

# The Trichotillomania Impact Project (TIP): Exploring Phenomenology, Functional Impairment, and Treatment Utilization

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**Background:** Trichotillomania (TTM) occurs in 0.6% to 3.4% of adults. Questions remain about phenomenological features of the disorder, its impact on functioning, and treatment utilization. The current study (i.e., The Trichotillomania Impact Project) was designed to provide initial information regarding these issues.

**Method:** An Internet-based survey was completed by 1697 individuals who self-reported symptoms consistent with a diagnosis of TTM (DSM-IV-TR). The survey assessed phenomenological experiences; social, occupational, academic, and psychological impact; as well as treatment-seeking experiences. The survey link operated from April 2005 through May 2005.

**Results:** Survey results suggest considerable variability in TTM phenomenology. Individuals with more severe TTM symptoms endorsed more frequent phenomenological experiences of physical or mental anxiety prior to pulling and relief, pleasure, or gratification after pulling. Mild to moderate life impairment in social, occupational, academic, and psychological functioning was reported for the entire study sample. These impairments were more pronounced as TTM symptoms became more severe. A summary of treatment seeking in the sample suggests that pharmacotherapy was the most commonly received treatment, followed by behavior therapy. Unfortunately, treatment in general was perceived as relatively ineffective.

**Conclusion:** This study underscores the clinical significance of severe hair pulling and highlights the need for research on its pathogenesis and treatment.

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**T**richotillomania (TTM) involves repetitive pulling of one's own hair to the point of noticeable hair loss and occurs in 0.6% to 3.4% of adults.<sup>1</sup> Recent research has indicated that TTM is more common than previously believed,<sup>2</sup> may serve an affect regulation function,<sup>3</sup> is associated with functional impairment and psychiatric comorbidity,<sup>4-7</sup> and appears to be responsive to cognitive-behavioral treatment, at least in the short run.<sup>8,9</sup> These developments notwithstanding, important gaps remain in our knowledge about TTM and its impact on sufferers. It is critical that these gaps be closed with respect to TTM, as insufficient knowledge of psychopathology hinders treatment development and improvement in patient outcomes.<sup>10</sup>

## Phenomenology

Inherent in the diagnostic criteria (DSM-IV-TR) for the disorder, individuals with TTM must report a minimal level of tension prior to pulling that is relieved contingent on a pulling episode.<sup>11</sup> In addition, the pulling must result in noticeable hair loss, but the specific site from which pulling must occur is unspecified. It remains unclear how reports of the requisite tension prior to pulling (criterion B) and pleasure, gratification, or relief

### TAKE-HOME POINTS

- ◆ Trichotillomania has significant impact on social, psychological, academic, and occupational functioning.
- ◆ Individuals with trichotillomania do not view their health care providers as very knowledgeable about the disorder.
- ◆ Individuals with trichotillomania do not perceive current treatment for the disorder to be particularly effective.

when pulling (criterion C) may differ as a function of disorder severity.<sup>3,12</sup>

### Functional Interference

Available data on the functional impact of TTM are limited. Existing data, which have come primarily from small treatment-seeking samples, show that individuals with TTM (1) go to great lengths to conceal its effects from both friends/family and treatment providers<sup>4</sup>; (2) may be unlikely to seek treatment due to embarrassment<sup>13,14</sup>; (3) experience higher levels of disability, lower life satisfaction, and lower self-esteem when compared to nonpsychiatric controls; and (4) report a widespread impact on day-to-day activities and a resulting negative affect.<sup>4,15,16</sup> In addition to the apparent psychosocial consequences, TTM can produce a variety of physical consequences, including hair loss, scalp irritation, follicle damage, structural changes in regrown hair, dental problems (from hair mouthing),<sup>17</sup> and carpal tunnel syndrome.<sup>18</sup> Those who ingest the hair are susceptible to trichobezoars. Although rare, these blockages may lead to vomiting, weight loss, and possibly death.<sup>19</sup>

Although the aforementioned findings are suggestive of substantial impairment, generalizability of them to the entire population of those with TTM is limited by the small sample sizes and a narrow sampling band. Specifically, clinic-based samples, as used in the earlier studies, may not include those at the mild end of the spectrum, those with a lack of available care, or those who do not seek treatment for the problem due to a host of factors including lack of knowledge about available treatments or embarrassment about the condition.

To counter these problems, researchers have begun to utilize Internet sampling procedures. Although there appear to be a number of questions about the validity of data collected through such means, Gosling and colleagues<sup>20</sup> demonstrated that data collected from Internet samples “generalize across presentation formats, do not appear to be tainted by false data or repeat responders, and are, so far, consistent with results from traditional methods.”<sup>20(p102)</sup> Nevertheless, to increase confidence in studies conducted using these methods, researchers have suggested other precautions when using Internet data collection methods, including the use of (1) much larger

samples, (2) procedures to identify and eliminate duplicative data sets sent from the same individual, and (3) statistics that are less sensitive to outliers.<sup>21</sup>

To date, only 1 study has utilized Internet sampling to collect data on the impact of TTM.<sup>7</sup> In this study, 381 individuals who met self-reported diagnostic criteria for TTM completed an anonymous Web-based survey. Data from the Internet sample were compared to data from a separate sample of 36 individuals with TTM who were recruited in person at an educational research conference sponsored by a national TTM patient organization (i.e., the Trichotillomania Learning Center [TLC]). Results showed that the 2 groups were equal in terms of demographics, TTM severity, and, generally, the bodily sites from where hair was pulled. In addition, Wetterneck and colleagues<sup>7</sup> found 43.5% of the Internet and 50% of the face-to-face sample reported having refrained from close relationships because of pulling, and 14.1% of the face-to-face sample and 16% of the Internet sample felt the pulling interfered with job duties on a weekly basis. Combined, these findings suggest that samples of patients with TTM obtained from anonymous online surveys can be quite similar to those obtained via face-to-face interview. Despite these initial findings, the study was limited by a number of factors including disparate sample sizes that increased the risk for type II error, a relatively small sample size given the mode of data collection,<sup>21</sup> and a nonsystematic strategy to guide the development of the survey.

