

TRICHOTILLOMANIA: A JOURNEY OF PERSONAL EMPOWERMENT<  
A QUALITATIVE STUDY OF WOMEN WHO  
ENGAGE IN CHRONIC HAIR PULLING

by

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## ABSTRACT

Trichotillomania is an understudied chronic condition with unknown etiology and epidemiology that affects a significant number of girls and women. This study addressed the overarching question, *What are the experiences and perceptions of women who engage in hair pulling?* “Trichotillomania: A Journey of Personal Empowerment” was a qualitative study of 22 women that addressed their lived experience of hair pulling and their assigned meaning of their hair pulling. Data were collected through in-depth interviews with each participant. A grounded theory approach to analysis was applied to the data. The narratives of the participants yielded an understanding of when and why hair pulling took hold, how others’ conceptualizations of trichotillomania created barriers to accountability and acceptance, and how women empowered themselves to conceptualize their hair pulling and to determine the role that hair pulling plays in their lives. The women’s conceptualizations of trichotillomania, based on their experiences and perceptions of their hair pulling, provided clear evidence for why it is so important to include hair pullers in the global conversation on trichotillomania.

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## CHAPTER 1

### REVIEW OF LITERATURE

#### Trichotillomania

“And when I heard this thing, I rent my garment and my mantle, and plucked off the hair of my head and of my beard, and sat down astonished.”

[Ezra, 9:3]

The phenomenon of pulling one’s own hair has a long and storied history. Representations of hair pulling exist in the Bible, Homer’s *Iliad*, and Shakespeare’s play *Troilus and Cressida* (Christenson & Mansueto, 1999). The Father of Medicine, Hippocrates (460-375 BC), contributed the earliest account of hair pulling to the medical literature in *Epidemics I* when he wrote about a woman who pulled her hair out during an intense state of grief (Sherrow, 2006). Hippocrates encouraged physicians to inquire as to a patient’s hair pulling behaviors during an examination to determine the presence of disease (Chadwick & Mann, 1983; Chamberlain, Odlaug, Boulougouris, Fineberg, & Grant, 2009).

Early medical texts cite an account of trichophagia, the eating of hair, prior to descriptions of trichotillomania. Trichophagia was cited in an 18<sup>th</sup>-century medical volume detailing a trichobezoar, or hair ball, in a 16-year-old male patient of the French physician Baudamant decades before trichotillomania was distinguished as a discrete medical disorder (Chamberlain et al., 2009; Christenson & Mansueto, 1999). The French

dermatologist Francois Henri Hallopeau first identified trichotillomania as a distinct medical syndrome in 1889 (Christenson & Mansueto, 1999; Khouzam, Battista, & Byers, 2002). Hallopeau coined the term trichotillomania from the Greek words *thrix* (hair), *tillein* (to pull), and *mania* (madness) giving it the meaning of “hair pulling madness” (Sherrow, 2006). He described a young male patient who pulled out all of his body hair. Hallopeau imputed trichotillomania to pruritis in an attempt to find relief from excessive itching. He concluded that there was not a cure for chronic hair pulling after a failed treatment attempt that used mentholated camphor and required that the person be wrapped in rubber (Chamberlain et al., 2009; Sherrow, 2006). While past professionals questioned individuals about their hair pulling behaviors to establish a diagnosis and to provide treatment, there is a lack of information on whether the affected individuals were asked about their reasons for pulling their hair out. While our understanding of chronic hair pulling has evolved over the past 2000 years, it is likely to continue to evolve as we invite those who engage in the behavior into the conversation of defining the phenomenon.

Trichotillomania (TTM; hair-pulling disorder) is distinguished by the repeated pulling out of one’s own hair and is marked by hair loss and repetitive efforts to reduce or cease hair pulling altogether, according to the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5; American Psychiatric Association [APA], 2013). Trichotillomania was not officially classified as a psychiatric disorder until the *Diagnostic and Statistical Manual of Mental Disorders*, Third Edition, Revised (DSM-III-R; American Psychiatric Association [APA], 1987) despite its longtime existence in the medical literature. The DSM-IV-TR expanded criteria to highlight tension felt by the

puller when resisting the urge to pull and classified TTM as an impulse-control disorder, not elsewhere classified, alongside intermittent explosive disorder, kleptomania, pathological gambling, and pyromania (APA, 2000).

Its classification has long been debated due to the controversy over the combination of its presenting compulsive and impulsive features (Cohen, Simeon, Hollander, & Stein, 1997). Some researchers suggested that TTM should be considered a distinct disorder along the obsessive-compulsive spectrum, because of its shared features (i.e., phenomenology, comorbidity, family history, clinical course, treatment response, and possible serotonergic mediation) with obsessive-compulsive disorder (Stanley & Cohen, 1999), or an addictive disorder (Grant, Odlaug, & Potenza, 2007). In 2013, TTM was reclassified in the DSM-5 under Obsessive-Compulsive and Related Disorders, not because it is caused by obsessions or preoccupations, but rather because of the various emotional states (e.g., anxiety or boredom) that often precede or accompany this body-focused repetitive behavior (APA, 2013). Prior to pulling out her or his hair, a person may feel a mounting sense of tension or an obsession, but this is not indicative of all hair pullers. While it is often the case that the hair puller may experience gratification, pleasure, or relief after pulling the hair out, this is no longer a symptom that must be present to meet diagnostic criteria of the disorder (APA, 2013). A requirement of repeated attempts to stop hair pulling has been added to the current diagnostic criteria, which aligns it more closely with the repetitive behaviors, rituals, and impulses of OCD (Van Ameringen, Patterson, & Simpson, 2014).

Despite its recent reclassification, TTM remains an understudied chronic condition with unknown etiology and epidemiology, in addition to being an

underdiagnosed and ineffectively treated disorder (Casati, Toner, & Yu, 2000; Duke, Keeley, Geffken, & Storch, 2010). Trichotillomania is often presented as a medical problem and conceptualized as such, which leads to treatments adhering to the medical model. This may provide some clues as to why TTM is underdiagnosed/misdiagnosed and as to why treatments have been mostly ineffective long term.

### Description of Trichotillomania

#### Diagnostic Criteria

DSM-5 diagnostic criteria for TTM (Hair-Pulling Disorder) include: a) “Recurrent pulling out of one’s hair, resulting in hair loss”; b) “Repeated attempts to decrease or stop hair pulling”; c) “The hair pulling causes clinically significant distress or impairment in social, occupational, or other important areas of functioning”; d) “The hair pulling or hair loss is not attributable to another medical condition (e.g., a dermatological condition)”; and e) “The hair pulling is not better explained by the symptoms of another mental disorder (e.g., attempts to improve a perceived defect or flaw in appearance in body dysmorphic disorder; APA, 2013, p. 251).

The current diagnostic criteria for TTM have changed very little from the previous criteria found in the DSM-IV-TR. The title now includes “hair-pulling disorder” to clarify meaning (APA, 2013, p. 251). It is no longer a requirement that hair loss be noticeable to others. The requirement of repeated efforts to stop hair pulling replaced requirements of a preceding sense of tension followed by gratification, pleasure, or relief once the hair is pulled. DSM-5 criteria distinguish hair pulling and/or hair loss due to medical conditions and mental health disorders into two separate criteria.

#### Epidemiology

Gleaning a full understanding of the disorder and its prevalence is difficult due to the secretiveness of those with the disorder, lack of disclosure in clinical and counseling settings, lack of awareness of the disorder, and lack of intervention (APA, 2000;

Christenson & Mansueto, 1999). Hair pulling as a result of TTM is typically secretive; those who engage in the behavior usually do not do so in front of others, with the exception of immediate family members (APA, 2013). People with TTM often avoid social situations, deny their hair pulling behavior, and cover the resulting alopecia (APA, 2000). Casati et al. (2000) identified embarrassment/shame, isolation, fear, guilt, anger/frustration, humiliation/pain, body image problems, lack of control, problems with self-disclosure, and lack of information from the medical community as psychosocial issues for women with TTM that contribute to the secretive nature of hair pulling. Additionally, some individuals may pull hair from other people, animals, dolls, or random materials such as carpets, which further confound clear estimates of the disorder.

