Perspectives on Genetics Among Individuals with Trichotillomania

Master's Thesis

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The Faculty of the Graduate School of Arts and Sciences
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in
Genetic Counseling

by
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ABSTRACT

Perspectives on Genetics Among Individuals with Trichotillomania

A thesis presented to the Graduate Program in Genetic Counseling

Graduate School of Arts and Sciences
Brandeis University
Waltham, Massachusetts

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An estimated 3.7 million people in the United States pull out their hair in a chronic or compulsive manner and suffer from excessive hair loss and consequent personal distress. This psychiatric disorder, Trichotillomania (TTM), may result in pronounced functional impairment and has been shown to be associated with depression, anxiety, low self-esteem and impaired quality of life. The purpose of this study was to explore beliefs of individuals with TTM about the role of genetics in causation and heritability of the disorder, and their opinions regarding genetic testing and counseling. We recruited individuals with a current or previous history of TTM through several online TTM support groups to participate in an online, anonymous survey. A total of 299 individuals completed the survey, which consisted of 40 multiple choice and open-ended questions. Respondents put a stronger emphasis on environmental versus genetic contribution to the development of TTM. Many
(35%) of our respondents were unsure of what they believe the heritability of TTM is, and of the participants who believe TTM is inherited, the greatest proportion (29%) overestimated what is currently thought to be a 10.6% inheritance rate of TTM (Keuthen et al., 2014). Many (63%) reported being interested in hypothetical genetic testing for TTM and 43% indicated that they would be interested in genetic counseling. However the largest proportion (48%) of our cohort did not understand how genetic counseling would be beneficial for them. Additionally, very few (n=11) individuals from our study were offered genetic counseling and those who met with a genetic counselor reported that this meeting was not helpful. Our findings suggest that although there is interest in pursuing counseling for TTM, there is an apparent gap between this interest and current practice and understanding of genetic counseling for TTM. Future studies addressing why few people with TTM have ever been referred for genetic counseling, why this lack of understanding regarding what people with TTM will gain from meeting with a genetic counselor exists, and what people with TTM view as an effective genetic counseling session, are warranted.

**Key Words:** Trichotillomania, psychiatric disorder, hairpulling, genetic testing, genetic counseling, causation, heritability, perspectives
Table of Contents

Acknowledgements ................................................................................................................... iii

Abstract .................................................................................................................................. iv

List of Tables ............................................................................................................................ vii

List of Figures .......................................................................................................................... viii

Introduction .............................................................................................................................. 1

Methods ................................................................................................................................... 4
  Sampling Methods and Study Population ................................................................................. 4
  Data Collection and Data Analysis .......................................................................................... 5

Results .................................................................................................................................... 6
  Sample Characteristics ............................................................................................................ 6
  Family Members with TTM ..................................................................................................... 6
  History and Impact of TTM .................................................................................................... 6
  Beliefs About Causes of TTM ................................................................................................. 9
  Beliefs About Inheritance of TTM ......................................................................................... 10
  Attitudes Toward the Idea of Genetic Counseling for TTM.................................................... 11
  Attitude Toward Genetic Testing for TTM ............................................................................. 13

Discussion ............................................................................................................................... 16
  The TTM Causation Debate .................................................................................................... 16
  Conflicting Opinions About Genetic Testing for TTM.......................................................... 20
  Variable Interest and Experiences in Genetic Counseling for TTM .................................... 24

Limitations .............................................................................................................................. 27

Conclusion ............................................................................................................................... 29

References ............................................................................................................................... 31

Appendix A: Recruitment Notice ............................................................................................ 33

Appendix B: Study Survey ....................................................................................................... 34
List of Tables

Table 1: TTM Characteristics of Participants ............................................................... 7
List of Figures

Figure 1: TTM Affect on Daily Life ................................................................. 8
Figure 2: Comorbid Conditions ................................................................. 9
Figure 3: Participant Responses to Causes of TTM ................................. 10
Figure 4: Inheritance of TTM ................................................................. 11
Figure 5: Benefits of Genetic Testing for TTM .................................... 13
Figure 6: Harms of Genetic Testing for TTM ....................................... 14
Figure 7: Usefulness of a Genetic Test for TTM .................................. 15
INTRODUCTION

Trichotillomania (TTM) is a psychiatric disorder that is characterized by recurrent hairpulling resulting in noticeable hair loss (American Psychiatric Association, 2000). TTM is estimated to affect about 1–3% of the general population (Duke, Keeley, Geffken, & Storch, 2010) or at least 3.7 million people in the United States (Flessner CA et al, 2012), with an average age of onset for adult patients estimated to be 13 years (Diefenbach, Tolin, Hannan, Crocetto, & Worhunsky, 2005). Individuals with TTM pull out their hair in a chronic or compulsive manner primarily from the scalp, eyelashes, and eyebrows as well as other areas. This results in excessive hair loss and consequent personal distress.

Historically, TTM has been thought to be a benign condition, however, more recent studies have shown that TTM may result in marked functional impairment and has been shown to be associated with depression, anxiety, low self-esteem and impaired quality of life (Diefenbach et al., 2005).

Several studies have described the significant impact that TTM can have on an individual’s functional and emotional well-being. Diefenach et al. (2005) found that TTM can be psychologically devastating and can lead to several physical complications such as significant scarring. Studies have demonstrated that most people with TTM experience pronounced psychosocial, academic, occupational, and economic impairment, and a high degree of comorbid conditions including depression and anxiety (Tung, Flessner, Grant, & Keuthen, 2015).
The specific cause of TTM is not known, and research in this area is still ongoing. In general, the etiology of psychiatric disorders is understood to be a complex combination of both genetic and environmental components. While potential susceptibility genes for psychiatric disorders have been identified, the interaction with the environment is a crucial component in disease development (Hill & Sahhar et al., 2006). Similarly, the etiology of hairpulling is likely a complex interaction of biological, psychological and social factors (Diefenbach et al., 2000).

The genetic component of TTM is not well understood, however, there have been previous reports of trichotillomania in a three-generation family, as well as several reports of other TTM familial findings. Christenson et al. [1992] reported that of 161 individuals with TTM, 8% reported a positive family history of the disorder in first-degree relatives. A more recent study by Keuthen et al (2014), found that 10.6% of individuals with TTM reported a positive family history of the disorder in first-degree relatives. These reports demonstrate that genetic factors contribute to the development of TTM, and according to Cohen (1995) it is likely that multiple genes play a role in imposing biological vulnerability. In addition, a twin concordance study by Novak et al (2009) demonstrated a significantly higher concordance rate for TTM among monozygotic twins (38.1%) than dizygotic twins (0%) in 34 twin pairs, which yielded an overall heritability estimate of 76.2% for hair-pulling, and is thus suggestive of a significant role of the genetic factors in the etiology of TTM (Novak et al. 2009). However, most people with TTM have no affected relatives and family studies are inconsistent with Mendelian modes of inheritance.
Genetic studies of TTM are currently in the early stages and little research has been done in this area, however three candidate genes that are suspected to have an influence on the risk for developing TTM have been identified (CHATTERJEE, 2011). Researchers identified mutations in the SLITRK1 gene, SAPAP3 gene and the CDH2 gene, suggesting that the cause of TTM is polygenic and the interplay with the environment increases susceptibility to developing the disorder (Flessner, Knopik, & McGeary, 2012).