### Treatment Utilization

The aforementioned advances in TTM research have improved our understanding of the phenomenology and potential functional impact of TTM, but collective knowledge about TTM and the efficacy of available treatments remains limited. At present there are 6 randomized controlled trials examining pharmacotherapy for TTM, and the results have been largely disappointing with respect to separation from placebo treatments.<sup>22</sup> Cognitive-behavioral interventions involving habit reversal training have also been studied using randomized controlled trial methodology. Although their acute efficacy appears to be encouraging,<sup>8,23</sup> follow-up data highlight the problem of relapse following treatment discontinuation.<sup>9,24,25</sup> Moreover, the degree to which these evidence-based treatments

**Table 1. Characteristics Across Entire Sample (N = 1697) and Those in the LOW and HIGH MGH-HS Groups<sup>a,b</sup>**

Characteristic	Full Sample (N = 1697)	LOW (N = 424)	HIGH (N = 470)
Gender, % (N)			
Male	6.5 (110)	7.8 (33)	5.5 (26)
Female	93.2 (1581)	92.0 (390)	94.0 (442)
Unspecified	0.4 (6)	0.2 (1)	0.4 (2)
Age, y			
Mean (SD)	30.9 (10.2)	31.5 (10.8)	31.0 (10.3)
Range	18–69	18–66	18–69
Education, % (N)			
High school/GED	<b>34.2 (580)</b>	30.7 (130)	<b>39.4 (185)</b>
Tech college/assoc	11.9 (202)	10.8 (46)	13.6 (64)
BA/BS	33.3 (565)	<b>35.8 (152)</b>	28.5 (134)
Master's	14.4 (244)	16.0 (68)	12.1 (57)
Doctoral	2.8 (47)	2.1 (9)	3.6 (17)
Unspecified	3.4 (58)	4.5 (19)	2.8 (13)
Ethnicity, % (N)			
White/Caucasian	<b>87.1 (1478)</b>	<b>85.4 (362)</b>	<b>87.0 (409)</b>
African American	3.1 (53)	4.0 (17)	3.4 (16)
Hispanic/Latino	3.7 (62)	5.0 (21)	3.0 (14)
Asian	1.9 (32)	1.7 (7)	2.3 (11)
Native American	0.5 (9)	0.2 (1)	0.6 (3)
Multi-racial	2.1 (36)	2.1 (9)	1.9 (9)
Other	1.4 (23)	1.4 (6)	1.7 (8)
Annual income, % (N)			
< \$9999	21.7 (368)	19.6 (83)	<b>26.2 (123)</b>
\$10,000–19,000	12.6 (213)	13.2 (56)	11.9 (56)
\$20,000–29,000	14.4 (245)	12.7 (54)	16.2 (76)
\$30,000–49,000	<b>23.1 (392)</b>	<b>20.8 (88)</b>	23.2 (109)
\$50,000–75,000	14.4 (245)	16.0 (68)	10.6 (50)
> \$75,000	12.4 (211)	15.8 (67)	10.6 (50)
Marital status, % (N)			
Single/never married	<b>53.6 (909)</b>	<b>50.7 (215)</b>	<b>55.7 (262)</b>
Currently married	36.8 (624)	39.4 (167)	34.9 (164)
Divorced	8.7 (147)	8.7 (37)	8.5 (40)
Separated	0.2 (4)	0.5 (2)	0.2 (1)
Widowed	0.4 (6)	0.5 (2)	0.2 (1)
Reported having been formally diagnosed with TTM, % (N)	56.6 (960)	52.1 (221)	63.8 (300)
Reported having sought help for psychosocial problems other than TTM, % (N)	32.1 (544)	30.7 (130)	37.0 (174)

<sup>a</sup>Modal data are in bold type.

<sup>b</sup>The LOW group consisted of low scorers ( $\leq 1$  SD below the sample mean) on the MGH-HS. The HIGH group consisted of high scorers ( $\geq 1$  SD above the sample mean) on the MGH-HS.

Abbreviations: assoc = associate's degree, BA = Bachelor of Arts, BS = Bachelor of Science, GED = General Educational Development test, MGH-HS = Massachusetts General Hospital Hair-Pulling Scale, TTM = trichotillomania.

are broadly available and acceptable to individuals with TTM has been questioned.<sup>26,27</sup>

Responding to a call from researchers at a jointly sponsored National Institute of Mental Health (NIMH)/TLC meeting in which a number of significant gaps in the TTM literature were noted,<sup>28</sup> we sought to examine the phenomenology, functional impact, and perceived treatment utilization of those experiencing TTM symptoms in a large "Trichotillomania Impact Project" (TIP). Internet sampling procedures were utilized to maximize sample size and increase generalizability of results. Given poten-

tial problems with Internet sampling methods, the current study was designed to provide preliminary description and hypothesis testing regarding the impact of TTM symptoms across numerous life domains and set the stage for subsequent rigorous epidemiologic, psychopathology, and clinical studies.

## METHOD

### Participants

This study was approved by the University of Wisconsin-Milwaukee's Institutional Review Board. Participants were recruited through a link established on the TLC home page (<http://www.trich.org>). The survey link operated from April 2005 through May 2005. A total of 2558 responses were received. Duplicate surveys (N = 106), defined as those surveys containing identical information on all survey items, were excluded from all analyses. Respondents were included in subsequent analyses if they met diagnostic criteria for TTM<sup>11</sup> as modified for the purposes of the current study.

The modified TTM diagnostic criteria required the respondent to indicate that he or she (1) pulled hair resulting in either noticeable hair loss or thinning of the hair; (2) experienced increased physical tension immediately before pulling or when trying to resist pulling, or pulled to relieve an uncomfortable bodily sensation at least "a little of the time" (i.e., 11%–29%); (3) experienced pleasure, gratification, or relief after pulling, or he/she pulled to relieve an uncomfortable bodily sensation at least "a little of the time" (i.e., 11%–29%); (4) "never/almost never" (0%–10%) pulled his/her hair in response to voices others may not be able to hear or due to beliefs that bugs/insects were crawling on their skin; (5) reported experiencing at least "mild to moderate" impairment (a score of 3 or greater on a 9-point Likert scale) in day-to-day, social, interpersonal, occupational, or academic functioning; and (6) were at least 18 years of age. A total of 1697 participants met study criteria for TTM, and their demographic data are reported in Table 1. Because an actual diagnosis of TTM could not be confirmed by clinical observation, the term *TTM symptoms* is used in the current article rather than *TTM*.

### Materials

**Trichotillomania Impact Survey.** The Trichotillomania Impact Survey (TIS) was developed in several stages. Initially, the first 3 authors (D.W.W., C.A.F., M.E.F.) developed a set of questions to assess the domains of interest, and chose standard measures to assess a broad range of areas of importance to individuals with TTM symptoms (e.g., phenomenology, social impact, treatment history, hair-pulling severity, depression, anxiety, and stress). Next, the survey was sent to the fourth and sixth authors (N.J.K., D.J.S.), who are TTM experts.

These authors provided suggestions and feedback (e.g., suggested the removal as well as the addition of items to the survey) and returned the survey for revisions. After revisions were completed, the survey was sent to an expert in survey methodology and epidemiology (R.D.G.) for feedback about the wording of items and survey structure. Revisions were made, and the survey was then sent back out to members of the TLC's Scientific Advisory Board (TLC-SAB) for feedback, criticism, and suggestions for improvement. The suggestions of the TLC-SAB were integrated into the TIS, and a finalized version of the TIS was placed online. A link to the TIS was placed on the TLC homepage.

The final version of the TIS (available from the first author) included questions assessing demographics (e.g., age, race, income), the phenomenology of the participant's hair pulling (e.g., "Do you experience any pleasure or gratification after pulling?"), the social and economic impact of hair pulling (e.g., "Have you ever avoided going on vacation because of your hair pulling?"), and treatment history and outcome (e.g., "How old were you when you first sought treatment for pulling?"). In addition, 3 established measures were administered, including the Sheehan Disability Scale (SDS),<sup>29</sup> the Depression Anxiety Stress Scale 21-Item Version (DASS-21),<sup>30</sup> and the Massachusetts General Hospital Hairpulling Scale (MGH-HS).<sup>31</sup> Each of these is described below.