### Prevalence

One to two percent of the general population of adults and adolescents are estimated to have TTM in the course of 1 year (APA, 2013). Trichotillomania, once thought to be a rare condition, with prevalence rates as low as 0.5%, has been recognized in recent research literature as more common (Christenson & Mansueto, 1999; Duke, Keeley, Geffken, & Storch, 2010; Schachter, 1961). While the lack of rigorous epidemiological studies in the published literature makes it difficult to estimate the true prevalence of TTM in adult or child populations (Duke et al., 2010; Walther, Ricketts, Conelea, & Woods, 2010), reported prevalence estimates of TTM in the US population range between 0.6% and 3.4% depending on the criteria used to define TTM (Christenson, Pyle, & Mitchell, 1991; Stanley, Borden, Bell, & Wagner, 1994; Walther et al., 2010). Prior to 2013, descriptive studies in the extant literature suggested the DSM-IV-TR definition of TTM complicated prevalence estimates, arguing that these estimates

unduly excluded individuals who showed clinically meaningful hair pulling, yet did not demonstrate the range of symptomology necessary for a formal diagnosis. This led to the proliferation of divergent definitions of hair pulling with some using more lenient criteria to be more inclusive (Christenson & Mansueto, 1999; Duke et al., 2010; Khouzam et al., 2002). With the adoption of the DSM-5 in 2013, there are no prevalence studies available in the literature using this most current diagnostic criteria for TTM.

Christenson, Pyle, and Mitchell (1991) surveyed over 2500 US college students about hair pulling and found that 0.6% met DSM-III-R diagnostic criteria for TTM (APA, 1987). The number of individuals (3.4% female and 1.5% male) engaged in hair pulling resulting in noticeable hair loss rose when tension-gratification information was not needed for diagnosis, suggesting that hair pulling occurs on a continuum, ranging from unnoticeable and not distressful, to disfiguring and significantly stressful (Christenson, Pyle, & Mitchell, 1991; Stanley et al., 1994; Stanley, Borden, Mouton, & Breckenridge, 1995). Other research consistently demonstrated that DSM-IV-TR criteria for TTM were not met by a considerable number of individuals who engage in hair pulling that resulted in significant suffering and distress (Christenson, Mackenzie, & Mitchell, 1991; Flessner et al., 2006; Graber & Arndt, 1993). Further, DSM-IV-TR criterion A, “noticeable hair loss” (APA, 2000, p. 677), was both subjective and variable as it related to TTM because pulling 20 hairs from the scalp daily will go undetected for some time compared with pulling 20 eyelash or brow hairs on a daily basis, even more so when the puller has thick hair on his or her scalp (Duke et al., 2010). For the purposes of the current study, all participants were required to meet DSM-IV-TR criteria to be

included because recruitment and participation occurred prior to the introduction of the DSM-5.

Prevalence rates for hair pulling in college student populations range from 1.0% to 13.3% (Duke et al., 2010; Graber & Arndt, 1993; Shaw, Morris, & Ninan, 1993; Stanley et al., 1995; Stanley et al., 1994; Woods & Miltenberger, 1996). Conservative estimates suggest that approximately 2.5 million individuals in the United States (US) are affected by TTM at some point during their lifetimes (Diefenbach, Mouton-Odum, & Stanley, 2002). Trichotillomania prevalence rates may be higher than estimated due to limitations in study methods (i.e., multiple definitions of hair pulling, small sample sizes, self-report measures, limited standardized measures, and the use of college student populations), the secretive nature of this disorder that forces hair pullers to hide evidence of their behavior from family and friends and to avoid seeking treatment from health care professionals, and the general lack of awareness about TTM in the health care community (Duke et al., 2010; Swedo, 1993).

### Gender and Age

Trichotillomania is equally represented in child populations by males and females, yet there are a greater number of females who have TTM compared to males in the adult population at an approximate ratio of 10:1 (APA, 2013). Community samples and lifetime prevalence rates were found to be about equal for both genders in studies by Christenson, Pyle, and Mitchell (1991) and Graver and Arndt (1993; Duke et al., 2010). In contrast, clinical samples of adult populations support the traditional view that TTM affects females far more often than males. Research has supported this view, reporting anywhere from a 70% to 97% female prevalence rate (Christenson & Mansueto, 1999;

Wetterneck, Woods, Nordberg, & Bogotá, 2006). Christenson and Mansueto (1999) suggested that the disproportion of males to females in the extant literature may be artificial and may reflect a tendency of men who pull their hair out to either avoid seeking professional help or to pursue help consistent with hair loss due to male pattern baldness. This may reflect a true gender difference, or it may be indicative of differential treatment seeking due to cultural or gender-based attitudes specific to appearance (e.g., acceptance of normative hair loss among males; APA, 2013, 2000; Panel, 2003). Males might be more inclined to target the beard or mustache as their selected hair pulling sites. Shaving can serve as a preventative measure to preclude further development of the problem (Christenson & Mansueto, 1999). Also, males are advantaged in that they can shave their heads with little social stigma attached (Penzel, 2003). As TTM among males appears to be underreported in the current literature, most of the information available to date specific to TTM was gleaned largely from studies of women with the disorder.

The disparity in gender representation within the TTM literature and community at large may be directly related to the cultural importance of women's hair. In Western culture, the presence of long hair for women is viewed as feminine. Females who are bald or who have patches of no hair are thought to have something wrong with them, are viewed as less than, and are encouraged to cover their head. This cultural view of women and hair may be a reason that more females seek treatment for hair pulling, thereby contributing to the overall difference between genders. Most treatment models follow the medical model, a model that is entrenched in male-dominated culture, thereby shaping public understanding of hair pulling as a mostly female issue because more females seek treatment compared to their male counterparts. Another potential cultural contributor to



the gender disparity could be the disproportionate number of women who are victims of violence, resulting in the possibility that some women use hair pulling as a method of coping with their trauma experience in greater numbers than men.

Christenson et al. (1994) reported similarities among adult males and females with respect to chronological age, age at onset, hair pulling sites, hair pulling characteristics, and psychiatric comorbidity. Studies indicate that the average age of onset for TTM is 13.1 years (APA, 2000; Cohen et al., 1995; Schlosser et al., 1994; Swedo & Leonard, 1992, as cited in Christenson & Mansueto, 1999), but it can even occur in infancy (APA, 2000; Christenson, Mackenzie, & Mitchell, 1991). Hair pulling in very young children (less than 8 years old), known as “baby trich,” is thought to resolve on its own and is considered atypical (Chamberlain et al., 2009). Onset that occurs at a later age is associated with increasingly severe symptoms, treatment resistance, and additional psychopathology (Duke et al., 2010).

### Demographics

The majority of research study populations in Western culture have been Caucasian. However, the occurrence of TTM has been demonstrated among other ethnicities in the US, including African American, Hispanic/Latino, Asian American, Native American, and multiracial populations (Flessner, Woods, Franklin, Keuthen, & Piacentini, 2009; Neal-Barnett et al., 2010), as well as in Asian and Hispanic/Latino populations outside of the US (Ferrão, Almeida, Bedin, Rosa, & Busnello, 2006; Hussain, 1992). Neal-Barnett et al. (2010) reported that TTM was underdiagnosed in minority populations and that minority populations are less likely to report hair pulling from eyelashes and eyebrows and less likely to report increased tension before pulling. Further,

minority populations experienced increased levels of interference at home specific to managing their hair pulling compared with Caucasians (Neal-Barnett et al., 2010).

Additionally, socio-economic levels are not a limiting factor of trichotillomania, as it is present in individuals with varying economic backgrounds (Christenson, Mackenzie, & Mitchell, 1991; Cohen et al., 1995).