According to a 2006 report by the National Institutes of Mental Health, psychiatric disorders are common in the population, and therefore most genetic counselors will inevitably encounter many clients with personal or family histories of psychiatric illness (Peay et al., 2008). TTM may be the motivation for seeking genetic counseling or it may come up during a session by way of gathering personal or family history during a referral for a different indication. Little is known about what people with trichotillomania understand about the genetic basis of TTM, or what they perceive are the possible benefits and risks of potential genetic testing and genetic counseling for this condition. Therefore the consideration of the perspectives of people with TTM is critical to understanding the implications of ongoing TTM genetic research and testing.

The purpose of this study was to explore the beliefs of individuals with TTM about the role of genetic factors in causation of the disorder, as well as opinions regarding genetic testing and counseling. Specifically we sought to:

1. Assess beliefs about the causation and heritability of TTM
2. Explore opinions regarding hypothetical genetic testing for TTM
3. Examine experiences with and opinions of genetic counseling for TTM
METHODS

The Brandeis University Institutional Review Board approved this study protocol and materials and was deemed exempt from further IRB oversight. We utilized an online, anonymous survey (see Appendix B) consisting of both quantitative and qualitative questions to assess participants’ experiences and opinions.

Sampling Methods and Study Population

We recruited participants for this study through several online Trichotillomania support organizations, including:

- Trichotillomania Learning Center (TLC)
- The Center for Emotional Health of Greater Philadelphia
- Trichotillomania Support Worldwide
- Trichotillomania Hope
- Trichotillomania Recovery
- Trichotillomania Acceptance
- Trichotillomania Facebook group
- Trichotillomania 24/7 Impulse Disorder Nationwide.

We provided the leaders of the support groups with the recruitment notice (see APPENDIX A) and asked them to distribute the information to their members at their meetings or to post the recruitment notice on the support group website.
To be eligible for participation, participants had to meet the following inclusion criteria:

1. Current age of 18 years or older
2. Fluency in English
3. Current or previous history of TTM

**Data Collection and Data Analysis:**

We constructed and administered the online survey using Qualtrics software. The survey was available from January 21, 2015 to February 21, 2015. By entering the survey, participants indicated their consent to participate in the study. The survey included a total of 40 questions (34 multiple choice and 6 open-ended). The questions on the survey were divided into 6 sections. Sections 1-3 were designed to learn about respondents’ personal experiences with TTM. Sections 4 and 5 focused on respondents’ perceptions about the causes of TTM and their opinions regarding potential benefit or harm of hypothetical genetic testing for TTM. The final section included a number of multiple-choice questions to obtain demographic information about our respondents.

We analyzed quantitative data using IBM SPSS 22.0 and Microsoft Excel. We used Pearson correlations to compare several variables. We ran frequencies and percentages for each of the response sets and used a thematic approach to analyze qualitative data.
RESULTS

Sample Characteristics

A total of 299 respondents completed the survey. A majority of our study participants were white (80%) and female (97%), with a mean age of 31 years (ranging from 18 to 63 years old). As a group the respondents were highly educated, with 84% reporting either some college education, a college degree, or a graduate degree.

Family Members with TTM

We asked respondents about any additional family members who have ever had a problem with hairpulling. The majority of respondents (62%) reported that they are not aware of anyone else in their family who has TTM. However, a small but significant fraction (13%) of our cohort indicated that they have a mother who has TTM and 5% reported having a father with TTM. Other first-degree relatives with TTM included: 5% who have a sister, brother (3%) or a child (4%) with TTM. Three respondents reported having other family members with dermatillomania as opposed to TTM.

History and Impact of TTM

In an attempt to better understand our study population, we asked a set of questions addressing our respondents’ personal history of trichotillomania. As detailed in Table 1, most of our respondents first experienced symptoms as teenagers, and most reported that they have been symptomatic for at least a decade. The majority of respondents reported that the degree of their hairpulling during the past three months has
been moderate (44%) to severe (33%). Most respondents (74%) indicated that when their hairpulling was “at its worst”, they would characterize it as being severe.

Table 1: TTM Characteristics of Participants

<table>
<thead>
<tr>
<th>Study Participants (N=299)</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Mode</td>
<td>Minimum</td>
<td>Maximum</td>
</tr>
<tr>
<td>Age when respondents first realized they had a problem with hairpulling</td>
<td>13.49</td>
<td>12</td>
<td>2</td>
<td>50</td>
</tr>
<tr>
<td>Number of years with the diagnosis of TTM</td>
<td>13.68</td>
<td>14</td>
<td>0</td>
<td>46</td>
</tr>
</tbody>
</table>

We used a Likert scale to assess how having TTM has affected various aspects of our participants’ lives (Appendix B- Section 3). As illustrated in Figure 1, many of our respondents indicated that TTM has either slightly, moderately or greatly affected their physical appearance (94.6%), extra time spent on grooming (84.8%), extra expenses spent on grooming (74.7%), romantic relationships (71.2%), activities/hobbies (59.7%), sexual relationships (58.5%), school effectiveness (53.6%), physical health (53%), and friendships (51.3%). Other areas of our participants’ lives that appeared less likely to be affected by TTM include work effectiveness (43.8%), school attendance (43.2%), career choice (40.6%) and work attendance (30.9%).
It is well known that TTM often manifests with other psychiatric comorbidities (Diefenbach et al. 2002). In our study population 59% of respondents indicated that in addition to TTM they have at least one other psychiatric diagnosis, such as generalized anxiety disorder (GAD), obsessive-compulsive disorder (OCD), major depressive disorder (MDD), dermatillomania, or social phobia (Figure 2). Of note, 29% of the respondents indicated that they have at least two psychiatric conditions in addition to their TTM.
Beliefs About Causes of TTM

We asked a series of questions aimed at gaining a more thorough understanding of what our respondents believe to be the cause of their personal experience with TTM (Appendix B- Section 4). We used a scale to determine how strongly respondents believe that genetics alone is responsible for their TTM and to assess how strongly respondents believe that environmental factors alone were the cause of their TTM. Finally, using this scale we assessed how confident respondents’ were in their beliefs about genetic and/or environmental causation. As illustrated in Figure 3, as a group our respondents appeared more likely to believe that environmental factors alone caused their TTM, but most did not express a high degree of confidence in their responses.
A 2014 study by Keuthen et al. reported a 10.6% hairpulling recurrence estimate in the first-degree relatives of people with TTM. In order to assess what respondents believe about the heritability of TTM, we asked what they think is the likelihood that trichotillomania can be passed down from affected parents to their children. There was no consensus among our population and most participants, approximately one third (35.2%), indicated that they did not know/ were not sure what they believe the likelihood is that TTM is inherited. However, of the participants who believe that TTM may be inherited to some degree, the greatest proportion of our participants (28.5%) overestimated what is currently thought to be a 10.6% inheritance rate of TTM (Keuthen et al, 2014).
Interestingly, we found no correlation between respondents who have a first degree relative with TTM and the degree to which they believe that TTM is inherited.

