found that verbal harassment occurred in five specific interpersonal behaviors: Laughing at the person with TS in response to their symptoms, telling the person with TS to stop ticcing, asking if the person with TS is “okay,” asking the person
with TS what they are doing, and directly pointing out that the person with TS is ticcing. Nearly half of our participants reported being laughed at for their TS symptoms. Certainly not unique to TS, this type of “disabling humor” (Reid et al., 2006) is frequently reported by persons with disabilities and it has been documented in detail, from analyses of centuries’ old “freak shows” (Fahy, 2006) to previous findings specifically within the TS community (Malli & Forrester-Jones, 2021).

Specifically, Malli & Forrester-Jones identified a relationship between jokes about TS and the stigmatization and trivialization of the condition. These jokes, which “have not incurred severe social censure in contrast to jokes about other disabilities, race and gender, which are considered ‘politically incorrect’” (Malli & Forrester-Jones, 2021, p. 21), serve to promote stigmatization and discrimination against persons with TS (Ferguson & Ford, 2008). Although none of the participants in the present study described being the target of or overhearing formulaic jokes about TS, a social climate in which TS jokes are considered acceptable contributes to the acceptability of laughing at someone’s TS symptoms and may promote its prevalence.

Many participants also report being told by observers to stop their ticcing behavior, asked if they are “okay” by observers witnessing their tics, or asked what they are doing in response to observations of their ticcing behavior. Analyzing the participant responses, it is clear that observers are uninformed about TS as the actual cause for the ticcing behaviors. In the latter two cases, it is clear that the behavior is not understood by and is concerning to the observer, a possibility that we explored more directly with our second research question. The observer is unsure what to attribute the behavior to and is asking about it, if in an invasive and uncomfortable manner. In the former case, a clear misunderstanding is taking place with respect to the nature of the ticcing behaviors. When observers tell persons with TS to stop ticcing, the misunderstanding is the assumption that they are capable of stopping their tics at all. They are misunderstanding the behaviors as being controllable, when this is not the case.

To elucidate the implications of misperceiving TS behaviors as controllable, the application of attribution theory is helpful. Originating with Heider (1958), attribution theory “deals with how the social perceiver uses information to arrive at causal explanations for events. It examines what information is gathered and how it is combined to form a causal judgment” (Fiske & Taylor, 1991, p. 23). Though there are many formulations or proposed dimensions of attribution theory, a common approach views attributions through the lenses of internal or external locus of control (Rotter, 1966), stable or unstable causes (Heider, 1958; Rotter, 1966), and, importantly, controllable or uncontrollable behaviors (Weiner, 1979).

When a person’s behaviors are perceived by observers as controllable, the person is more likely to be held responsible for those behaviors (Weiner et al., 1988) and attributed responsibility has been linked to stigmatization (Ruybal & Siegel, 2017, 2019). Underlying a demand that persons with TS stop ticcing is an incorrect understanding that tics are controllable behaviors. This can lead to observers becoming more annoyed or frustrated by the tics than they might be otherwise and feel entitled to make demands that they otherwise would not, had they been aware of the tics’ actual cause. Holding persons with TS responsible for their tics may be the basis for this form of verbal harassment, in addition to other forms of unwanted attention described in this study.
The second portion of this study examined reported misinterpretations of TS behaviors in greater depth, identifying three primary types of interpersonal misunderstandings: Misunderstanding communicative intention, misunderstanding TS, and misunderstanding cause. Similar to the verbal harassment subthemes of “asking if they are okay” and “asking what they are doing,” the “cause” category encompasses instances in which observers made incorrect attributions of a tic behavior, assuming they indicate something they do not. For instance, observers misattributed tic behaviors to mental handicaps, seizures, asthma, hiccups, and drug usage, among others. This type of misunderstanding has implications for the treatment and general quality of life for persons with TS.

In addition to the annoyance or embarrassment of having to deal with these types of misunderstandings from strangers, misattributions can have an impact on how others communicate with persons with TS. Participants in this study described being talked to or treated differently by observers who believed they had a mental illness. Also, when tics are misattributed to behaviors such as drug usage, as in examples provided by multiple participants, persons with TS are at risk of further harassment or abuse, particularly from authority figures.