### Phenomenology

Hair is pulled from any part of the body (e.g., head, limbs, pubic region, face), with the scalp being the most commonly pulled-from site, followed by eyebrows, eyelashes, beard, and pubic areas (Woods, Flessner, Franklin, Wetterneck et al., 2006). Male hair pullers most often pull from the beard or mustache (Penzel, 2003). Hair pulling might occur in only one area, but often multiple locations are involved (Christenson, Mackenzie, & Mitchell, 1991). The number of pulling sites typically increases with age as an individual moves into adulthood (Flessner, Woods, Franklin, Keuthen, & Piacentini, 2008). Meunier, Tolin, and Franklin (2009) reported that, initially, children associate pain and pleasure with hair pulling about equally, but over time, pleasure overtakes pain. Hair is typically pulled one strand at a time, but it can be pulled in clumps (Christenson, Pyle, & Mitchell, 1991). Trichotillomania varies in intensity (e.g., pulling a few hairs vs. pulling out all of the hair on the right side of the scalp in one sitting) and duration of episode (e.g., lasting from minutes to hours, months to years).

Results of hair pulling vary for each individual TTM sufferer. Sometimes, the consequences of hair pulling go unnoticed because the individual may pull hair from all over the scalp, resulting in general thinning of the hair without bald spots. This type of hair pulling is known as grazing (APA, 2013; Penzel, 2003). Hair pulling may go

unnoticed because hair is pulled from small patches on the scalp that can easily be covered with other hair or hair accessories. Additionally, clothing, accessories, or makeup may be used to conceal hair loss (APA, 2013). It is with the more severe cases of hair pulling that hair loss is most noticeable, because there may be large bald areas on the scalp separated by areas of regrowth that are difficult to disguise. One distinguishable pattern of pulling noted in some individuals with TTM is the “Friar Tuck,” in which the hair is missing from the crown of the head and the hair in the front and on the sides is left unpulled (Penzel, 2003). Hair loss and complete absence of hair in the eyebrow and eyelash regions of the body is most noticeable given their visibility due to location (Penzel, 2003). Individuals with TTM primarily use their fingertips to pull their hair out; however, tweezers, combs, and other aids are reportedly used as well (Walther et al., 2010).

### Precursors to Pulling

Sensory stimulation, emotions, and cognitions are described as antecedents to hair pulling. Some individuals with TTM scan their scalp and/or body for a target hair that is differentiable due to color, texture, length, and location (Stein, Christenson, & Hollander, 1999; Walther et al., 2010). A hair puller’s perception is that the hair does not belong because it stands out in some way, and therefore must be removed. In addition, skin irritation, itchiness, and sensitivity are physical sensations that may act as catalysts to hair pulling (Christenson & Manseuto, 1999). Some people with TTM describe a physical sensation such as an itch that they have to attend to, and they find that they can relieve the itch by pulling a particular hair or hairs. Hair pullers with TTM often deny feeling pain as a result of hair pulling (Penzel, 2003).

Emotional precursors to hair pulling that have led to increased pulling in adults include anxiety, boredom, tension, and anger (Christenson, Ristvedt, & Mackenzie, 1993; Diefenbach, Mouton-Odum, & Stanley, 2002; Diefenbach, Tolin, Meunier, & Worhunsky, 2008; du Toit et al., 2001). Sometimes stressful events (e.g., a death in the family, starting a new school or job, parents divorcing, and/or moving) are perceived as antecedents to hair pulling (Penzel, 2003). Rigid thought patterns (e.g., “gray hair is bad”), catastrophizing (e.g., “my life will never get better if I continue to have wiry hair”), overgeneralization (e.g., “everyone notices the wiry hairs on my head”), and general thoughts about specific hairs being out of place and using hair pulling as a way to reduce stress may serve as cognitive antecedents to pulling (Walther et al., 2010).

### Subtypes

Trichotillomania research literature supports the idea that TTM is a disorder characterized by three different types of hair pulling: early onset, automatic, and focused (Christenson & Mansueto, 1999; Duke et al., 2010; Flessner et al., 2008). Early onset hair pulling, or “baby trich,” is thought to be a relatively benign form due to less enduring symptoms and fewer comorbidities (Diefenbach et al., 2000; Duke et al., 2010; Keuthen et al., 2001; Swedo, Leonard et al., 1992; Swedo, Rapoport et al., 1992; Walther et al., 2010; Winchel, 1992). “Baby trich” frequently resolves with little or no intervention during the child’s early development (APA, 2013; Walther et al., 2010). Keuthen et al. (2001) reported that it is unlikely that early onset hair pullers experience tension and anxiety prior to pulling or relief afterward. Longitudinal studies of early onset TTM are unavailable in the literature, making it difficult to assess whether TTM remits in early onset individuals or if it remains a lifelong issue. In a study conducted by Cohen et al.

(1995), 6% of their adult study population ( $N=123$ ) experienced an onset of hair pulling at 6 years of age or less, suggesting that early onset is not as benign as previously thought and warrants further study (Duke et al., 2010).

Automatic hair pulling is used to describe a situation where the puller is not aware of, or is only partially aware of, what they are doing. Automatic pulling occurs during periods of relaxation or distraction, such as when an individual is watching television, reading, and/or driving (APA, 2000; Christianson & Mansueto, 1999). Automatic pulling is the most common style of hair pulling, with approximately three quarters of individuals with TTM being unaware of their hair pulling behavior in the moment and only later recognizing that they pulled (Christenson et al., 1994; Flessner et al., 2008). Flessner et al. (2009) compared pulling styles across age groups and found that children (age 10-12) predominantly engage in automatic pulling.

Conversely, focused hair pulling involves a conscious awareness of the pulling behavior, intense urges, mounting tension, thoughts of pulling, and subsequent relief (APA, 2013; Duke et al., 2010). It appears to be intentional and goal-directed. Focused hair pulling includes targeting specific types of hair and/or locations or the use of tools to increase pulling effectiveness (Flessner et al., 2008). Some hair pullers consciously limit themselves to a specific number of hairs to be pulled at any given time (Christina Pearson, personal communication, March 7, 2005). Christenson et al. (1994) reported that focused hair pulling is the dominant style of pulling for one quarter of all hair pullers. Focused hair pulling has been phenomenologically linked to compulsions that are typically seen in Obsessive Compulsive Disorder (Christianson & Mackenzie, 1994). Research suggests that some adults utilize focused pulling as a form of emotion

regulation (Begotka, Woods, & Wetterneck, 2004; Diefenbach, Mouton-Odum, & Stanley, 2002; Woods, Wetterneck, & Flessner, 2006). In a 2009 study comparing pulling styles of those with TTM across age groups, Flessner and colleagues reported that focused pulling was more prevalent among adolescents and adults (Flessner et al., 2009).

Automatic and focused styles of hair pulling do not appear to be strongly related to each other in adult or child populations (Flessner et al., 2008; Flessner et al., 2007). Yet focused and automatic styles of pulling are usually not mutually exclusive of each other, either, with a mixture of both pulling behaviors reported by many individuals with TTM (APA, 2013; Christianson & Mansueto, 1999). It is not unusual for a woman with TTM to engage in automatic pulling while watching television or reading and then purposely search for hair on her scalp because it feels different in an episode of focused pulling.

### Associated Features

Individuals who pull hair often follow a certain routine and have particular rituals that they associate with pulling. Some researchers and psychologists believe that the rituals associated with hair pulling stimulate visual, tactile, and oral processing centers in the brain. Associated rituals of TTM include searching for a particular type of hair based on texture or color, pulling out the hair in a specific way to maintain its integrity, immediately discarding the hair after it is pulled or saving it in a particular location, examination of the hair and root, hair twirling or winding it around a finger, running the hair between lips, teeth, or fingers, eating and swallowing the hair and/or the root, rubbing the hair against the face, tongue or other body part, rolling the hair into a ball or tying it in a knot, breaking the hair, and removing the root from the hair shaft (APA,

2013, 2002; Duke et al., 2010). Trichophagia or eating hair is a ritual of TTM that may be the most physically hazardous because it can lead to the formation of trichobezoars (i.e., hair balls) in the stomach or intestines, which may cause anemia, abdominal pain, hematemesis, nausea and/or vomiting, bowel obstruction, perforation, gastrointestinal bleeding, acute pancreatitis, and obstructive jaundice (APA, 2013, 2000; Christenson & Mansueto, 1999).