![Figure 4. Inheritance of TTM](image)

**Attitudes Toward the Idea of Genetic Counseling for TTM**

We asked study participants about their experiences with genetic counselors and their perceptions of the potential benefits and harms of genetic testing (Appendix B-Section 5). We found that the vast majority (96%) had never been referred to see a genetic counselor. Of the 11 participants who had been referred to see a genetic counselor, 7 were referred by their healthcare provider and 4 individuals referred themselves. Only 7 of the 11 who were referred ultimately met with a genetic counselor. Of the 7 participants who met with a genetic counselor, 3 were self-referred and 4 were referred by a healthcare provider. Reasons for referral were varied and included referrals for a personal history of a medical condition (n=3), personal history of a genetic condition (n=1), personal history of TTM (n=3), and personal history of a psychiatric condition (n=2). Additionally, respondents were referred based on family history of a medical condition (n=1) and a family history of a genetic condition (n=1). None of the individuals who met with a genetic counselor answered any of our additional questions specifically addressing if the history of their TTM
came up during the session or if their TTM was discussed at all. Of note, 4 of the 11 participants who were referred to see a genetic counselor did not have a meeting with a genetic counselor.

When we asked the group of participants who had not seen a genetic counselor if they would be interested in meeting with a genetic counselor specifically about trichotillomania, 43% indicated that they would be interested in having a meeting with a genetic counselor. A small group (9%) indicated that they would not be interested in meeting with a genetic counselor. The most significant proportion of respondents (48%) responded that they were not sure how meeting with a genetic counselor would be helpful for them. This large group of respondents who were not sure how meeting with a genetic counselor would be helpful for them, as well as the group who would not be interested in meeting with a genetic counselor, may help to inform us as to why the 4 participants who were referred to see a genetic counselor did not go to their meeting. Although we did not directly ask any questions addressing why these respondents did not end up meeting with a genetic counselor, and there may be numerous reasons for this, it is important to question what expectations people with TTM may have for a genetic counseling session and what they would hope to gain from meeting with a genetic counselor. Almost 50% of our study population did not know how meeting with a genetic counselor may be helpful for them, therefore future studies addressing what people with TTM think would be effective for them and how they believe that healthcare providers could be better suited to provide the most beneficial care for them is the next critical step in research of this area.
Attitudes Toward Genetic Testing For TTM

We asked respondents what they thought might be some of the benefits and/or harms of genetic testing for TTM (Figures 5 and 6). As a group our respondents seemed more likely to endorse the potential benefits of testing than potential harms of testing. The most frequently cited potential benefits were an increase in personal knowledge, an increase in public awareness, reduction of uncertainty/self blame, and the potential for improvement in treatment. The most commonly cited potential harm was the idea that a genetic test might increase concern about transmission of TTM to offspring.

![Figure 5: Perceived Benefits of Genetic Testing For TTM](image)
When asked whether they personally would be interested in pursuing genetic testing for TTM if it were available, over half (62.7%) indicated that they would be interested in pursuing testing, 25.8% were undecided and 11.4% said they would not be interested in this testing. There was no correlation between those who considered themselves to be more severely affected by TTM during the past three months and how interested they would be in pursuing genetic testing.

We also asked respondents how useful they think a genetic test for TTM would be, the results of which are found in Figure 7. Just over half of the respondents (51%) indicated that a genetic testing would be either very useful or useful. We did not find any statistically significant correlation between the degree of severity of hairpulling during the past three months and how useful respondents think a genetic test for TTM would be.
Figure 7: Perceived Usefulness of a Genetic Test for TTM

<table>
<thead>
<tr>
<th>% of Respondents</th>
<th>Perceived usefulness of a genetic test for TTM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very useful</td>
<td>27.8</td>
</tr>
<tr>
<td>Useful</td>
<td>23.1</td>
</tr>
<tr>
<td>Somewhat useful</td>
<td>30</td>
</tr>
<tr>
<td>Not useful</td>
<td>8.1</td>
</tr>
<tr>
<td>Do not know</td>
<td>11</td>
</tr>
</tbody>
</table>
DISCUSSION

A 1993 study by Richards et al points out that if genetic counseling is to be useful it is vitally important that geneticists and other counselors understand clients’ beliefs about causation and inheritance. Our study was the first of its kind to address the beliefs that people with trichotillomania have regarding genetic causation and heritability as well as their perceptions regarding hypothetical genetic testing and the possibility of genetic counseling for TTM.

The TTM Causation Debate

The identification of trichotillomania susceptibility genes may inform our understanding of TTM’s pathophysiology, facilitate the development of more effective treatments and allow opportunities for improving the validity of psychiatric diagnosis and classification. Finding genes also raises the possibility of genetic testing and the potential for increased stigma and discrimination for those at risk. There has been no research on the how people with TTM interpret the genetic involvement in the development of the disorder. The understanding of what people with TTM think about genetic causation of TTM is particularly important given the frequent presumption that a genetic explanation of mental illness will reduce stigma, while recent findings suggest that it exacerbates stigma for other mental illnesses (Easter, 2012).

This study indicated that most participants expressed uncertainty about the cause of TTM.
The majority of our study participants did not believe that genetics alone was responsible for their TTM nor did they believe that environmental factors were solely responsible for their TTM. As is often observed, people in families with a high prevalence of mental illness emphasize the interactions of genetic and environmental factors in their accounts of the etiology of disease (Meiser, Mitchell, McGirr, Van Herten, & Schofield, 2005). Many of our respondents were more inclined to believe that environmental factors and other biological factors had a stronger effect on the development of TTM versus an exclusive underlying genetic cause and are more confident of this answer relative to their degree of confidence in a solely genetic cause of their TTM (Figure 3). Although the majority of participants did not attribute genetics alone to be the cause of their TTM, many alluded to concept of genetic predisposition and environmental triggers and numerous respondents indicated in our open-ended spaces that they believe genetic changes are at least one factor involved in the development of TTM.

Our findings are consistent with previous research which suggests that individuals with neuropsychiatric disorders and their relatives attribute disease etiology to a complex mix of biology genetics, and life experiences (Peay et al., 2008). Some studies have found that it is likely that genetic influences impose a vulnerability to emotional dysregulation through biological processes; hair-pulling is learned to reduce associated discomfort, rewarding a behavior pattern that becomes classically conditioned to associated stimuli over time (Duke et al., 2010). Consistent with this concept, we found that many of our respondents believe that a genetic predisposition is the initial risk factor, while the condition itself is expressed when environmental factors trigger this behavioral response further stressing the concept of the interaction between genetic susceptibility and
environmental factors. Some respondents expressed that they do not have any sense of what causes TTM and voiced a strong desire to learn the cause. We did not observe a general consensus regarding beliefs about the cause of TTM and the high degree of variability among our participant responses is consistent with the lack of consensus among the scientific community. While many hypotheses have been suggested, there is little agreement regarding the cause of TTM and current knowledge is limited regarding the etiology of TTM (Duke et al., 2010).