**Sheehan Disability Scale.**<sup>29</sup> The SDS is a 3-item scale designed to assess perceived disability across home, work, and social settings. Items on the SDS are worded similarly (e.g., "Because of my problems, my work/social life/home responsibilities is/are impaired."). Items are measured using a 10-point Likert scale ranging from 1 ("not at all") to 10 ("very severely") with higher scores indicating greater perceived disability. Items can be summed to provide an overall perceived disability score ranging from 3 to 30.

**Depression Anxiety Stress Scale 21-Item Version.**<sup>30</sup> The DASS-21 is a 21-item scale designed to measure features of depression, anxiety, and stress in clinical and nonclinical populations. The measure provides separate scores for the empirically derived factors of depression, anxiety, and stress. Each factor consists of 7 items measured on a 4-point Likert scale ranging from 0 ("did not apply to me at all") to 3 ("applied to me very much, or most of the time"). Scores for each scale are calculated by summing the 7 items and multiplying by a factor of 2. Each scale has a minimum score of 0 and a maximum score of 42. Higher scores are indicative of more frequent symptoms in a given domain. The DASS-21 scales have demonstrated good internal consistency and strong convergent<sup>34,35</sup> and divergent validity.<sup>35</sup> Population-based norms are available (depression: mean = 2.12 [SD = 3.64]; anxiety: mean = 1.22 [SD = 1.77]; stress: mean = 3.51 [SD = 3.78]).<sup>34</sup>

### **Massachusetts General Hospital Hairpulling Scale.**<sup>31</sup>

The MGH-HS is a 7-item self-report instrument designed to assess hair-pulling severity over the past week. Individual items are rated from 0 to 4. Three questions ask specifically about the urge to pull, 3 ask about actual pulling, and 1 asks about how much distress the person experiences as a result of pulling. In the initial patient sample, scale item mean ( $\pm$  SD) scores ranged from 1.72 ( $\pm$  1.21) to 2.73 ( $\pm$  1.15). The MGH-HS has shown good to very good internal consistency ( $\alpha$  = .80–.89),<sup>31,32</sup> excellent test-retest reliability ( $r$  = 0.97),<sup>33</sup> and strong convergent validity ( $r$  = 0.63–0.75)<sup>32,33</sup> and has demonstrated divergent validity.<sup>33</sup>

### **Procedure**

**Data collection.** The link to the TLC Web site operated for 2 consecutive months. Participants were directed to the link by e-mails sent from the TLC to individuals on its contact list. After clicking on the link, participants were required to read an informed consent document. They were informed that the purpose of the study was to examine the social and economic impact of TTM and that to participate they needed to be at least 18 years of age and chronically pull their hair. Finally, participants were informed that submission of the survey indicated consent. The entire survey took approximately 45 minutes to complete. The second author subsequently received the survey via e-mail as an "anonymous user." The electronic copy of each survey was printed from the second author's computer, surveys were numbered according to when the survey was received (e.g., the first survey received was coded number 1, etc.), and a hard copy of the survey was placed in a locked filing cabinet.

**Data entry and reliability checking.** A team of 6 research assistants entered data from each survey into a statistical program (SPSS software, version 13.0, SPSS Inc., Chicago, Ill.). To ensure data were entered correctly, a 2-step process was followed. First, 19% of the surveys ( $N$  = 459) were randomly selected and checked by an independent rater who compared each variable in the study's database against the participants' responses on the hard copies. Any errors were corrected. Accuracy of data entry was quite high (99.8% accuracy). The second step involved an outlier analysis for each data element in the survey. Across the entire sample, a research assistant conducted frequency checks on each existing numeric element. Any data element(s) appearing outside the acceptable range (e.g., a score of 23 on a 4-point scale) was identified, checked against the original hard copy of the survey, and corrected.

**Analytic strategy.** Study analyses addressed multiple domains including demographics, phenomenology (e.g., pulling site), impairment (social, academic/occupational, and psychological), and treatment (percent receiving treatment, type of provider and treatment, perceived bene-

**Table 2. Body Sites From Which Hair Is Pulled, Across Entire Sample and Between Those in the LOW and HIGH MGH-HS Groups<sup>a</sup>**

Area of Body	Full Sample (N = 1697)		LOW (N = 424)		Group Comparison <sup>b</sup>	HIGH (N = 470)	
	N	%	N	%		N	%
Scalp	1235	72.8	286	67.5	<	370	78.7
Brows	957	56.4	227	53.5	=	258	54.9
Lashes	875	51.6	223	52.6	=	218	46.4
Pubic	860	50.7	196	46.2	=	253	53.8
Legs	370	21.8	64	15.1	<	121	25.7
Arms	211	12.4	32	7.5	<	68	14.5
Armpits	210	12.4	41	9.7	<	68	14.5
Trunk	121	7.1	17	4.0	<	39	8.3
Moustache	92	5.4	9	2.1	<	34	7.2
Beard	73	4.3	9	2.1	<	23	4.9
Other	137	8.1	23	5.4	=	40	8.5
Pets/animals	8	0.5	1	0.2		1	0.2
Breasts/ nipples	9	0.5	2	0.5		1	0.2
Back	3	0.2	1	0.2		2	0.4
Feet/toes	15	0.9	0	0.0		4	0.9
Other people	7	0.4	0	0.0		4	0.9
Beauty/ birthmarks	1	0.1	0	0.0		1	0.2
Cheek/chin	29	1.7	7	1.7		9	1.9
Nose	14	0.8	4	0.9		5	1.1
Ear	6	0.4	5	1.2		1	0.2
Fingers	21	1.2	3	0.7		8	1.7
Perineum	2	0.1	0	0.0		2	0.4
Wigs	1	0.1	0	0.0		1	0.2
Neck	8	0.5	2	0.5		1	0.2
Stomach	3	0.2	0	0.0		1	0.2
Shoulder	1	0.1	1	0.2		0	0.0
Chest	4	0.2	1	0.2		0	0.0
Bottom	1	0.1	0	0.0		1	0.2

<sup>a</sup>The LOW group consisted of low scorers ( $\leq 1$  SD below the sample mean) on the MGH-HS. The HIGH group consisted of high scorers ( $\geq 1$  SD above the sample mean) on the MGH-HS.

<sup>b</sup>Directional arrows indicate significance and directionality of differences between LOW and HIGH groups at  $p < .004$ . An equal sign reflects nonsignificant group differences.

Abbreviation: MGH-HS = Massachusetts General Hospital Hairpulling Scale.

fit). For each domain, data are reported for the entire sample of subjects who by self-report satisfied the aforementioned criteria ( $N = 1697$ ). Following a description of the overall sample, an attempt was made to examine the impact of variability in symptom severity comparing low (LOW:  $\leq 1$  SD below the sample mean) and high (HIGH:  $\geq 1$  SD above the sample mean) scorers on the MGH-HS. This split resulted in a significant separation between MGH-HS scores between the 2 groups. The LOW group had a mean MGH-HS score of 9.8 ( $SD = 3.1$ ), and the HIGH group had a mean MGH-HS score of 22.1 ( $SD = 2.0$ ).