Hair pulling usually occurs when the person is alone or only in the presence of close immediate family. The hair puller may deny her or his behavior to others. Sometimes, individuals have the urge to pull other people's hair and might secretly look for ways to do so. Some hair pullers may pull hairs from pets, dolls, clothing, or carpets (APA, 2013). Most hair pullers engage in other self-injurious acts and/or body-focused repetitive behaviors such as skin picking, scratching, nail biting, and lip chewing (APA, 2000; Christenson & Mansueto, 1999).

#### Impairment/Impact

One of the most obvious effects of TTM is visible hair loss. However, there are a number of other, often devastating, consequences associated with chronic hair pulling. Specifically, hair growth and quality may be damaged irreversibly (APA, 2013). Individuals with TTM have reported a variety of physical problems, emotional issues, social concerns, and economic repercussions. Although some negative consequences are not always the direct result of hair pulling, some studies suggest that their presence is specific to TTM and would not otherwise be seen.

## Physical

The physical effects of hair pulling can be categorized as tactile and visual. The physical touch and manipulation of hair that may result in reinforcement of hair pulling itself are considered to be tactile consequences of the behavior (Rapp, Miltenberger, Galensky, Ellingson, & Long, 1999). A hair puller might target a specific hair because it has a different texture (i.e., coarse or wiry hair). Some hair pullers achieve a physical sensation while manipulating or playing with the hair before, during, and after pulling. For example, at least half of the individuals with TTM achieve a tactile sensation that functions as a reinforcer after running the hair between their lips to feel the root bulb on the lips (Christenson, Mackenzie, & Mitchell, 1991). Additionally, some with TTM go a step further by ingesting the pulled hair. Visual behaviors, such as scanning the hair, looking at the root, and looking at the texture of the hair, may be visually stimulating, thereby reinforcing the hair pulling behavior (Walther et al., 2010).

While the act of hair pulling is not typically accompanied by pain, the physical outcomes and subsequent medical problems associated with TTM may be painful (APA, 2013). Repetitive hair pulling may cause mild to serious physical impairment for some individuals. The physical impact of TTM has been linked to skin irritations and infections, dental problems, gastrointestinal problems, ophthalmological issues, and orthopedic and neurologic complications. Individuals with TTM may have callused fingertips, skin infections, and/or bleeding due to excessive pulling. Oral behaviors associated with TTM such as chewing hair and running it between the teeth may lead to the erosion of tooth enamel. Gastrointestinal complications of continued ingestion of hair due to the formation and lodging of hairballs (trichobezoars) can occur (APA, 2013).



Williams (1986) reported mortality rates as high as 30% when gastrointestinal symptoms such as bleeding, destruction, or perforation were left untreated. Hair pulling may result in eye and eyelid infections. Some hair pullers do not receive annual physicals in an effort to avoid exposure of their hair pulling, thereby leaving other unrelated health issues to go undiagnosed and untreated. Repetitive strain injuries of the neck, back, elbow, and shoulders, as well as tendonitis and carpal tunnel syndrome, have been associated with TTM (O'Sullivan, Keuthen, Jenike, & Gumley, 1996; Penzel, 2003). Further, hair pullers who do seek help may be looking in the wrong place. For instance, hair pullers who experience infections resulting from pulling might seek to treat the infection, which can be done successfully with antibiotics and changing the pulling site, but if the act of pulling is unknown to the treatment provider and goes untreated, it is likely that the infection will return, causing additional physical difficulties.

### Emotional

Current DSM-5 criteria for TTM indicate hair pulling to be the cause of clinically significant distress including negative affective states (e.g., feeling of loss of control, embarrassment, shame) felt by hair pullers (APA, 2013). The emotional effects of hair pulling range from pleasure to pain. Some individuals with TTM report feelings of pleasure during and after pulling episodes (Mansueto et al., 1997), while others indicate a decrease in anxiety, boredom, sadness, stress, and tension as a result of pulling (Diefenbach et al., 2008 as cited in Walther et al., 2010). Conversely, Diefenbach and colleagues (2002) reported an increase in negative emotions, such as guilt and sadness, both during and after hair pulling episodes.

Poor self-esteem and negative self-worth have been reported as correlates of chronic hair pulling. Low self-esteem has been linked to lower levels of academic and employment-related achievement in individuals with TTM. Many hair pullers avoid relationships for fear of exposing their secret to others, which can lead to social isolation and additional emotional strain (Penzel, 2003).

In a study surveying self-esteem in 62 women with trichotillomania, Soriano et al. (1996) identified frequency of hair pulling, body dissatisfaction unrelated to hair pulling, and levels of anxiety and depression as factors related to self-esteem. The authors of this study suggested that trichotillomania has an equally negative impact on self-esteem that is unrelated to severity of hair loss or number of hairs pulled (Soriano et al., 1996). Similarly, low self-esteem has been noted in the TTM samples of other studies when compared to control subjects (Diefenbach, Tolin, Hannon, Crocetto, & Worhunsky, 2005a). Awareness of others' unfavorable perceptions of hair pulling, coupled with personal invalidation, may combine to form a negative reinforcement cycle for hair pullers that maintains low self-esteem.

Diefenbach et al. (2005) conducted a study exploring the impact of hair pulling on psychosocial functioning for individuals diagnosed with TTM. The researchers reported results indicating that TTM individuals experience higher levels of distress compared to normal controls. Their results highlighted the associative emotional features of hair pulling. Their findings showed that impairments in life satisfaction and functioning are associated with hair pulling, but cautioned that this finding was complex in that it was mediated by the presence of depression. Diefenbach et al. (2005a) reported that severity of hair pulling symptoms predicted more severe functional disability and lower life

satisfaction after controlling for depression. Additionally, they found that, after controlling for depression, self-esteem was significantly affected by severity of hair loss. Overall, the researchers concluded that TTM and psychosocial impairment are affiliated with one another, but that the presence of depression may contribute to the association (Diefenbach et al., 2005a).

Negative affective states are often associated with TTM. Townsley-Stemberger et al. (2000) reported that 49–87% of their study population experienced feelings of unattractiveness, secretiveness, depression/bad mood, low self-esteem, shame, irritability, and being argumentative. In 2009, Lewin et al. conducted a self-report Internet study designed to assess the relationships between symptoms of depression/anxiety and TTM-related impairment in children (ages 10-17;  $N=133$ ). They found that over 45% of their study population endorsed clinically significant symptoms of depression and that anxiety symptoms were reported by 40% of the participants. These findings suggested greater functional impairment specific to social, interpersonal, and academic functioning for youth with TTM in the presence of severe depressive and anxiety symptoms (Lewin et al., 2009).

### Social

Studies of individuals with trichotillomania indicate that the very act of hair pulling is both interpersonally and socially destructive. Social functioning is negatively affected by chronic hair pulling (Diefenbach, Tolin, Crocetto, et al., 2006; Diefenbach, Tolin, Hannan, et al., 2005; Townsley-Stemberger, McCombs-Thomas, Mansueto, & Carter, 2000; Wetterneck, Woods, Norberg, & Begotka, 2006; Woods, Flessner, Franklin, Keuthen et al., 2006). Interpersonal problems related to relationships, reluctance to

socialize with others, and academic and occupational difficulties are experienced by those with TTM (Duke et al., 2010). Casati et al. (2000) reported that isolation and negative effects (i.e., humiliation, fear, guilt, embarrassment, anger, and frustration) coexisted with TTM and significantly impacted the way women engaged in everyday activities.

Specifically, activities that most people engage in regularly, such as being intimate with a partner, attending social events, being in the wind, having medical exams, getting a haircut, and participating in sporting activities are activities that individuals with TTM were reluctant to engage in for fear of exposing their secret (Penzel, 2003).

Diefenbach, Tolin, Crocetto, et al. (2005) and Flessner, Conelea, et al. (2008) provided additional evidence of TTM interfering with academic and occupational activities. Neal-Barnett et al. (2010) highlighted the differences in social impairment for different ethnicities. Utilizing an Internet survey assessing ethnic differences in TTM, Neal-Barnett et al. (2010) found that Caucasian participants experienced significantly more interference particular to academic functioning as a result of hair pulling compared to their counterparts who were participants of color. Further, results indicated that hair pulling by participants of color significantly interfered with managing at-home tasks (Neal-Barnett et al., 2010).