Based on the lack of formal scientific understandings of genetics and heredity of mental illness, subjects often hold “personal theories of inheritance” (McAllister 2003). Some participants referenced their own family histories to justify the importance of genetics and used our open-ended spaces to support the role of genetics in the development of TTM, based on their own family history of TTM. Previous studies have shown that relatives of TTM probands have shown higher rates of hair pulling behaviour versus controls (Flessner et al., 2012). The literature has numerous reports of TTM familial transmission [e.g., Delgado and Mannino, 1969; Sanderson and Hall-Smith, 1970; Kerbeshian & Burd, 1991]. A more recent study by Keuthen et al (2014) found that 10.6% of individuals with TTM reported a positive family history of the disorder in first-degree relatives. Our study findings are consistent with the confirmed familial inheritance of TTM (Keuthen et al. 2014), however, in our study, respondents reported a significantly higher proportion of first degree relatives affected with TTM (30.8%), compared with the 10.6% familial rate of TTM observed in previous studies. This significant difference in heritability estimates is possibly due to lack of diagnostic criteria in our study; our findings are based solely on participant responses.
Although most respondents did not attribute genetic changes to be the sole cause of their TTM, in our open-ended spaces, some expressed significant concerns about passing down TTM to future children. As seen in Figure 4, about one third of respondents were unsure of what they believed was the likelihood that TTM could be passed down from parent to child, however the largest cohort (28.5%) believed that there is a 26-50% chance of having a child with TTM. Most individuals often overestimated risk of familial transmission. Other studies looking at the perceptions of familial recurrence in people with bipolar disorder and schizophrenia also found affected individuals often overestimate family risk (Peay et al. 2009). This cohort (28.5%) which indicated a high likelihood of passing down TTM from parent to child may be the same group of individuals (30.8%) who have a first degree relative affected with TTM and thus their perceptions of heritability may be heightened in comparison to the perceptions of someone who is part of the 62.2% who do not have any family members with TTM. Therefore, we found that most people in our study overestimate the heritability of TTM and thus this over-estimation of risk suggests that genetic counseling for patients with TTM may be beneficial in facilitating a more accurate understanding of risk, as has been shown for other disorders (Watson et al., 1999; Butow et al., 2003).

Overall, our findings suggest that although genetics is believed by many to be a part of their TTM experience, genetics does not dominate people’s understandings of TTM, even for people who believe TTM may run in families. Although some participants expressed fears of passing on a TTM susceptibility gene to children, most, however, stressed that genetic susceptibility and environmental factors interacted. Participants distinguished
between largely ‘non-genetic’ factors that required an environmental trigger, whether it be hormonal, biochemical, or underlying psychological conditions.

**Conflicting Opinions About Genetic Testing for TTM**

Respondents were asked directly about their perceptions of genetic testing and how genetic testing could be helpful and/or harmful to people with TTM (Appendix B- Section 5). Many (62.7%) of our respondents indicated that they would participate in genetic testing if it were available and over three quarters (80.9%) of our population expressed that genetic testing for TTM would be useful to some extent. Our results suggest that people with TTM may look favorably on the development of genetic testing for TTM susceptibility genes. In the present study, we have demonstrated predominantly positive attitudes in our sample population towards the development of genetic tests for TTM susceptibility in adults. In addition, we found no statistically significant difference between those who were more severely affected by TTM and those who were less affected regarding interest in pursuing genetic testing.

Our findings are similar to those of a study by Smith et al. (1996) which examined attitudes towards genetic testing among members of a manic depressive support group and found generally positive attitudes and a high hypothetical demand for testing. Trippitelli et al. (1998) also recruited patients from a support group in addition to participants in their genetic linkage study and found the overwhelming majority of patients and spouses would take advantage of genetic tests if available. These views may be representative of sufferers more generally. However, research indicates that reported hypothetical interest in genetic testing only modestly predicts the choices individuals eventually make (Sanderson, O’Neill, Bastian, Bepler, & McBride, 2010). Therefore, we additionally asked our respondents what
they believe may be possible risks, benefits, and implications of genetic testing as this may reveal key aspects of what is involved in genetic testing from their perspectives.

When we asked participants to explain why they may or may not pursue such testing, reasons to pursue genetic testing included an overwhelming desire to find a cure and understanding of the cause of TTM, a hope to reduce self-blame/shame, and to determine the likelihood of passing down TTM to their children. Responses to our open-ended questions included statements such as:

“I might pursue the testing, if it also meant that there were a possible cure, or if getting tested would help the people testing find a cure... The number one question I ask myself is WHY!? Do I do this to myself?” (R1)

“I have two young sons. I know what I went through as a child living with TTM and would do anything in my power to keep my children from it.”(R2)

Other respondents believe that identifying a genetic cause would make explaining TTM to other people easier and may help to prove to others (and to themselves) that their condition is not their fault. Some examples of our respondent’s thoughts about genetic testing include:

“I would feel like I had permission to tell my family and friends about it... and that they would be more accepting because it is a biological cause, not my own fault or bad decisions that made me have TTM. ... telling them that I had a genetic test for ttm and that is why my hair looks so munted would be such an easier and less shameful experience too.”(R3)

“It would help me personally in terms of self blame. Knowing its not my fault would go along way in helping me get myself better. Everyone believes I can just stop but maybe this could serve as some sort of proof as to why there is something wrong with me.”(R4)

Respondents ultimately identified several ways that genetic information would be beneficial to them (See Figure 5). The primary themes identified behind the general aims of genetic testing included a hopeful attitude towards learning about why they have TTM and therefore reducing self-blame, raising public awareness and understanding and to reduce stigma associated with TTM. As such, respondents expected genetic involvement to
increase compassion and reduce blame by making TTM seem less like a choice.

Study participants also expressed a strong motivating factor for the identification of a genetic cause through testing as this might lead to new treatment options or a “cure” for TTM. In addition, some of our study participants believe that a genetic test may help to identify TTM in potential children and a positive result may be used to implement early intervention strategies. Other respondents expressed a desire to pursue genetic testing solely for purposes of general curiosity and understanding of their condition. However, some respondents explained that they do not know if they would be interested in pursuing testing and gave reasons such as “I’m not sure it would help me stop, which is all I care about doing.” (R5) Several other studies have assessed the perceptions of hypothetical genetic testing for psychiatric conditions and shown that it is viewed favorably [Trippitelli et al., 1998; Milner et al., 1999; Jones et al., 2002; Austin et al., 2005; Coors, 2005; DeLisi and Bertisch, 2006], as is demonstrated in our study.