In all tests comparing HIGH and LOW groups, 2-tailed nonparametric tests were used as recommended by Kraut and colleagues.<sup>21</sup> To control for familywise error rate, a Bonferroni correction was utilized for each of the domains being assessed (e.g., demographics, pulling site, antecedent/consequence phenomenology, social

interference, occupational/academic interference, and psychological interference). Alpha levels for each domain are as follows: demographics,  $\alpha = .0063$ ; pulling site,  $\alpha = .004$ ; antecedent/consequence phenomenology,  $\alpha = .0038$ ; social interference,  $\alpha = .008$ ; occupational/academic interference,  $\alpha = .0031$ ; psychological interference,  $\alpha = .005$ .

## RESULTS

### Demographics

Demographic data for the entire sample and 2 severity groups are presented in Table 1. Examination of possible demographic differences between the LOW and HIGH groups showed that the 2 groups were no different in terms of age, gender distribution, ethnicity, or level of education. However, the LOW group had a higher annual income than the HIGH group ( $\chi^2 = 16.38$ ,  $df = 1$  [ $N = 880$ ],  $p = .006$ ). Conversely, those in the HIGH group were more likely to have been formally diagnosed with TTM ( $\chi^2 = 11.75$ ,  $df = 1$  [ $N = 891$ ],  $p < .001$ ).

### Description of Pulling Sites and Phenomenology

**Pulling sites.** Table 2 lists the number and percentages of individuals endorsing the various sites from which they had pulled hair in the last 2 weeks. As expected, hair was most commonly removed from the scalp, followed by the eyebrows and eyelashes. Over one half of the sample reported pulling from the pubic area. If participants reported pulling from an "other" area of the body in the last 2 weeks, they were given the opportunity to list the areas from which they pulled. Table 2 shows the diversity of areas from which pulling occurred. When asked how much hair was missing from the pulling site most frequently targeted, the modal response was 30% to 70% hair loss (37% of the sample reported this level of hair loss), and 68% reported having lost between 30% and 100% of their hair in the target area.

When pulling-site data were compared across the HIGH and LOW groups, the HIGH group was more likely to have pulled from the scalp, legs, arms, armpits, trunk, moustache, and beard, but were as likely to have pulled from the eyelashes, eyebrows, and pubic region, when compared to the LOW group (see Table 2).

**Antecedent/consequence phenomenology.** Participants were also asked a number of questions about pulling phenomenology. Results are presented in Table 3. A high percentage of respondents reported the presence of antecedent somatic phenomena or urges, which were relieved as a result of the pulling. Likewise, a large percentage of respondents felt that pulling led them to feel more anxious, and 69% were aware of their pulling most or all of the time. When asked to rate the unpleasantness of the antecedent "urge," using a scale from 0 to 4, with 0 being "not at all unpleasant" and 4 being "extremely unpleasant," 63% of

Table 3. Percentage of Entire Trichotillomania Sample Endorsing Various Phenomenological Items (N = 1697)<sup>a</sup>

Question	All of the Time (90%–100%), N (%)	Most of the Time (71%–89%), N (%)	Some of the Time (30%–70%), N (%)	A Little of the Time (11%–29%), N (%)	Never/Almost Never (0%–10%), N (%)	Don't Know, N (%)
Do you experience an increasing sense of physical tension or an "urge" immediately before pulling your hair or when you try to resist pulling?	639 (37.7)	<b>722 (42.5)</b>	238 (14.0)	44 (2.6)	21 (1.2)	33 (1.9)
Do you experience a sense of pleasure/gratification/relief after pulling your hair?	<b>668 (39.4)</b>	629 (37.1)	240 (14.1)	72 (4.2)	55 (3.2)	30 (1.8)
How much time have you actually spent pulling your hair this past week?	36 (2.1)	229 (13.5)	<b>682 (40.2)</b>	592 (34.9)	73 (4.3)	77 (4.5)
How often do you experience some bodily sensation (urge, building tension, etc) right before your hair pulling?	461 (27.2)	<b>523 (30.8)</b>	402 (23.7)	157 (9.3)	144 (8.5)	10 (0.6)
What % of your pulling is done to achieve a specific bodily sensation?	256 (15.1)	393 (23.2)	<b>409 (24.1)</b>	223 (13.1)	392 (23.1)	24 (1.4)
How often do you feel a sense of physical anxiety before pulling or if you try to prevent or delay yourself from pulling?	260 (15.3)	324 (19.1)	331 (19.5)	264 (15.6)	<b>512 (30.2)</b>	6 (0.4)
How often do you experience mental anxiety, such as a sense of worry or fear that something bad will happen if you do not pull promptly or correctly?	100 (5.9)	152 (9.0)	193 (11.4)	242 (14.3)	<b>1000 (58.9)</b>	10 (0.6)
What % of your pulling episodes are initiated to make your hair appear more symmetrical?	103 (6.1)	151 (8.9)	252 (14.8)	267 (15.7)	<b>915 (53.9)</b>	9 (0.5)
What % of your pulling episodes lead to you feeling more anxious?	<b>1342 (79.1)</b>	343 (20.2)	2 (0.1)	2 (0.1)	1 (0.1)	7 (0.4)
How aware are you of your hair pulling?	580 (34.2)	<b>592 (34.9)</b>	373 (22.0)	110 (6.5)	34 (2.0)	8 (0.5)

<sup>a</sup>Modal responses are in bold type.

respondents rated the unpleasantness a 2 or higher, suggesting a moderately uncomfortable urge prior to the pulling.

The phenomenology data were also compared across LOW and HIGH groups (see Table 4). The HIGH group (mean = 2.03, SD = 1.38) rated the urge as more unpleasant than the LOW group (mean = 1.75, SD = 1.19;  $U = 87,338$ ;  $Z = -3.27$ ,  $p < .001$ ) and also reported missing more hair ( $U = 75,906$ ;  $Z = -6.33$ ,  $p < .001$ ). The HIGH group reported that pulling was more likely to be preceded by some bodily sensation ( $U = 69,400$ ;  $Z = -7.96$ ,  $p < .001$ ), felt that a greater percentage of the pulling was done to achieve a specific bodily sensation ( $U = 75,192$ ;  $Z = -5.75$ ,  $p < .001$ ) and reported that a greater percentage of pulling was likely to be preceded by physical anxiety ( $U = 72,438$ ;  $Z = -7.12$ ,  $p < .001$ ) and mental anxiety ( $U = 83,258$ ;  $Z = -4.54$ ,  $p < .001$ ) but not a need for symmetry ( $U = 97,090$ ;  $Z = -0.42$ ,  $p = .68$ ). In addition, the HIGH group was more likely to report an increased tension/urge before pulling or while resisting ( $U = 69,601$ ;  $Z = -8.33$ ,  $p < .001$ ) and was also more likely to experience pleasure/gratification or relief after pulling ( $U = 84,312$ ;  $Z = -4.13$ ,  $p < .001$ ). Those in the HIGH group also spent more time pulling in the last week ( $U = 42,679$ ;  $Z = -15.41$ ,  $p < .001$ ), and pulling was more likely to lead to additional anxiety for this group ( $U = 90,801$ ;  $Z = -3.02$ ,  $p < .001$ ). HIGH and LOW groups did not differ on the extent to which they were aware of their pulling ( $U = 95,202$ ;  $Z = -1.03$ ,  $p = .30$ ).