These studies offer further proof of the destructive personal nature of trichotillomania. Individuals with this condition experience relationship, social, occupational, and academic problems, all of which come as no surprise to individuals affected by chronic hair pulling. Keuthen et al. (2004) studied functional impairment and quality of life of chronic hair pullers. Findings of this study were insignificant and resulted in the following explanation by the researchers: that it is difficult to completely

assess the psychosocial experiences of hair pullers using general quality of life measures due to the uniqueness of each individual (Keuthen et al., 2004). Insignificant findings aside, study participants reported impairment specific to social, occupational, and leisure functioning, which provided further evidence of the necessity for trichotillomania specific quality of life measures.

### Economic Impact

The economic impact of hair pulling is quite significant, albeit understudied. A study of the social and economic impact of trichotillomania conducted by Wetterneck et al. (2006) reported that study participants reported avoidance of social situations, sought help from multiple health professions for pulling, spent considerable time engaged in hair pulling activities, and had interference of both work and school due to pulling. Woods et al. (2006) reported that a significant number of participants indicated that, over the past year, hair pulling interfered with their job functioning. Several participants quit their job as a result of hair pulling. The majority, however, did not pursue job promotions, job advancement, or employment interviews because of hair pulling, thus resulting in lost income otherwise due to a qualified individual.

Hair pulling impacted academic functioning (i.e., missed school days, difficulties completing school-related responsibilities, and interference in studying) (Seedat & Stein, 1998; Woods et al., 2006). Specifically, individuals affected by trichotillomania reported missing days of school because of hair pulling symptoms, as well as having trouble performing school responsibilities, which led a number of participants to drop out of school and/or choose not to pursue further education (Woods et al., 2006).

Trichotillomania significantly impacts everyday functioning and relationships (Seedat &

Stein, 1998). In response to questions regarding the effects of trichotillomania on participants' abilities to participate in everyday life, respondents informed that they experienced a moderate degree of distress as a result of chronic hair pulling. Further, several respondents reported that they were unable to continue with their academic careers and/or experienced a disruption in employment due to trichotillomania.

The economic impact of trichotillomania as it relates to education is significant in that money is lost due to nonattendance at school. If the puller is young, a parent may be required to stay home with the child/adolescent on a missed school day, resulting in lost wages or the use of sick/vacation days. Parents of hair pullers may miss out on the potential to earn additional monies if they are passed up for promotion as a result of missing work. Missing school due to trichotillomania may require the parents to hire someone to care for their child because they have to work. Individuals, families, and schools lose money when the hair puller does not attend class regardless of whether the school is public or private. Money spent on books and supplies for school is potentially lost when the puller misses school.

Seedat and Stein (1998) reported that chronic hair pulling might result in treatment seeking and misdiagnoses. Individuals spend multitudes of money inappropriately on unnecessary treatments and supplies for improper diagnoses. Even when the diagnosis is relevant, treatments (e.g., therapy, medications, hospitalization) or supplies to conceal the results of hair pulling may have a significant economic impact on the hair puller and her family. Both health care professionals and the public are in need of further education on trichotillomania diagnoses and treatment options in an effort to increase general awareness of the condition as a way of decreasing its economic impact.

## Associated States

### Affective

A variety of emotional states may precede or accompany hair pulling. Feeling anxious or bored may trigger the behavior. Feelings of a mounting sense of tension (immediately prior to pulling or while resisting an urge to pull) may be present for some individuals with TTM. Hair pullers may feel a sense of relief, gratification, or pleasure once the hair is pulled (APA, 2013). In DSM-IV-TR, to qualify for a diagnosis of TTM, individuals had to report a mounting sense of tension prior to hair pulling and a feeling of gratification or sense of relief after pulling out hair (Van Ameringen et al., 2014; APA, 2000), but this is no longer a diagnostic requirement for TTM in DSM-5. Various researchers proposed that this criterion was not always present in those with TTM, because some do not experience tension and obsession preceding hair pulling. These researchers suggested a much broader scope of affective states associated with the behavior. Mansueto et al. (1997) reported that classical conditioning is at play in the hair pulling cycle. They hypothesized that the urge to pull and the cycle of pulling is associated with a number of internal and external cues that reinforce the hair pulling behavior when a cue is present. Researchers identified the following affective correlates of hair pulling—which occurred prior to and after hair pulling: angry, anxious, bored, calm, embarrassed, frustrated, guilty, happy, indifferent, lonely, relieved, sad, and tense (Diefenbach, Mouton-Odum, & Stanley, 2002; Duke, Bodzin, et al., 2009; Duke et al., 2010; Duke, Ricketts et al., 2009). Significant increases in anxiety, boredom, frustration, and tension were noted prior to hair pulling, with significant increases in anger, guilt

relief, and sadness reported over time (Diefenbach, Mouton-Odum, & Stanley, 2002; Duke et al., 2010).

### Environment

Environment plays an important role in hair pulling behavior. Not only is one's physical setting important to hair pulling, but so, too, are external cues such as the accessibility of implements that aid in hair pulling, as well as body positioning. External triggers of hair pulling include environments both inside and outside the home. The bedroom, bathroom, living room, family room, and home office are examples of in-home environments conducive to hair pulling. Common settings for hair pulling that are located outside of the home include the car, classrooms, the workplace, and public restrooms (Duke et al., 2010; Grant, Stein, Woods, & Keuthen, 2012; Penzel, 2003). Mansueto et al. (1997) suggested that secondary associations formed when pulling in a particular environment link external environmental cues and the urge to pull hair. Implements such as tweezers and hand and wall mirrors may serve as a trigger to hair pull when the puller has access to such instruments. For example, an individual's pattern of pulling may have been established when alone and feeling anxious and being in the bathroom with access to both a mirror and tweezers. Further, body position and hand position (e.g., lying down, resting hand on head, or grooming hair) can initiate a hair-pulling episode. It is likely that, over time, the urge to pull is triggered by associations among any of these cues (Duke et al., 2010; Grant et al., 2012; Mansueto et al., 1997).



## Comorbidities

Population comorbidities are often difficult to assess in trichotillomania studies. Christenson et al. (1991) reported a lifetime prevalence of Axis I disorders to be as high as 82%. Chronic hair pulling has not been consistently linked to one single diagnosis, but research indicates that trichotillomania may have comorbidities with anxiety disorders (Flessner et al., 2008), impulse control disorder (Christenson, Mackenzie, & Mitchell, 1991; Stein, Simeon, Cohen, & Hollander, 1995), mental retardation (Kanner, 1948), mood disorders (Flessner et al., 2008), obsessive compulsive disorder (Adam & Kashani, 1980; Swedo, 1993), schizophrenia (Chauhan, Jain, & Dhir, 1985), self-mutilation (Favazza, 1998), substance use (Duke et al., 2010), and trauma (Boughn & Holdom, 2003; Lochner et al., 2002). According to the DSM-5, major depression and excoriation (skin picking) are the most common mental disorders that accompany a TTM diagnosis (APA, 2013).

In a study of hair pulling and Axis 1 disorders in a large community sample, Duke et al. (2009) reported positive relationships between hair pulling and symptoms of depression for men and women, as well as a significant relationship between hair pulling and anxiety symptoms for women. An Internet study of young individuals aged 10–17 with trichotillomania showed that 40 to 45% of participants endorsed symptoms of anxiety and depression. Body-focused repetitive behaviors (BFRB), such as nail biting and excoriation, have been linked to trichotillomania. Stein et al. (2008) conducted a web-based survey of hair pulling and other BFRBs. Seventy percent of their sample population ( $N=990$ ) reported the presence of both hair pulling and other BFRBs including nail biting and skin picking (Stein et al., 2008). Trichotillomania and

stereotypic movement disorders have also been linked together (Duke et al., 2010), with as many as 85% of chronic hair pullers engaging in a stereotypic movement such as nail biting or skin picking (Christenson, Mackenzie, et al., 1991).