However, respondents also identified a number of ways in which genetic testing could harm people with TTM (see Figure 6). Reasons our respondents provided for not being motivated to pursue genetic testing if it were available included a common belief that determining a genetic cause would not change the fact that they have TTM and that a positive test result would not make trichotillomania any less damaging to them. As one respondent stated, “I already know I have trich. I don’t need another test to tell me I do.” (R6) Over half (55.2%) of our respondents expressed concerns that a genetic cause for TTM may result in an increased degree of concern about transmitting the genetic susceptibility to develop TTM to children. Respondents often expressed concern about
becoming paranoid regarding passing on the gene to children and openly made statements such as:

“I know that I have it. I know that it runs in my family now. I did not realize this when I had my daughters, I would feel awful if it was a genetic problem. I don’t think I could face knowing that I’d passed it on to my children.”(R7)

Several participants expressed worries about an increased sense of self-blame and permanency. As is often observed in other studies looking at the impact of genetic information on psychiatric conditions, reports of concerns regarding a genetic cause resulting in increased or decreased feelings of self-blame were conflicting. Some participants felt as though feelings of self-blame would be increased with a positive genetic cause for TTM, while others felt that a genetic cause would decrease self-blame and alleviate some of their guilt. Other common concerns included the possibility of using a positive result as an excuse to not attempt to reduce hairpulling behaviors while also expressing concern that a genetic cause would restrict people by preventing them from seeking treatment. Statements made against genetic testing for TTM included:

“Even if there is a visible genetic link, that doesn’t mean we can’t find ways to overcome it. I wouldn’t want it to suggest people latch onto the idea of trich being incurable. If I have a genetic disease that is considered incurable, I feel such knowledge enables many people to give up hope.”(R8)

Additionally, in our open-ended space, a few respondents expressed concerns about terminating affected pregnancies, blaming parents, and feelings of hopelessness with regards to ever “curing” their TTM. Our respondents comments point to concerns that genetic testing information might make TTM seem more genetically determined than it is, which could thus be more constraining for those affected by it. Conversely, there was a strong sense among respondents that research of TTM genetics might improve the lives of people affected by TTM by making it a better-understood and less shameful condition.
Respondent’s assessments of the possible risks, benefits, and implications of genetic testing reveal key aspects of what our TTM study population may be worried about when considering possible future genetic testing for TTM. The majority of our respondents suggested that genetic information might offer a particularly powerful means of increasing public understanding of TTM, allowing for people with TTM to feel more comfortable disclosing their condition to others and ultimately benefit from current and possible future treatment options. Our findings suggest that individuals with TTM are likely to welcome and benefit psychologically from information about the genetic basis of TTM. These results are consistent with several studies of attitudes towards genetic testing for bipolar disorder or schizophrenia have found positive attitudes and a high hypothetical demand for genetic testing (Hill & Sahhar et al., 2006). However, as a preliminary study we were unable to investigate the values and reasoning behind the responses and larger studies using more sophisticated methodologies would be beneficial.

**Variable interest and experiences in genetic counseling for TTM**

Currently, there is little research concerning the awareness and experiences of genetic counseling among individuals affected with TTM. As previously described, we looked at the interest in hypothetical genetic testing for TTM, which can be an important although non-integral part of genetic counseling. In addition, we wanted to determine whether individuals affected with TTM are aware of genetic counseling, have experienced genetic counseling and would be interested in genetic counseling for TTM. This study also aimed to understand affected individuals’ experiences of genetic counseling.

Almost all (96.1%) of the respondents had not been offered genetic counseling by medical professionals. Given that previous studies (Austin et al., 2005) suggest that genetic
counseling may be beneficial for individuals with psychiatric conditions, it is questionable as to why these individuals have never been referred to meet with a genetic counselor. Perhaps the most salient explanation for why hairpulling disorder has received so little attention from the scientific community may be connected to the fact that few mental health practitioners are knowledgeable about hairpulling disorder (Marcks et al., 2006). A few of the possible explanations for the lack of referrals to genetic counselors may include medical practitioners’ lack of information regarding the potential benefits of genetic counseling for TTM, a lack of available genetic counseling services specific for psychiatric conditions, physicians may be providing genetic counseling themselves negating their perceived need to refer to genetic counselors, or due to the lack of disclosure of the condition by people with TTM.

Out of our entire study population (N=299), only 7 individuals previously met with a genetic counselor. In addition, of those individuals who were referred for genetic counseling, several were actually referred for another condition, not TTM. As noted above, this limited sample may therefore suggest that physicians do not refer patients for genetic counseling for TTM, few people discuss their TTM with physicians, or that there is a lack of psychiatric genetic counseling services, among other reasons. Very few respondents had actually experienced genetic counseling and thus the information from the meetings was limited, however, we were able to gather that the overall experience was not felt to be very beneficial for those respondents. When we asked participants about their perceptions of their genetic counseling experiences, two respondents stated that “the genetic counselor did not know what trichotillomania was” and participants felt that they did not get any answers from the meeting. Such findings are consistent with the general lack of
understanding of trichotillomania among the medical health community and the lack of TTM genetic counseling referrals by physicians. Our group of study participants experiences, as well as their lack of experience with genetic counselors, support reports of previous studies that many medical and mental health practitioners possess inadequate knowledge about the disorder and it’s effective treatment, resulting in patients reporting they often receive uninformed and ineffective care (Woods et al., 2006). The lack of understanding by physicians of the psychosocial concerns of hair pullers (Casati, Toner, & Yu, 2000) may further reinforce feelings of shame and embarrassment among people with TTM and make seeking treatment less likely (Casati et al., 2000). This could be another reason that so few of our study participants (7 out of the 11 participants who were referred) have ever met with a genetic counselor.

We asked the remaining participants (96.1% of our population) if they would be interested in meeting with a genetic counselor specifically about trichotillomania. Only 9% of the study population responded that they would not be interested in meeting with a genetic counselor, 43% would be interested and 48% are not sure how meeting with a genetic counselor would be helpful. Our results indicate that participants are willing to seek help from providers and are interested in learning about the potential genetic factors in trichotillomania, yet there is a lack of understanding about the genetic counseling profession and it’s relation to psychiatric illnesses, this is apparent based on the significant proportion of our study population (48%) who did not know how meeting with a genetic counselor would be helpful for their condition. This lack of understanding about the role of a genetic counselor demonstrates the need for the genetic counseling profession to provide additional education to this population. An assessment of what people affected by TTM
hope to gain from a meeting with a genetic counselor and their expectations regarding genetic counseling for TTM is thus an important area to address in future research studies.

Research participants were recruited through web sites relating to TTM and this sample was therefore self-selected from an information-seeking population. As such, it is likely that the awareness of genetic counseling would be even lower among the general population of individuals affected or impacted by TTM. This finding might suggest that efforts to introduce a greater awareness of psychiatric genetic counseling services appear to have been unsuccessful in this population.