## Interference

The impact of TTM symptoms was evaluated across 3 domains: social interference, occupational/academic interference, and psychological interference.

**Social interference.** Respondents reported that in the past 12 months, pulling moderately interfered with their home management tasks, their social lives, and their abilities to maintain close relationships with others (see Table 5). In addition, a significant number reported avoiding various social/recreational activities. When asked how much time was spent per day covering the effects of pulling, the modal response was 0 to 15 minutes per day. Eighteen percent reported spending 15 to 30 minutes per day in concealment behavior, and 8% spent between 30 to 60 minutes per day. A relatively small percentage (1.4%,  $N = 23$ ) reported having been hospitalized for pulling.

There were numerous differences between those in the HIGH and LOW groups. The HIGH group reported greater interference with home management tasks ( $U = 65,119$ ;  $Z = -8.93$ ,  $p < .001$ ), with social lives ( $U = 71,195$ ;  $Z = -7.29$ ,  $p < .001$ ), and in maintaining close relationships ( $U = 72,997$ ;  $Z = -6.51$ ,  $p < .001$ ) than the LOW group. In addition, the HIGH group was more likely to have avoided going on vacation ( $\chi^2 = 12.59$ ,  $df = 1$  [ $N = 890$ ],  $p < .001$ ), refrained from social events ( $\chi^2 = 18.27$ ,  $df = 1$  [ $N = 892$ ],  $p < .001$ ), and avoided group activities ( $\chi^2 = 16.96$ ,  $df = 1$  [ $N = 890$ ],  $p < .001$ ).

**Occupational/academic interference.** A significant proportion of respondents noted that in the past 12

**Table 4. Percentage Endorsing Various Phenomenological Experiences, for LOW (N = 424) Versus HIGH (N = 470) MGH-HS Groups<sup>a,b</sup>**

Question	All of the Time (90%–100%)		Most of the Time (71%–89%)		Some of the Time (30%–70%)		A Little of the Time (11%–29%)		Never/ Almost Never (0%–10%)		Don't Know	
	LOW	HIGH	LOW	HIGH	LOW	HIGH	LOW	HIGH	LOW	HIGH	LOW	HIGH
Do you experience an increasing sense of physical tension or an "urge" immediately before pulling your hair or when you try to resist pulling?	26.9	<b>51.5</b>	<b>41.7</b>	35.7	23.1	8.5	4.0	1.5	1.7	0.9	2.6	1.9
Do you experience a sense of pleasure/gratification/relief after pulling your hair?	33.5	<b>49.1</b>	<b>40.1</b>	30.0	17.0	11.3	4.5	4.3	4.0	2.3	0.9	2.6
How much time have you actually spent pulling your hair this past week?	0.2	6.4	3.1	26.8	24.8	<b>44.9</b>	<b>55.4</b>	16.8	12.0	0.6	4.2	4.0
How often do you experience some bodily sensation (urge, building tension, etc) right before your hair pulling?	18.9	<b>37.2</b>	25.7	32.3	<b>28.8</b>	17.2	12.5	7.2	13.9	5.5	...	...
What % of your pulling is done to achieve a specific bodily sensation?	12.0	20.0	17.5	<b>25.7</b>	22.2	24.3	14.9	9.8	<b>31.4</b>	18.9	...	...
How often do you feel a sense of physical anxiety before pulling or if you try to prevent or delay yourself from pulling?	10.1	<b>23.8</b>	14.6	19.1	16.3	19.4	17.7	13.4	<b>41.3</b>	23.6	...	...
How often do you experience mental anxiety, such as a sense of worry or fear that something bad will happen if you do not pull promptly or correctly?	5.0	8.3	5.4	13.8	9.4	10.4	13.2	13.2	<b>66.7</b>	<b>53.4</b>	...	...
What % of your pulling episodes are initiated to make your hair appear more symmetrical?	6.8	6.6	8.0	8.7	14.4	15.5	15.1	14.7	<b>55.2</b>	<b>53.8</b>	...	...
What % of your pulling episodes lead to you feeling more anxious?	<b>83.0</b>	<b>74.7</b>	16.5	24.3	0.2	0.2	0.0	0.4	0.0	0.0	...	...
How aware are you of your hair pulling?	32.3	<b>39.6</b>	<b>38.4</b>	27.7	17.5	23.8	8.5	6.6	2.8	2.1	...	...

<sup>a</sup>Modal responses for HIGH and LOW groups are in bold type.

<sup>b</sup>The LOW group consisted of low scorers ( $\leq 1$  SD below the sample mean) on the MGH-HS. The HIGH group consisted of high scorers ( $\geq 1$  SD above the sample mean) on the MGH-HS.

Abbreviation: MGH-HS = Massachusetts General Hospital Hairpulling Scale.

**Table 5. Social Interference in the Past 12 Months Caused by Pulling, Across Entire Sample and Those in the LOW (N = 424) and HIGH (N = 470) MGH-HS Groups<sup>a</sup>**

Domain	Full Sample	LOW	Group Comparison <sup>b</sup>	HIGH
Interference with home management tasks, mean (SD) <sup>c</sup>	3.86 (2.38)	3.22 (2.25)	<	4.70 (2.47)
Interference with social lives, mean (SD) <sup>c</sup>	5.15 (2.46)	4.66 (2.38)	<	5.88 (2.49)
Interference with ability to maintain close relationships with others, mean (SD) <sup>c</sup>	4.50 (2.67)	4.02 (2.58)	<	5.24 (2.75)
Avoided going on vacation because of pulling, %	20.0	16.1	<	25.9
Avoided social events because of pulling, %	40.0	34.9	<	48.7
Avoided group activities because of pulling, %	36.0	31.9	<	45.4

<sup>a</sup>The LOW group consisted of low scorers ( $\leq 1$  SD below the sample mean) on the MGH-HS. The HIGH group consisted of high scorers ( $\geq 1$  SD above the sample mean) on the MGH-HS.

<sup>b</sup>Directional arrows indicate significance and directionality of differences between LOW and HIGH groups at  $p < .008$ . An equal sign reflects nonsignificant group differences.

<sup>c</sup>Rated on a 1 (mild interference) to 9 (severe interference) point scale. A score of 4 or greater indicated moderate interference.

Abbreviation: MGH-HS = Massachusetts General Hospital Hairpulling Scale.

months, pulling had interfered with their job duties on at least a monthly basis (see Table 6). Few had actually quit their jobs because of pulling, but relatively greater percentages of respondents had failed to pursue job advancement or avoided a job interview because of the pulling. Overall, respondents reported that pulling had a mild impact on their ability to work.

Impact on academic functioning (e.g., missed school, difficulties in performing school responsibilities, difficulties in studying because of pulling) was also common.

Overall, respondents said that pulling had a mild to moderate impact on academic functioning.