Trichotillomania was reclassified as an obsessive-compulsive disorder under the DSM-5 because experts thought that TTM was more closely related to OCD, even with only partial overlap with OCD, when compared to impulse control disorders (Van Ameringen et al., 2014). Previous research suggested that trichotillomania was similar to, if not the same disorder as, obsessive compulsive disorder (OCD) due to a higher frequency of OCD in chronic hair pullers. The prevalence of OCD in the trichotillomania population is as high as 13% (Christenson, 1995) to 16% (Swedo & Leonard, 1992), which is considerably higher than general population estimates of 1–3% (Duke et al., 2010; Robbins et al., 1984)

Ferrão, Miguel, and Stein (2009) reported that cognitive mechanisms (i.e., inflated sense of responsibility, the need for control over thoughts, and thought–action fusion) characteristic of OCD were not present in individuals with trichotillomania. Ferrão et al. (2009) specified that the hair pulling associated with OCD is a repetitive behavior performed as part of an obsession, and they considered hair pulling in trichotillomania to be an impulse behavior. Contrarily, the authors of the DSM-5 (APA, 2003) classified TTM as OCD by changing DSM criteria to include repeated attempts to stop hair pulling, which is closely aligned with the repetitive and ritualized behaviors and impulses in OCD (Van Ameringen et al., 2014)

Trichotillomania and personality disorders studies are limited in the extant literature. In an Iranian study of individuals ( $N=43$ , 34 females, 9 males) investigating the

personality characteristics of those diagnosed with TTM, Hagh-Shenas et al. (2004) found significant differences between TTM participants and normal controls for the personality domains of neuroticism and agreeableness. They concluded that individuals with TTM in their study have personality profiles consistent with borderline personality disorder. Swedo and Leonard (1992) reported a lifetime prevalence of 38% for personality disorders in their sample population. They indicated Histrionic Personality Disorder as the most prevalent (26%) with Borderline Personality Disorder (18%) and Passive/Aggressive Personality Disorder (16%) following (Swedo & Leonard, 1992). The limited available literature linking TTM and personality disorders indicates a need for further research to determine if there is a definitive connection between trichotillomania and disordered personality (Penzel, 2000).

### Etiology

Trichotillomania is currently classified as an obsessive compulsive disorder under the DSM-5 due to shared characteristics of hair-pulling disorder and OCD such as repetitive and ritualized behaviors that persons with both TTM and OCD engage in that are perceived to hold little or no outward purpose for the individual. Under DSM-IV criteria, TTM did not align with OCD. Previous researchers reported that the internal experiences of those with TTM and OCD were the differentiating factors between the two disorders (Duke et al., 2010; Hollander & Evers, 2004; Hollander, Fiedberg, & Wasserman, 2005). Specifically, they cited compulsive behaviors in OCD as being utilized to decrease anxiety associated with obsessions that were not in line with the individual's self-image. The DSM-5 authors and working group challenged this body of research when they reclassified TTM. Despite its reclassification, there are some distinct

differences between TTM and OCD. Specifically, OCD compulsions often change over time; it is not characteristic of TTM to transform into other rituals (Duke et al., 2010; Lochner et al., 2004; Walsh & McDougle, 2001). In a study comparing impulsivity and compulsivity in patients with TTM or skin picking (SP) compared with patients with OCD, Ferrão et al. (2006) found six significant differences between the two groups. These differences included 1) the belief among individuals with TTM/SP that their impulses occur suddenly, whereas individuals with OCD have the ability to delay their impulses; 2) individuals with TTM/SP act immediately when there is a will to act, and those with OCD think about acting and formulate a plan as to how to act; 3) individuals with OCD who give in to their obsession with a compulsive act feel more overall long-term guilt compared to individuals with TTM/SP, who feel indifferent or pleased immediately following their hair pulling; 4) guilt is felt by both groups (TTM/SP and OCD) after acting out, but persons with TTM/SP feel intense guilt immediately after pulling compared to those with OCD; 5) rituals are associated with acting out for OCD, but are not associated with TTM/SP; and 6) persons with TTM/SP believe that they will be better off if they do not engage in hair pulling or skin picking, whereas, if prevented from acting, those with OCD believe that something harmful might happen (Ferrão et al., 2006).

Presently, the etiology of trichotillomania is unknown. However, researchers continue to study the disorder and speculate as to what factors contribute to its development and maintenance. Several precipitating social factors have been correlated with the onset of TTM, including illness and injury of self or others, death, moving house, relationship difficulties, family dynamics, adolescence, school, and physical and

sexual abuse (Boughn & Holdom, 2003; Casati et al., 2000; Christenson & Mansueto, 1999). Onset of hair pulling has also been linked to witnessing hair pulling by others (Christenson & Mansueto, 1999). Multiple etiological theories, known as models, are available explaining TTM, including biological theories (i.e., genetic, neurobiological, ethological, and hormonal) and psychological theories (i.e., behavioral, emotion regulation, psychoanalytic, and trauma). It is likely that TTM is the result of a complex interaction of biological, psychological, and social factors given the multitude of factors that can affect any one person at any given time during her or his lifespan (Diefenbach et al., 2000). For example, genetics and environment may simultaneously contribute to the manifestation of hair pulling as a method of regulating emotions or soothing oneself and the maintenance of the behavior. Furthermore, hair pulling behavior is maintained and rewarded through classical conditioning when it is paired with emotional dysregulation. It is likely that etiological theories contributing to TTM are not mutually exclusive of each other (Duke et al., 2010). However, more research is necessary to understand the cause of TTM.

### Biological

Various biological hypotheses as to the cause of TTM are supported by sound research. Biological models include serotonin deficiencies (Christensen et al., 1991b; Koran, Ringold, & Hewlett, 1992; Stanley et al., 1997; Stein, O'Sullivan, & Hollander, 1999; Swedo, Lenane, & Leonard, 1993; Swedo et al., 1989), structural brain abnormalities (Insel, 1992; O'Sullivan et al., 1997; Robinson et al., 1995; Stein, O'Sullivan, & Hollander, 1999), abnormal brain metabolism (Christensen et al., 1991b; Stein, O'Sullivan, & Hollander, 1999), and genetics (Greer & Capecchi, 2002).

## Genetics

It is likely that genetics play an important role in imposing biological vulnerability on individuals and families for hair pulling (Cohen et al., 1995; Duke et al., 2010). Family members of hair pullers have a 5–8% chance of increased risk of engaging in the behavior (Christenson et al., 1992; Lenane, Swedo, & Rapoport, 1992). Twin studies revealed significant differences in TTM concordance rates occurring in monozygotic (MZ; 38.1%) and dizygotic (DZ; 0%) twin pairs for meeting DSM-IV criteria, as well as a heritability estimate of 76.2% (Novak, Keuthen, Stewart, & Pauls, 2009). This suggests that a person's genetics factor heavily in the expression of the phenotype. Family and twin studies of TTM suggest a heritable link. Further, it is thought that TTM susceptibility may be influenced by “functional polymorphisms in genes involved in neuronal pathways” (Chattopadhyay, 2012).

In 2002, Greer and Capecchi discovered that mice with a mutation in the neurodevelopmental gene called *Hoxb8* excessively groomed themselves by pulling their hair out. A follow-up to this study is the recent work by Chen et al. (2010) linking pathological grooming dysfunction in *Hoxb8* mutant mice with microglia deficiency in the brain. Chen et al. found that normal bone marrow transplantation in adult *Hoxb8* mutant mice rescued their pathological phenotype. Further, the researchers found that restricting *Hoxb8* expression in the hematopoietic system of a mouse led to the reintroduction of excessive grooming behaviors in mice, whereas restricting *Hoxb8* expression in the spinal cord does not, thereby implying a relationship between immunological dysfunction and excessive grooming or hair pulling (Chen et al., 2010).