Almost half of our respondents (43%) thought that genetic counseling would be appropriate for them and many individuals indicated that they would like to or might like to see a genetic counselor. For example, one of our participants stated, “I would be willing to try anything that would explain why I have this condition.” (R9). There are potentially many advantages of genetic counseling for people affected with TTM. Psychiatric genetic counselors are trained to help alleviate some of the psychosocial burdens associated with mental illness, including the feelings of stigma, shame, guilt and self-blame, as well as to increase the understanding of the etiology. Genetic counseling for TTM may help to provide a balanced assessment of the risk of recurrence in family members as well as to clarify misconceptions about the causes of TTM. They may also provide referrals for more in-depth counseling and support, information about self-care and/or medical care.

Limitations of the study

The study was an online anonymous survey, in which case individuals actively sought out participation in a research study. This could have therefore skewed our cohort,
as our group appears to be actively interested in disclosing information about their TTM experience. Our results also need to be considered within the limitation that this study included a sample of participants who were predominantly female, Caucasian, and support-seeking. Therefore, results may not generalize to the general population of TTM patients. The samples were relatively small and larger samples may be needed. Family history was obtained from the subjects and not through direct interviews with family members. Additionally, this study may reflect a more severe group than found in the community and given the study's title, which was posted on the recruitment notice, the participants had some idea of what questions they might be asked. This could have drawn additional participants to the study or further discouraged others from participating in the study – as some individuals who believe in genetic causation for TTM might be more inclined to participate in a study addressing genetic testing and causation issues; while others who do not attribute their TTM to genetic causes may not have been interested in participation. Another limitation of our study involved the lack of response by individuals who were referred to a genetic counselor. None of our 7 participants who indicated that they had a meeting with a genetic counselor answered our questions about whether the history of their TTM came up during the session and if their TTM was discussed during the session; however 2 respondents reported in a previous question that the genetic counselor they met with did not know what TTM was. Thus, the information we were able to obtain regarding their experiences with genetic counselors was minimal.
CONCLUSION

The aims of this study were to explore beliefs about the causation and heritability of TTM among people with TTM, and to explore opinions regarding hypothetical genetic testing for TTM while examining experiences with and opinions of genetic counseling for TTM. Many of the participants in this study attributed central importance to the role of genetic inheritance in the cause of their TTM, most, however, stressed the contribution of environmental factors to the development of the disorder. Many of our respondents were unsure of what they believe the heritability of TTM is, while a large portion of our cohort overestimated what is currently known about the heritability of TTM and often used our open-ended spaces to express concerns about the possibility of passing this condition on to their children.

Despite expressing concerns about genetic testing, many of our respondents believe that genetic information may have potential benefits. Approximately half of the participants in this study indicated that they are interested in and willing to meet with a genetic counselor and would be interested in genetic testing for TTM. Of importance, very few respondents had actually experienced genetic counseling and the few who did have a meeting with a genetic counselor indicated that this meeting was not beneficial for them. In addition, a significant portion of our participants expressed uncertainty regarding how a meeting with a genetic counselor may benefit them. This study provides insight into potential avenues for future research. An assessment of what people affected by TTM hope
to gain from meeting with a genetic counselor and their expectations regarding genetic
counseling for TTM is an important area to study further. Understanding what topics
people with TTM hope to address during a genetic counseling session may help to provide
further guidance for psychiatric genetic counselors and allow them to be an important
source of support and information for people with TTM.

Irrespective of the availability of genetic testing for TTM, psychiatric genetic
counseling could help individuals with TTM understand etiology and inheritance,
psychosocially, exploring feelings of guilt and/or shame and potentially make more
appropriate referrals for people with TTM. However, future studies exploring genetic
counselors level of comfort with addressing TTM during a session may provide additional
insight regarding what genetic counselors currently understand about TTM and how they
may be helpful for people with TTM, which may thereby provide further educational efforts
for genetic counseling for TTM.
REFERENCES


Odlaug, B. L., Kim, S. W., & Grant, J. E. (2010). Quality of life and clinical severity in pathological skin picking and trichotillomania. *J Anxiety Disorder, 24*(8), 823-829. doi: 10.1016/j.janxdis.2010.06.004.


APPENDIX A: Recruitment Notice

Do you have a history of Trichotillomania?

I am a graduate student in the Genetic Counseling Program at Brandeis University and I am seeking volunteers to participate in a research study for completion of my master’s thesis. The purpose of this study is to understand the experiences of people with trichotillomania (TTM) and their perspectives on healthcare services. My interest in this topic stems from the fact that I have TTM and I am eager to learn about the opinions of others who have this condition.

Participation in this study is open to any individual who:

• Is 18 years of age or older
• Is English speaking
• Has had symptoms of Trichotillomania at some point in his/her life, this includes:
  Individuals who currently have Trichotillomania, or
  Individuals who struggled with TTM in the past

Participation in this study is voluntary and will involve completing an anonymous online survey. If you decide to participate the survey should take only 15-20 minutes to complete. If you would like to participate, please follow the link below to access the online survey:

https://brandeis.qualtrics.com/jfe/form/SV_3WwA8mT1CShsz0J

Upon completion of the survey, you will be eligible to enter a raffle for one of three $50 Amazon gift cards. Your raffle entry will not be linked to your survey responses.

If you have any questions or comments, please feel free to contact me at lameesn@brandeis.edu. Thank you in advance for your participation.

Thank you,
Lamees Nassereddine
Brandeis University Genetic Counseling Student, Class of 2015
APPENDIX B: STUDY SURVEY

Thank you for your interest in participating in this study. The purpose of this study is to understand the experiences of people with trichotillomania and their perspectives on healthcare services. The estimated time commitment is between 15-20 minutes. The Brandeis University Committee for Protection of Human Subjects (IRB) has approved this research study. Your participation is completely anonymous and voluntary. By completing the survey, you are consenting to participate in this research study. You may discontinue participation at any time for any reason.

Should you feel the need to speak with someone about thoughts or feelings that may arise as a result of this survey, please feel free to contact Licensed Genetic Counselor Beth Rosen Sheidley, MS, CGC at beth.sheidley@childrens.harvard.edu. Upon completion of the survey, you will have the opportunity to be entered into a drawing for one of three $50 Amazon.com gift certificates. Please feel free to contact me with any questions or if you need assistance accessing the survey. I greatly appreciate your participation.

Lamees Nassereddine
Brandeis University Genetic Counseling Program, Class of 2015
Lameesn@brandeis.edu

Section 1: Personal History of Trichotillomania

Trichotillomania (TTM), also known as hair pulling disorder, is a condition characterized by repetitive pulling out of one’s hair which can often lead to significant distress or impairment in one or more areas of an affected person’s life.