As predicted, the HIGH group reported greater impact on nearly every indicator of occupational and academic functioning than the LOW group. The HIGH group reported that pulling was more likely to interfere with job duties on a daily ( $\chi^2 = 42.92$ ,  $df = 1$  [ $N = 879$ ],  $p < .001$ ), weekly ( $\chi^2 = 30.55$ ,  $df = 1$  [ $N = 872$ ],  $p < .001$ ), and monthly ( $\chi^2 = 26.8$ ,  $df = 1$  [ $N = 867$ ],  $p < .001$ ) basis. The HIGH group was more likely to miss work in the previous

**Table 6. Occupational/Academic Interference in the Past 12 Months Caused by Pulling, Across Entire Sample and Those in the LOW (N = 424) and HIGH (N = 470) MGH-HS Groups<sup>a</sup>**

Domain	Full Sample	LOW	Group Comparison <sup>b</sup>	HIGH
Reporting interference with job duties daily, %	23.0	15.3	<	34.6
Reporting interference with job duties weekly, %	28.6	20.9	<	38.0
Reporting interference with job duties monthly, %	33.6	26.1	<	42.9
Quit a job because of pulling, %	4.1	1.9	<	7.3
Failed to pursue job advancement because of pulling, %	14.7	12.0	<	19.9
Avoided a job interview because of pulling, %	18.2	13.4	<	26.6
No. of work days missed in previous 6 months, mean	0.26	0.17	<	0.42
No. of work days tardy in previous 6 months, mean	2.9	1.4	<	2.9
Work Interference Rating for past 12 months, mean <sup>c</sup>	2.5	1.9	<	3.1
Reporting having missed school as a result of pulling, %	23.5	20.5	<	31.4
Reporting that pulling has caused difficulties in performing school responsibilities, %	42.6	39.6	<	49.6
Reporting that pulling has caused difficulties in studying, %	76.2	72.6	=	80.8
Reporting that pulling led to dropping out of school, %	5.3	4.1	<	9.6
Reporting that pulling led to avoidance of additional educational opportunities, %	9.3	6.9	<	15.1
No. of school days missed in previous 12 months, mean	0.9	0.2	<	1.4
Academic Interference Rating for past 12 months, mean <sup>c</sup>	3.4	2.8	<	4.1

<sup>a</sup>The LOW group consisted of low scorers ( $\leq 1$  SD below the sample mean) on the MGH-HS. The HIGH group consisted of high scorers ( $\geq 1$  SD above the sample mean) on the MGH-HS.

<sup>b</sup>Directional arrows indicate significance and directionality of differences between LOW and HIGH groups at  $p < .0031$ . An equal sign reflects nonsignificant group differences.

<sup>c</sup>Rated on a 1 (mild interference) to 9 (severe interference) point scale. A score of 4 or greater indicated moderate interference.

Abbreviation: MGH-HS = Massachusetts General Hospital Hairpulling Scale.

6 months ( $U = 76,850$ ;  $Z = -3.36$ ,  $p < .001$ ) and had more tardy workdays in the prior 6 months ( $U = 74,221$ ;  $Z = -3.26$ ,  $p < .001$ ) than the LOW group. The HIGH group was also more likely to have quit a job ( $\chi^2 = 14.16$ ,  $df = 1$  [ $N = 883$ ],  $p < .001$ ), to have failed in pursuing job advancement ( $\chi^2 = 10.21$ ,  $df = 1$  [ $N = 886$ ],  $p < .001$ ), and to have avoided a job interview ( $\chi^2 = 23.72$ ,  $df = 1$  [ $N = 884$ ],  $p < .001$ ) because of the pulling. Overall, the HIGH group rated the interference in ability to work caused by TTM symptoms to be higher than the LOW group ( $U = 66,285$ ;  $Z = -7.71$ ,  $p < .001$ ).

Academically, the HIGH group was more likely to have missed school because of TTM symptoms ( $\chi^2 = 13.29$ ,  $df = 1$  [ $N = 876$ ],  $p < .001$ ). The HIGH group was also more likely to report that pulling had caused difficulties in performing school responsibilities ( $\chi^2 = 8.77$ ,  $df = 1$  [ $N = 870$ ],  $p = .003$ ), led them to drop out of school ( $\chi^2 = 10.05$ ,  $df = 1$  [ $N = 869$ ],  $p = .002$ ), and led them to terminate the pursuit of additional educational opportunities ( $\chi^2 = 14.65$ ,  $df = 1$  [ $N = 858$ ],  $p < .001$ ). In addition, the HIGH group missed more days of school in the last 12 months because of the pulling than the LOW group ( $U = 51,404$ ;  $Z = -4.46$ ,  $p < .001$ ). Finally, the HIGH group reported greater levels of academic interference produced by TTM symptoms when compared to the LOW group ( $U = 59,465$ ;  $Z = -6.61$ ,  $p < .001$ ).

**Psychological interference.** The psychological impact of TTM symptoms was assessed across 3 domains: (1) alcohol/substance use as a means to control or cope with the problem; (2) participants' perceptions of TTM symptom impact on the development of other emotional problems; and (3) examination of scores on the DASS-21 anxiety, depression, and stress scales.

A notable minority of the sample reported currently using tobacco products, alcohol, and/or illicit substances to help relieve negative feelings associated with hair pulling or to reduce the urge to pull, and a significant majority felt that TTM symptoms directly contributed to the development of their comorbid emotional disturbance (see Table 7). Scores on the DASS-21 confirmed relatively high levels of depression, anxiety, and stress in the sample and were relatively comparable to those found in a clinical sample of adults with obsessive-compulsive disorder (OCD) (stress, mean = 17.59, SD = 10.98; depression, mean = 13.30, SD = 11.83; anxiety, mean = 9.26, SD = 7.56).<sup>34</sup>

Compared to the LOW group, the HIGH group was more likely to use tobacco products to help relieve negative feelings associated with hair pulling ( $\chi^2 = 8.14$ ,  $df = 1$  [ $N = 893$ ],  $p = .004$ ) and to reduce the urge to pull ( $\chi^2 = 12.39$ ,  $df = 1$  [ $N = 887$ ],  $p < .001$ ). Likewise, those in the HIGH group were more likely to use alcohol to relieve negative feelings associated with pulling ( $\chi^2 = 8.00$ ,  $df = 1$  [ $N = 893$ ],  $p = .005$ ) and to reduce the urge to pull ( $\chi^2 = 16.04$ ,  $df = 1$  [ $N = 888$ ],  $p < .001$ ). The 2 groups did not differ with respect to using illegal drugs to reduce the urge to pull ( $\chi^2 = 3.16$ ,  $df = 1$  [ $N = 888$ ],  $p = .08$ ) or to reduce the negative feelings associated with pulling ( $\chi^2 = 5.23$ ,  $df = 1$  [ $N = 889$ ],  $p = .02$ ).