Attribution theory is also useful for explaining what we term “misunderstanding communicative intention.” This subtheme includes misunderstandings that occur when a conversational partner or observer misinterprets a tic behavior as a communicative signal. This form of misunderstanding manifests as a “wink tic” being misattributed as a romantic overture, a tic-induced pause in conversation misattributed as a relinquishing of turn order, or tic behaviors being misattributed as intentional acts of disrespect, among many other examples. These examples illustrate the polysemic nature of tic behaviors. Though not willfully imbued with any communicative intent, nonverbal cues, such as tics, have “indeterminacy or ambiguity… reveal[ing] their polysemous potential (i.e., multiple possible meanings/sources), which allows for a great deal of variation in how people interpret what a nonverbal cue ‘meant’” (Manusov, 2011). Tics may be interpreted as any number of communicative actions, and observers might use context clues to make (inaccurate) attributions regarding their meaning.

An assumption of intentionality is inherent in this type of misattribution. Intentionality has been proposed as another dimension of attributions (Weiner, 2006), understood as an “inference about whether an action is intended and compatible with the individual’s goals” (Yao & Siegel, 2021, p. 200). Intentionality is also a component of what Manusov (2016) describes as “function-based approaches” to communication. Scholars utilizing these approaches propose discrepant definitions of what qualifies as communication, centered on the concept of intentionality. Nonverbal behaviors such as tics are understood as communication when either the behavior is “encoded with communicative purpose,” the behavior is “decoded as intentional,” or when “most people who use the communication system would generally agree to the cues having communicative meaning” (Manusov, 2016, p. 3; see also Burgoon et al., 2009).

Tic behaviors would not be considered communication by some scholars, because they lack communicative intent, but they would be understood as communication by other scholars in instances in which observers decode the behaviors as intentionally-
communicative or where most would agree that the behaviors generally have communicative meaning. This highlights a tension present within many interpersonal interactions for persons with TS and epitomizes one of the primary issues they face when communicating. They are not encoding tics with communicative purpose, but their tics are being decoded with intention and meaning by observers. It is ultimately the misattribution of communicative intent to tic behaviors that causes many misunderstandings reported by adults with TS and leads to a plethora of interpersonal, communicative challenges.

Limitations and Conclusion

We believe that our data speak to the interpersonal context, the specific challenges, and the nature of meanings and reactions given to behaviors that result from TS. But our study is not without limitations. Similar to prior studies surveying or interviewing adults with TS (e.g., Conelea et al., 2013; Malli et al., 2019), we had more females (10) than males (8) in our study, although males are diagnosed at a higher rate than are females (4.3:1 in childhood, though it seems this difference narrows into adulthood, Freeman et al., 2000, which may partially explain this discrepancy). In addition, all of the participants in this study identified as white, which also has important implications for the generalizability of the findings and the voices that were heard. The use of purposive, nonrandom sampling also makes it difficult to generalize the results of this study to broader populations. These methods align with the interpretive aims of this study, however, and allowed for specific targeting of the small, underrepresented population of individuals making up the TS community.

The semi-structured interviews for this study were conducted via audio Skype calls or email. As opposed to a face-to-face format, the less personal format may have led participants to be less likely to disclose some sensitive information regarding their experiences (Merrigan & Huston, 2009). It is also likely that the first author’s disclosure of his own experience with TS at the outset of the interviews provided some sense of camaraderie and comfort for participants, however.

This study provides an in-depth analysis of the ways in which tics direct unwanted attention on adults with TS. It identifies interpersonal misunderstandings as a common outcome of ticcing around others, and explores how these misunderstandings involve the misattribution of tic nonverbal behaviors, misattributions regarding the intentionality of persons with TS, and misattributions regarding their disposition. Importantly, these misunderstandings are what ultimately contribute to much of the unwanted attention described by the participants in this study and documented in previous work, highlighting the value of a greater awareness of how misunderstandings take place with respect to TS.

This study focused primarily on examining the interpersonal challenges faced by persons with TS and considering how they manifest in communication. We did not provide information on the strategies that persons with TS use to overcome these challenges, which were often reported by participants during our interviews. Future research should examine the strategies persons with TS report using to overcome challenges, as well as how relevant actions are performed communicatively. In addition, nearly all of the interpersonal challenges described by persons with TS occurred in
face-to-face settings. These interviews took place before the COVID-19 outbreak and it is likely that new types of communicative challenges have arisen with the increased time spent on online communication platforms such as Zoom. Future research might find rich data regarding the unique impact of increased online video conferencing on the social and communicative challenges experienced by persons with TS, whether it be in work meetings, online classes, or other types of online events.

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**Declarations**

**Ethics Approval**  This study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. This study was approved by the University of Washington Human Subjects Division.

**Consent to Participate**  Informed consent was obtained from all individual participants included in the study.

**Consent to Publish**  The participants have consented to the submission of the case report to the journal.

**Conflict of Interest**  The authors have no relevant financial or non-financial interests to disclose.

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