1. How did you first come to recognize that you had TTM? Please check one
   a. I recognized it on my own.
   b. Somebody I know pointed it out to me.
   c. A healthcare provider brought it up with me.
   d. A mental healthcare provider (therapist) brought it up with me.
   e. Other (please specify) ____________________________________________

2. Approximately how old were you when you first realized that you had a problem with hair pulling?
— years old

3. Do you have an official diagnosis of TTM from a healthcare or mental health provider?

Yes or No

4. If you answered YES to question 3: How long have you had the diagnosis of TTM?

— years and _____ months

5. During the past three months, for each of the possible hair pulling sites listed below, please indicate how frequently you engage in hairpulling.

<table>
<thead>
<tr>
<th>Site</th>
<th>Once a day</th>
<th>Several times a day</th>
<th>Once a week</th>
<th>Several times a week</th>
<th>Once a month</th>
<th>Several times a month</th>
<th>Seldom</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scalp</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Eyebrows</td>
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<tr>
<td>Eyelashes</td>
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<td></td>
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<tr>
<td>Arms</td>
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<tr>
<td>Legs</td>
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<tr>
<td>Pubic hair</td>
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<tr>
<td>Facial hair</td>
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<tr>
<td>Other (please specify)</td>
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</tbody>
</table>

6. How would you rate the degree of your hairpulling during the past three months?
   a. None
   b. Mild
   c. Moderate
   d. Severe

7. How would you rate the degree of your hairpulling when it is at its worst?
   a. None
   b. Mild
   c. Moderate
d. Severe
8. The table below lists a number of conditions that people with TTM sometimes have in addition to TTM. For each of these conditions please place a check in each of the columns that apply to you.

<table>
<thead>
<tr>
<th>Additional Conditions</th>
<th>I do not have this condition</th>
<th>I was diagnosed with this condition BEFORE having symptoms of TTM</th>
<th>I was diagnosed with this condition AFTER having symptoms of TTM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obsessive-Compulsive Disorder</td>
<td></td>
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<tr>
<td>Major Depressive Disorder</td>
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<td></td>
<td></td>
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<tr>
<td>Bipolar Disorder</td>
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<tr>
<td>Generalized Anxiety Disorder</td>
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<tr>
<td>Post-traumatic Stress Disorder</td>
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<tr>
<td>Eating Disorder</td>
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<tr>
<td>Substance use disorder</td>
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<tr>
<td>Panic Disorder</td>
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<td></td>
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<tr>
<td>Social Phobia</td>
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<tr>
<td>Skin picking</td>
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<tr>
<td>Any medical condition (i.e diabetes, cancers, thyroid disorders, etc.)</td>
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<tr>
<td>Please specify:</td>
<td></td>
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<tr>
<td>Other (please specify)</td>
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<td></td>
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</tbody>
</table>

**Section 2. Disclosure**

9. Have you openly discussed your TTM symptoms/diagnosis with anyone?
   a. Yes
   b. No
10. If you answered YES to question 8. Who did you discuss your TTM with? Please check all that apply.

a. Mother  
b. Father  
c. Sister(s)  
d. Brother(s)  
e. My minor child/children  
g. My adult child/children  
h. Maternal relatives  
i. Paternal relatives  
j. Spouse/ partner  
k. A TTM support organization member/group  
l. A religious figure in my community  
m. A mental health therapist  
n. A physician  
o. Other (please specify) ________________________________

11. What made you decide to disclose this information? ________________________________

12. Who else in your family has ever had problems with hairpulling or trichotillomania?  
Please check all that apply.

a. Mother  
b. Father  
c. Sister  
d. Brother  
e. Child/children  
f. Maternal grandparent  
g. Paternal grandparent  
h. Maternal first cousin  
i. Paternal first cousin  
j. Maternal aunt  
k. Maternal uncle  
l. Paternal aunt  
m. Paternal uncle  
n. Spouse/ partner  
o. I am not aware of anyone else in my family who has TTM  
p. Other (please specify) ________________________________
Section 3. Affect on Daily Living

13. To what degree has having Trichotillomania affected your daily life? Please check one:

<table>
<thead>
<tr>
<th>Area</th>
<th>No affect</th>
<th>Slightly affected</th>
<th>Moderately affected</th>
<th>Greatly affected</th>
<th>Not sure</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extra time spent on grooming / getting dressed</td>
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<tr>
<td>Extra expenses spent on grooming, hats, wigs, supplements, therapy, etc.</td>
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<tr>
<td>Physical Health (i.e. avoiding doctors, avoiding healthcare)</td>
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<tr>
<td>Physical appearance (i.e. bald spots, scars, skin irritation, skin infections, etc.)</td>
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<tr>
<td>Romantic Relationships</td>
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<tr>
<td>Sexual Relationships</td>
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<tr>
<td>Work attendance</td>
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<tr>
<td>Work effectiveness</td>
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<tr>
<td>School attendance</td>
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<tr>
<td>School effectiveness</td>
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<tr>
<td>Career Choice</td>
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<tr>
<td>Activities/Hobbies</td>
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</tbody>
</table>
14. How has having TTM affected how you feel about yourself?
____________________________________________________________________
____________________________________________________________________

15. In the list below are a number of resources that people with TTM can turn to for help to cope with their condition. Please indicate whether following resources have been helpful to you as sources of support for your TTM.

<table>
<thead>
<tr>
<th></th>
<th>Very helpful</th>
<th>Slightly helpful</th>
<th>Not helpful</th>
<th>I did not seek help from this resource</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>My spouse/partner</td>
<td></td>
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<td></td>
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<tr>
<td>My mother</td>
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<tr>
<td>My father</td>
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</tr>
<tr>
<td>Sibling(s)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friend(s)</td>
<td></td>
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<tr>
<td>Child/children</td>
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<tr>
<td>My personal spiritual beliefs</td>
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<tr>
<td>My religious community</td>
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<tr>
<td>TTM support organization(s)</td>
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</tbody>
</table>
### Online TTM support community or social media

### Behavior therapy (Habit reversal therapy, stimulus control, etc.)

### Mental health counseling

### Hobbies

### Physical activities (exercise, meditation, yoga, etc.)

### Herbal

### Psychiatric medications

### Medications for physical symptom relief (e.g. topical creams, astringents, etc.)

### Adjunctive therapies (acupuncture, massage, acupressure, etc.)

### Other (please specify)

---

### Section 4. Understanding of Trichotillomania

16. In your opinion, what causes Trichotillomania?

____________________________________________________________________

____________________________________________________________________

40
17. Please circle a number between 1 and 10 according to how much you think YOUR TTM was caused by genetic factors. For example, circling 1 would indicate that you believe that genetic factors did not contribute at all to your TTM, circling 5 would indicate that you believe that genetic factors contributed a moderate amount, and circling 10 would indicate that you believe your TTM was caused *entirely* by genetic factors.

<table>
<thead>
<tr>
<th>Genetics did not contribute at all</th>
<th>Genetics contributed moderately</th>
<th>Genetics alone caused my TTM</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

18. Now, please circle a number between 1 and 9 according to how confident or sure you are of the answer you provided above. For example, circling 1 would indicate that you are not at all sure that the answer you provided is correct, and circling 10 would indicate that you are absolutely certain that the answer provided above is correct.