Support for the genetic contribution to hair pulling comes from research in human populations focused on SLITRK1 genes (Zuchner et al., 2006) and the Sapap3 gene (Bienvenu et al., 2009; Zuchner et al., 2009). Two study participants with TTM had mutations in SLITRK1 genes, whereas the gene mutation was not found for the 2000 control subjects (Zuchner et al., 2006). The SLITRK1 gene is thought to play a role in cortex development, neuronal growth, and Tourette syndrome (Abelson et al., 2005 as cited in Duke et al., 2010), which is suggestive of a link between Tourette syndrome and TTM. Additionally, Bienvenu et al. (2009) studied the Sapap3 protein in individuals with OCD or TTM compared with controls. Findings indicate that hair pulling is nominally associated ( $p < .05$ ) with variations within the human Sapap3 gene, suggesting that Sapap3 is a promising functional candidate gene for human grooming disorders such as TTM. This research was conducted as a follow-up to mouse model studies linking Sapap3 mutant mice and OCD and TTM-like repetitive behaviors (Welch et al., 2007; Zuchner et al., 2009).

### Neurobiological

Various studies have reported the neurochemical and neuroanatomical aspects of TTM. Such studies imply that problems in brain chemistry and structure contribute to TTM. Swedo et al. (1989) conducted one of the first studies to link hair pulling with a brain serotonin problem. Results of this study revealed clomipramine to be an effective treatment for hair pulling, thus indicating problems with brain serotonin as a possible cause for TTM. Since that time, other serotonergic drugs have proven effective in treating TTM, but their effectiveness did not hold over time (Pollard, IBE, Krojanker, Kitchen, Bronson, & Flynn, 1991; Stein & Hollander, 1992), thereby suggesting that a decrease in

brain serotonin does not provide a complete explanation of TTM. Further, the neurotransmitter dopamine is thought to be a contributing factor of TTM because dopamine-blocking drugs have been effective in decreasing repetitious body movements similar to hair pulling that are associated with Tourette syndrome, OCD, and tic disorders (Penzel, 2003). Dopamine-blocking neuroleptics or antipsychotics and serotonin reuptake inhibitors (SSRI) used in combination have been more effective in treating a small subset of persons with TTM (Stein & Hollander, 1992).

Grant, Odlaug, and Kim (2009) conducted a study examining the efficacy of a glutamatergic agent in the treatment of trichotillomania. Results indicated that taking N-acetylcysteine significantly reduced hair pulling in the TTM study population when compared to placebo. Findings suggest that the glutamate system may be useful in understanding and treating TTM (Duke et al., 2010; Grant, Odlaug, & Kim, 2009).

It is impossible to pinpoint exactly what medications are acting upon in the brain despite the indication that they are involved in TTM etiology (Penzel, 2003). Specifically, it is unknown whether SSRIs are targeting hair pulling directly or if they are reducing other symptoms often associated with TTM such as anxiety, depression, or stress that may exacerbate hair pulling behavior. Additionally, dopamine-blocking medications may directly affect brain locations where tics and other repetitive behaviors originate; they may increase the effectiveness of antidepressants when used in combination and/or they may work to improve mood and reduce anxiety. However, their exact impact is unknown (Penzel, 2003).



## Neuroanatomical

Limited studies of brain structure abnormalities exist for TTM sufferers, but they offer no definitive explanations for hair pulling behavior. The brains of individuals with TTM had condensed left putamen structures compared with control subjects, suggesting fronto-striatal motor circuit differences (O'Sullivan et al., 1996) and smaller cerebellar volumes compared to controls that were associated with TTM symptom severity (Keuthen et al., 2007). A recent study looking at differences in brain white matter between TTM subjects and controls implicated the disorganization in white matter tracts involved in motor habit generation and suppression, and affective regulation, in the pathophysiology of trichotillomania (Chamberlain et al., 2010). Swedo et al. (1992) reported significantly increased glucose metabolism in the right and left cerebellum and in the right superior parietal areas in people with TTM compared to individuals without TTM. Chamberlain and Sahakian (2007) utilized functional magnetic resonance imagery (fMRI) to increase the understanding of impulsivity and brain structure. They reported significant differences for response inhibition in the right inferior frontal gyrus. Using magnetic resonance imaging (MRI) to measure differences in the brains of those with TTM compared to controls, Grachev (1997) found significantly reduced left inferior frontal gyrus volume and an enlarged right cuneal cortex volume in trichotillomania patients (Duke et al., 2010).

Ansell, Rando, Tuit, Guarnaccia, and Sinha (2012) conducted a recent study examining the effects of cumulative stress on the brain. They imaged 100 brains of healthy volunteers who answered questions about stressful life events. They reported a dramatic change in brain volume due to the cumulative effects of traumatic stress.

Specifically, a decrease in the grey matter of the prefrontal cortex was linked to cumulative adversity. This area of the brain is responsible for top-down emotion regulation, cognition, and self-control. The prefrontal cortex plays an important role in maintaining metabolic homeostasis, and for survival and adaptation to life's challenges. Life traumas (e.g., loss of a relationship with a loved one due to death or divorce) acutely affect mood centers and skew ability to regulate pleasure and reward. Anxiety and depression have been linked to smaller brain volumes in these centers (Ansell et al., 2012). It is conceivable to think that chronic hair pulling over many years constitutes a life trauma that contributes to brain changes associated with anxiety and mood.

### Ethological

Research supporting an ethological model of TTM posits that innate grooming behaviors in animal models are similar to hair pulling in humans. Hair pulling in animals is similar to human hair pulling in that the hair may be ingested, pulling can be from self or others, is difficult to treat, and manifests more often in females than males (Reinhart, 2005). Hair pulling has been exhibited by a multitude of animals including cats, dogs, guinea pigs, mice, primates, rabbits, and sheep (Duke et al., 2010). Some researchers suggest that whisker barbering in mice is a repetitive behavior similar to TTM or OCD in humans (Garner, Dugour, Gregg, Weisker, & Mench, 2004). Another animal model suggestive of human TTM or OCD is canine acral lick dermatitis (ALD). Dogs with ALD compulsively lick their paws, which leads to hair removal and severe ulceration (Dodman & Olivier, 1996). Feather picking (pterotillomania) in birds is thought to be analogous to hair pulling in humans, and it is thought to be associated with ritualistic behavior such as grooming the plucked feather, which can be seen as similar to rituals that humans

perform after pulling hair (e.g., examining the hair and root) (Duke et al., 2010).

Additionally, animal hair pulling is often perceived as a self-soothing behavior in response to environmental stressors or as a displacement activity resulting from conflict (Moon-Fanelli, Dodman, & O'Sullivan, 1999).

### Hormones

Hormones are thought to be a contributor to TTM. The predominant population of TTM sufferers presenting for treatment are women. Age of onset is frequently reported as occurring around the time of onset of menstruation, with some women reporting premenstrual exacerbation of TTM symptoms (Keuthen et al., 1997). Flessner and colleagues (2009) conducted a cross-sectional study of 1,471 women with TTM and found that fluctuations in “focused” pulling coincided with age. Specifically, hair pulling changes occurred at ages typically associated with hormonal and biological changes (i.e., onset of puberty and perimenopause) (Flessner, Woods, Franklin et al., 2009). A double-blind controlled study comparing intranasal oxytocin and placebo in two women resulted in no significant changes in TTM symptoms either immediately or after 7 days (Epperson, McDougle, & Price, 1996). The researchers suggested that intranasal administration of the hormone might account for no changes in repetitive behaviors explaining that its administration methods did not allow for the crossing of the blood-brain barrier (Epperson et al., 1996). Additional studies in this area are necessary to define the role that hormones play in hair pulling.

### Psychosocial

Limitations in the current biological, anatomical, and ethological models suggest that there are other factors to consider when understanding hair pulling behavior. Given the overlap in physical and psychological symptoms associated with hair pulling, it is important to broaden our perspective as it relates to hair pulling to include psychological and psychosocial perspectives. Various psychosocial models including behavioral, emotion regulation, psychoanalytic, and trauma have been employed to understand TTM. While one model provides insight on hair pulling from its particular perspective, the next model provides another perspective that equally explains the behavior. A commonality among all the models is that hair pulling is not a “one size fits all” understanding hair pulling.