The LOW group was less likely to believe that TTM directly contributed to the development of any existing comorbid emotional disturbance, compared to the HIGH group ( $\chi^2 = 32.63$ ,  $df = 1$  [ $N = 886$ ],  $p < .001$ ). On the DASS-21, the LOW group was less anxious ( $U = 62,080$ ;  $Z = -9.66$ ,  $p < .001$ ), less depressed ( $U = 57,520$ ;  $Z = -10.82$ ,  $p < .001$ ), and less stressed

**Table 7. Psychological Interference Caused by Pulling, Across Entire Sample and Those in the LOW (N = 424) and HIGH (N = 470) MGH-HS Groups<sup>a</sup>**

Domain	Full Sample	LOW	Group Comparison <sup>b</sup>	HIGH
Using tobacco to relieve negative feelings associated with pulling, %	17.7	15.1	<	22.6
Using tobacco to reduce the urge to pull, %	14.8	10.7	<	19.1
Using alcohol to relieve negative feelings associated with pulling, %	14.1	10.1	<	16.6
Using alcohol to reduce the urge to pull, %	7.6	3.6	<	10.5
Using illegal drugs to relieve negative feelings associated with pulling, %	6.0	4.7	=	8.6
Using illegal drugs to reduce the urge to pull, %	4.8	3.8	=	6.4
Felt TTM directly contributed to development of additional emotional disorder, %	70.2	64.2	<	81.3
DASS-21 depression score, mean (SD)	16.3 (12.2)	11.8 (10.8)	<	20.9 (12.7)
DASS-21 anxiety score, mean (SD)	10.0 (9.2)	7.2 (7.6)	<	13.6 (10.7)
DASS-21 stress score, mean (SD)	20.7 (10.8)	16.7 (10.2)	<	25.2 (10.7)

<sup>a</sup>The LOW group consisted of low scorers ( $\leq 1$  SD below the sample mean) on the MGH-HS. The HIGH group consisted of high scorers ( $\geq 1$  SD above the sample mean) on the MGH-HS.

<sup>b</sup>Directional arrows indicate significance and directionality of differences between LOW and HIGH groups at  $p < .005$ . An equal sign reflects nonsignificant group differences.

Abbreviations: DASS-21 = Depression Anxiety Stress Scale 21-Item Version, MGH-HS = Massachusetts General Hospital Hairpulling Scale, TTM = trichotillomania.

( $U = 56,076$ ;  $Z = -11.20$ ,  $p < .001$ ) than the HIGH group (see Table 7).

**Overall disability.** Across the whole sample, the SDS mean score was 10.06 (SD = 5.9), indicating mild to moderate perceived disability across the 3 domains of functioning. Correlations between MGH-HS scores and the SDS again demonstrated the relationship between pulling severity and functional impact. The MGH-HS was significantly correlated with the SDS total score ( $r = 0.27$ ,  $df = 1553$ ,  $p < .001$ ). As depression may explain a significant proportion of variance associated with the psychosocial impact in those with TTM symptoms,<sup>4,5</sup> a partial correlation was conducted to evaluate the relationship between SDS scores and MGH-HS scores after removing variance associated with the DASS-depression scores. Results showed that there was still a small, but significant correlation between perceived disability and pulling severity ( $r = 0.14$ ,  $df = 1545$ ,  $p < .01$ ).

### Treatment Utilization and Perceived Efficacy

If participants reported ever having received treatment for their TTM symptoms ( $N = 1048$ ), they were asked which professional they first told about their pulling, the knowledge their treatment providers had about TTM, the different types of treatment received, and how efficacious they perceived treatment for TTM symptoms to be. Psychologists/therapists/counselors/social workers (39.5%,  $N = 414$ ) were most often the first provider informed of the disorder, followed by psychiatrists (27.3%,  $N = 286$ ) and primary care physicians (25.2%,  $N = 264$ ). When asked about their provider's perceived knowledge of TTM, 28.1% ( $N = 295$ ) felt the provider was not at all knowledgeable, 27.7% ( $N = 290$ ) felt the provider had heard of the disorder, 33.9% ( $N = 355$ ) felt the provider had some information about TTM, 12.4% ( $N = 130$ ) felt their provider knew much about TTM, and 3.1% ( $N = 32$ ) of respondents considered the provider an expert in TTM.

The most common intervention utilized by persons with TTM symptoms was medication, the most common class of which were selective serotonin reuptake inhibitors (see Table 8). The most common type of nonpharmacologic intervention was behavior therapy. When patients were asked about the most commonly used types of behavior therapy, self-monitoring and relaxation training were the most likely to be endorsed.

When patients were asked to rate the perceived efficacy of treatments they had received for TTM symptoms, 5.0% ( $N = 52$ ) reported being "very much improved," 9.8% ( $N = 103$ ) reported being "much improved," 20.8% ( $N = 218$ ) reported being "minimally improved," 37.7% ( $N = 395$ ) reported being "unchanged," 7.4% ( $N = 78$ ) reported being "minimally worse," 5.4% ( $N = 57$ ) reported being "much worse," and 3.2% ( $N = 34$ ) reported being "very much worse."

## DISCUSSION

There has been a growing consensus that TTM is a prevalent and impairing disorder, but in the absence of nationally representative epidemiological surveys of TTM or of large clinical samples, policymakers and funding agencies have been left to speculate as to the public health significance and importance of funding research on the disorder. To address this issue, we conducted a large survey of those with TTM symptoms. Although it must be replicated and extended in rigorous epidemiologic, psychopathology, and clinical research, the present investigation suggests that (1) TTM symptoms have a mild to moderate impact on numerous domains of functioning, (2) those with TTM symptoms view the efficacy and availability of treatment as inadequate, and (3) the impact of TTM symptoms is related to severity.

Data on levels of impairment found in this study are remarkably similar to those found in earlier studies. For ex-

**Table 8. Types of Interventions Received for Trichotillomania Symptoms (N = 1697)**

Treatment Intervention	Respondents Who Received, % (N)
Medication	42.0 (713)
Antidepressants	
Fluoxetine	24.6 (418)
Sertraline	19.4 (330)
Paroxetine	15.6 (265)
Venlafaxine	10.7 (181)
Clomipramine	10.4 (177)
Fluvoxamine	9.8 (166)
Escitalopram	9.5 (162)
Citalopram	8.6 (146)
Nefazodone	2.0 (34)
Amitriptyline	1.6 (28)
Trazodone	1.6 (28)
Nortriptyline	0.8 (13)
Desipramine	0.6 (11)
Antipsychotics	
Risperidone	3.1 (52)
Olanzapine	2.0 (34)
Quetiapine	2.0 (34)
Aripiprazole	1.5 (25)
Ziprasidone	0.6 (10)
Haloperidol	0.5 (9)
Pimozide	0.4 (6)
Anxiolytics	
Buspirone	6.8 (115)
Alprazolam	5.0 (85)
Clonazepam	3.8 (64)
Lorazepam	3.6 (61)
Diazepam	1.4 (23)
Other medications	
Lithium	2.1 (35)
Nutraceutical	1.6 (27)
Naltrexone	0.8 (13)
Divalproex sodium acid	0.5 (9)
Clonidine	0.2 (3)
Behavioral treatment	30.7 (521)
Self-monitoring	24.0 (408)
Relaxation training	21.6 (366)
Stress management training	16.4 (279)
Habit reversal	15.0 (255)
Stimulus control techniques	6.1 (104)
Relapse prevention training	3.0 (51)
Psychotherapy	19.1 (324)
Support group	13.4 (227)
Hypnosis	11.6 (197)
Other	3.3 (56)

ample, in the current sample, 36% avoided participating in group activities, a finding quite similar to that reported by Diefenbach and colleagues,<sup>4</sup> who found that 28% of the clinically ascertained sample avoided group social events. Similarly, 23% of the current sample reported that pulling interfered with work on a daily basis, compared to 26% in the Diefenbach study. Although this level of occupational impact does not appear extreme, it is worth considering the cumulative impact of TTM symptoms across the entire population. Assuming a 1% prevalence rate and a working-age (18–69 years) population of approximately 184 million,<sup>36</sup> results from the current study would suggest that nearly 1 million work days (956,800) may be missed per year due to TTM symptoms and that 73,600

people may have quit their employment because of TTM symptoms in the United States.