<table>
<thead>
<tr>
<th>I am not sure at all</th>
<th>I feel somewhat uncertain</th>
<th>I am completely confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

19. Please circle a number between 1 and 10 according to how much you think YOUR TTM was caused by your experiences (you can also think about this as things that happened to you, or environmental factors). For example, circling 1 would indicate that you believe that your experiences did not contribute at all to your TTM, circling 5 would indicate that you believe that your experiences contributed a moderate amount, and circling 10 would indicate that you believe your TTM was caused *entirely* by your experiences.

<table>
<thead>
<tr>
<th>My experiences did not contribute at all</th>
<th>My experiences contributed moderately</th>
<th>My experiences alone caused my TTM</th>
</tr>
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<tbody>
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<td>1</td>
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<td>10</td>
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</table>

20. Now, please circle a number between 1 and 10 according to how confident or sure you are of the answer you provided above. For example, circling 1 would indicate that you are not at all sure that the answer you provided is correct, and circling 10 would indicate that you are absolutely certain that the answer provided above is correct.

<table>
<thead>
<tr>
<th>I am not sure at all</th>
<th>I feel somewhat uncertain</th>
<th>I am completely confident</th>
</tr>
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<tr>
<td>1</td>
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</table>
21. In your opinion, what do you think is the likelihood that trichotillomania can be passed down from parents to their children?
   a. Less than 10%
   b. 10-25%
   c. 26-50%
   d. I do not know/not sure

Section 5. Genetic Counseling and Testing

22. Have you ever been referred to see a genetic counselor?
   a. Yes by my healthcare provider.
   b. Yes, I referred myself.
   c. No, I have never been referred to see a genetic counselor.

23. If you answered YES to question 22: Did you end up having a meeting with a genetic counselor?
   a. Yes
   b. No

24. If you answered YES to question 23: People are often referred to meet with a genetic counselor for various reasons. The options listed below include some of the most common indications for genetic counseling. Please check the option that best describes why you were referred to meet with a genetic counselor.
   a. A personal history of a medical condition.
   b. A personal history of a genetic condition.
   c. A family history of a medical condition.
   d. A family history of a genetic condition.
   e. A personal history of a psychiatric condition (other than TTM).
   f. A family history of a psychiatric condition (other than TTM).
   g. My personal history of TTM.
   h. My family history of TTM.
   i. To learn about genetic screening for diseases that are more common in my ethnic group.
   j. Advanced maternal age (pregnant and over the age of 35).
   k. To discuss a pregnancy exposure to medications, x-rays, chemicals, prescribed or illicit drugs during my pregnancy.
   l. Trouble getting pregnant (infertility).
   m. To discuss abnormal results from tests during pregnancy (such as a blood test, ultrasound, chorionic villus sampling (CVS), or amniocentesis).
   n. A genetic condition or birth defect occurred in a previous pregnancy.
   o. To find out if there is a genetic cause for developmental delays or health problems in my child.
25. If you answered YES to question 23: How did you feel about the meeting?

26. If you answered YES to question 24 (For all options EXCEPT g and h): Did the history of your TTM come up during the session?
   a. Yes
   b. No

27. If you answered YES to question 26: Was your history of TTM discussed during this session?
   a. Yes
   b. No

28. If you answered question 27. Please use this space to elaborate.

29. If you answered NO to question 22 and 27; AND if you answered question 24 (for all options EXCEPT options g and h): Would you be interested in meeting with a genetic counselor specifically about trichotillomania?
   a. Yes, I would be.
   b. No I would not be.
   c. I am not sure how meeting with a genetic counselor would be helpful.

30. Currently no genetic test can establish a diagnosis of TTM or predict who will develop symptoms of TTM. If a genetic test for TTM were possible in the future, please indicate how useful you think such a test would be (please choose one):
   a. Very useful.
   b. Useful.
   c. Somewhat useful.
   d. Not useful at all.
   e. I don’t know.
31. What, if any, do you think could be some of the benefits of a genetic test for trichotillomania? Please check all that apply.
   a. Personal knowledge
   b. Reducing anxiety
   c. Improving treatment
   d. Raising public awareness/understanding
   e. Increased sense of control
   f. Identifying a cause - reducing uncertainty and self blame
   g. Reduces stigma associated with TTM
   h. Identifying individuals at risk for developing TTM
   i. No benefits
   j. Other (please specify) ________________________________

32. What, if any, do you think could be potential harms of a genetic test for TTM? Please check all that apply.
   a. Genetic testing may be used to stigmatize and/or discriminate against people with trichotillomania
   b. Individuals may use a positive result as an excuse to limit themselves/ not get better
   c. Concern about transmitting the genetic susceptibility to children
   d. Increased self-blame
   e. Genetic mutation might jeopardize access to insurance/career opportunities
   f. No harms
   g. Other (please specify) ________________________________

33. If there were a genetic test that could detect a change in your DNA that may help to explain the cause of your TTM diagnosis, would you decide to have the test?
   a. Yes
   b. NO
   c. I’m not sure/undecided

34. Please use this space to explain why you might or might not pursue such testing.

35. If there were a genetic test that could predict prenatally if a person will have TTM at some point in their life, would you be in favor of/not be in favor of such prenatal testing for TTM?
   a. Yes I would be in favor
   b. No I would not be in favor
   c. I’m not sure/undecided
Section 6. Demographic Information

The following questions will tell us a little bit about our participants. Feel free to skip any questions that you prefer not to answer or feel are not applicable.

36. What is your gender?
   a. Male
   b. Female
   c. Other (please specify) ________________________________

37. How old were you on your last birthday?
   ___ ___ years old

38. How would you describe your current relationship status? Please check all that apply.
   a. Now married or in a registered domestic partnership or civil union
   b. Widowed
   c. Divorced
   d. Separated
   e. Other (please specify) ________________________________

39. How would you describe your racial identity? (Check all that apply)
   a. Black or African American
   b. White
   c. Asian
   d. Hispanic or Latino/a
   e. American Indian or Alaska native
   f. Hawaiian native or Pacific Islander
   g. Other (please specify) ________________________________

40. What is your highest level of education?
   a. Some elementary/middle/high school
   b. High school graduate or GED
   c. Some college
   d. College/University (i.e. Associates or Bachelor’s degree)
   e. Graduate school (i.e. Master’s, Ph.D, MD, etc.)
Thank you for taking the time to complete this survey.

If you are interested in entering the raffle to win one of three $50 Amazon.com gift cards, please send an email to Lameesn@brandeis.edu specifying the email address to which you would like to have the electronic gift card sent. Your email address information for the gift card raffle will not be linked to your completed survey.

If you know anyone who may be interested in participating in this study, please direct them to XXXXXXX, where they can find the information and the link to the survey.

Lamees Nassereddine
Brandeis University Genetic Counseling Program, Class of 2015