One interesting difference between the current study and earlier studies had to do with the target pulling sites. Contrary to earlier reports suggesting that pulling of pubic hair is relatively uncommon in samples collected using face-to-face data collection methods (e.g., 17%<sup>37</sup>; 34%<sup>3</sup>), the current study found that over 50% of the sample reported pubic pulling, a number that was similar to the 55% pubic pulling rate found by Wetterneck and colleagues.<sup>7</sup> Such findings suggest that pubic pulling may be much more common than previously believed.

Another interesting finding of the current study involved the large percentage of respondents who noted anxiety as both a precipitator and consequence of pulling. Given this finding, it is possible that pulling cycles may get created in which pulling produces the very condition that elicits additional pulling, an idea put forth by other TTM researchers.<sup>38</sup> Likewise, the current study highlighted the possibility that some individuals with TTM symptoms use substances to cope with or control the disorder. It is interesting to note that some studies have shown approximately 20% of TTM samples report a diagnosis of alcohol abuse/dependence, and 16.1% abuse or are dependent on other substances.<sup>39</sup> Perhaps the substance use patterns described in this study play a role in the later development of particular problematic usage. Future research should address these issues.

Overall, data on the state of treatment paint a grim picture. Over one half of the respondents have not received services, and perceptions are that the providers are not knowledgeable about TTM. Likewise, the commonly prescribed medications involve those for which randomized controlled trials show little efficacy in reducing TTM, although such medications may be effective for treating comorbid or secondary conditions (e.g., depression). Similarly, when receiving behavior therapy, very few respondents appear to receive interventions with empirical data to support their use. Confirming this observation, when asked to rate the perceived efficacy of treatment, the majority of participants felt treatment produced no change or made them worse.

Regarding treatment seeking and perceived efficacy, only about one half of the sample had sought treatment for TTM symptoms, and only 65% of those with MGH-HS severity scores of 1 standard deviation above the mean had spoken with a professional about their pulling. This percentage seems low and provides numerous hypotheses awaiting further confirmation. It is quite possible that providers simply do not exist in many of the areas from which respondents sought treatment.<sup>26</sup> Likewise, it is possible that in an effort to conceal the effects of the disorder, individuals fail to seek treatment. Clearly, additional studies will have to evaluate the extent to which these hypotheses are accurate.

In addition to the many strengths of the current study, a number of limitations must also be noted. First, the TTM diagnoses were not confirmed by clinician observation. Although (1) the demographic characteristics reported in the current study are similar to those of earlier studies, (2) the functional impairments reported in the current sample are similar to those found in earlier studies, and (3) the findings by Wetterneck et al.<sup>7</sup> showing that TTM samples ascertained directly or via the Internet are quite similar, care should be taken in generalizing the current findings to clinical populations and community populations who are not savvy to Internet usage. Relatedly, the method of data collection in this study may invite skepticism, but the benefits of collecting such a large amount of data on a relatively rare and oft-hidden disorder may outweigh the limitations. Likewise, we implemented a number of precautions recommended when using Internet sampling procedures.<sup>21</sup>

As a second limitation, it should be noted that we did not attempt to rule out the impact of possible comorbid conditions. Although a preliminary analysis suggested a link between pulling and functional impact even after controlling for depression, these findings need to be replicated in future research. Still, other psychiatric disorders such as body dysmorphic disorder and OCD were not ruled out as potential explanations for pulling. A third limitation involves our failure to pilot test the entire TIS on a sample of those with TTM. Although various portions of the survey had been previously pilot tested with actual TTM patients, the entire survey was not and is a limitation of survey development.

A fourth limitation involves the possible disconnect between what the subjects perceived they received as treatment, what they actually received, and whether the treatment they received was adequately administered. Given the nature of the survey, it was not possible to obtain reliability ratings with service providers to assure accurate reporting. As such, data about the types of treatment received and their perceived efficacy should be approached with caution. A final limitation involves the lack of psychometric data on the TIS. Clearly, these limitations should be addressed in future research.

The present study was an attempt to quantify the impact of TTM symptoms on the lives of those with the disorder. Clearly, the impact is broad, significant, and related to disorder severity. Nevertheless, future research should be conducted to confirm the current findings in representative community-based samples. Most importantly, it will be necessary to replicate the current study with a similar sample size, but using additional standardized measures and face-to-face ascertainment methods. Despite the limitations, these results provide initial and compelling evidence of the potential importance of including TTM in large-scale psychiatric epidemiologic studies in order to assess the public health impact of this disorder in

the general population, as such studies have done for major depression<sup>40,41</sup> and other anxiety disorders.<sup>42,43</sup> Such an approach can provide further confidence in the current findings and provide a broader view of the extent to which TTM symptoms affect the population, the range of severity within the community, and the potential role of other mental disorders on functional impairment in TTM symptoms (as well as the reverse). Likewise, it will be important to include a cost-care analysis in future research as a means of examining the financial impact of TTM symptoms and its treatment. It is our hope that this research is done soon and that the compelling impact of TTM symptoms will encourage researchers and funding agencies to invest resources toward developing a more comprehensive understanding of the disorder, improved treatments, and, eventually, treatment dissemination.

*Drug names:* alprazolam (Xanax, Niravam, and others), aripiprazole (Abilify), buspirone (Buspar and others), citalopram (Celexa and others), clomipramine (Anfranil and others), clonazepam (Klonopin and others), clonidine (Catapres, Duraclon, and others), desipramine (Norpramin and others), diazepam (Valium and others), divalproex sodium (Depakote), escitalopram (Lexapro and others), fluoxetine (Prozac and others), lithium (Lithobid, Eskalith, and others), lorazepam (Ativan and others), naltrexone (Revia, Vivitrol, and others), nortriptyline (Pamelor and others), olanzapine (Zyprexa), paroxetine (Paxil, Pexeva, and others), pimozone (Orap), quetiapine (Seroquel), risperidone (Risperdal), sertraline (Zoloft and others), venlafaxine (Effexor and others), ziprasidone (Geodon).

*Disclosure of off-label usage:* The authors have determined that, to the best of their knowledge, no medications are approved by the U.S. Food and Drug Administration for the treatment of trichotillomania. The medications mentioned in this article were reported to be used for trichotillomania by the patients but were not given to the patients by the authors of this study.

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