### Behavioral Model

Behavior theory perceives hair pulling as a problem behavior instead of a symptom of an underlying conflict, and target behaviors are not conceptualized as highly pathological (Keuthen, Aronowitz, Badenoch, & Wilhelm, 1999). Problem behaviors result from faulty learning and repeated practice, according to behavior theory (Penzel, 2003). Circumstantial and emotional triggers specific to hair pulling and the reinforcement mechanisms maintaining the hair pulling behavior are the focus of behavioral models (Keuthen, et al., 1999). Keuthen and colleagues (1999) describe behavioral theory as less interpretive, more client-centered, and of shorter duration.

Behavior theory posits that hair pulling is a learned behavior similar to habit formation (Azrin & Nunn, 1973) that may develop as a coping response to stress, and which is reinforced through tension reduction (Diefenbach et al., 2000; Mansueto et al.,

1997; Stein, Christenson, et al., 1999). Additionally, physical sensations associated with hair pulling may become conditioned to the hair pulling behavior, rendering them necessary by the puller (Duke et al., 2010; Friman, Finney, & Christophersen, 1984). Behavioral theory informs that hair pulling behavior is associated with both internal and external cues as the result of both classical and operant conditioning. Eventually, hair pulling becomes a habit that often occurs outside of one's awareness with the puller feeling that she does not have control over the behavior (Azrin & Nunn, 1977). Other researchers suggest that TTM may be the result of modeled behavior (Christensen et al., 1992; Diefenbach et al., 2000). Specifically, a child whose parent engages in hair pulling might begin pulling as a result of watching their parent pull, as a way of emulating and/or identifying with their parent. Limited research specific to modeled hair pulling behavior is available, necessitating the need for further study of this possible pathway to TTM (Duke et al., 2010).

### Emotion Regulation Model

The ways in which individuals identify and react to emotional experiences are referred to as affective regulation. Impulsive and harmful behaviors are utilized to regulate intense emotion when deficits in emotion regulation are present (Diefenbach et al., 2008). Emotion regulation models hypothesize that people with TTM engage in hair pulling to modulate mood states of high arousal (e.g., anxiety, sadness) and low arousal (e.g., boredom, indifference) (Penzel, 2003). Thus, hair pulling stems from the need to decrease an affective state on either end of the continuum of arousal, coupled with a lack of alternative coping strategies (Shusterman et al., 2009). With repeated hair pulling episodes, the behavior becomes associated with emotion, thereby strengthening the

behavior over time. “Thus, emotions serve as cues for hair pulling urges as a result of classical conditioning, while pulling behaviors are reinforced through operant conditioning resulting from the experience of pleasurable feelings and/or the reduction of unpleasant emotional states after pulling” (Diefenbach et al., 2008, p. 33).

Recent studies provide support for the emotion regulation hypothesis of TTM. A comparison study of clinical and nonclinical hair pulling reported larger decreases in boredom, sadness, anger, and tension, and larger increases in relief and calm from before to during pulling for individuals with TTM compared to controls. Further, significant differences were reported for guilt, sadness, anger, boredom, happiness, calm, and relief between groups (Diefenbach et al., 2009). Drysdale, Jahoda, and Campbell (2009) conducted a single case study of hair pulling and found that negative emotional arousal can increase and intensify hair pulling urges in individuals with TTM. Results of an Internet-based study of 1162 hair pullers and controls revealed a small to moderate relationship between affective regulation and TTM, suggesting that hair pullers experience increased difficulty in controlling their emotions compared with controls. Emotional control and disorder severity were significantly correlated for hair pullers (Shusterman, Feld, Baer, & Keuthen, 2009).

### Psychoanalytic Model

Psychoanalytic theory posits that psychological factors present in hair pulling are predicated on two specific elements, the first being that present and future physical and emotional development is influenced by tactile stimulation of the skin and appendages during the first months of life (Koblenzer, 1999), and the second that hair symbolically represents an individual’s emotional content. Stressful experiences similar to masked

unconscious conflicts can trigger or exacerbate hair pulling behavior (Koblenzer, 1999). One psychoanalytic model perceives hair pulling as a symbolic representation of unconscious conflicts resulting from poor object relations where hair pulling is utilized as a way of working through threats of object loss (Krishnan, Davidson, & Guajardo, 1985). For example, TTM may be the result of an ambivalent relationship between child and parents (i.e., a punishing and rigid parent) during the first 2 years of life. Hair symbolizes comfort, expression of pain over loss, and/or a target of anger due to loss (Koblenzer, 1999). Eating the hair (trichophagy) serves as either the oral incorporation of mother or as an aggressive destruction of mother. Hair pulling is also postulated to represent loss of power or castration, loss of attractiveness or love, and punishment—where the individual pulls her/his hair to punish her/himself for harboring loving wishes toward one parent and competitive anger toward the other (Stein et al., 1999). Hair pulling might also be perceived as punishment for feelings of guilt associated with the “forbidden wish for self-gratification” (Koblenzer, 1999, p. 138).

Some psychoanalytic theories suggest that trichotillomania develops as a result of trauma, specifically sexual abuse or trauma (Penzel, 2003; Singh & Maguire, 1989). A commonality among psychoanalytic theories is that they are not empirically validated. Further, such theories suggest that TTM sufferers are to blame for their problem because they unconsciously chose hair pulling and use it as a psychological defense to cope with anxieties and conflicts stemming from dysfunctional family interactions (Penzel, 2003).

### Trauma Model

Trauma is a deeply distressing or emotionally painful experience and a person’s overwhelmed emotional response to the terrible event or situation, which leaves them

powerless. Trauma theory posits that trauma occurs when an external threat prevails, disrupting coping mechanisms because the emotions associated with the experience are too intense to integrate (<http://www.apa.org/topics/trauma/>, retrieved 8/11/15). Traumatic experiences affect thinking, learning, memory, how one feels about self and others, and how one makes sense of the world. In the face of perceived danger, humans exhibit a fight or flight response—the built-in biological mechanism that protects us from harm. Exposure to danger has an additive effect in that the mind connects each episode to the next, leaving it more sensitive to future trauma exposures. Recurrent traumatic stress affects the basic brain neurochemistry (Bremner, 2006) that allows one to self-motivate out of dangerous situations. Trauma victims' ability to gauge the threat level of presented stimuli is altered due to a destabilized internal system of arousal that controls emotional responses to trauma leaving them with only an “on/off” emotional response to traumatic stimuli. As such, traumatized persons are at risk of using negative coping mechanisms (e.g., drugs, alcohol, food, self-harm behaviors, etc.) to regulate emotions (Sinha, 2008).

Humans are physiologically wired to respond to danger or stress; trauma impairs complex and clear thinking. Extreme stress changes mental processing and memory leaving the mind without access to speech (e.g., articulation of an experience with words). The loss of words shifts the mind to utilize other senses such as vision, smell, physical movement or sensations, and emotions to process and access memories, which often places past experiences in the present with the trauma victim reliving her trauma (<http://www.safeplaceolympia.org>). Dissociation is “characterized by a disruption of and/or discontinuity in the normal integration of consciousness, memory, identity, emotion, perception, body representation, motor control, and behavior” (APA, 2013, p.



291). It is the act of separating our emotional experience of the experience from the actual experience. Exposure to repetitive trauma leads to emotional numbing and avoidance (e.g., dissociation). When avoidance symptoms and intrusive symptoms (i.e., flashbacks or re-experiencing traumatic events) combine, PTSD can emerge.

Endorphins, endogenous opioid neuropeptides that are produced by the CNS and pituitary gland, are elevated during times of stress to help modulate our stress response, and when elevated may be a protective factor in the development of PTSD (Sherin & Nemeroff, 2011). Similar to the effects of certain drugs, exposure to prolonged stress and trauma can lead to the activation of arousal and attention systems, the neural circuitry underlying wanting and craving, thereby creating a situation where an individual only feels calm while under stress, and irritable and hyper-aroused when the stress is relieved. Trauma survivors may engage in behavior (e.g., hair pulling) that triggers the same endorphins (Sinha, 2008).

There is a wide body of research on the effects of trauma in children, adolescents, and adults. The brains of chronic trauma and stress survivors are wired differently than the brains of individuals who did not experience repeated trauma exposures and stress. An increased production of cortisol during stress is considered protective in emergencies, but it can reach toxic levels during chronic stress and kill off neurons in developing regions of the brain. When constant anxiety or dissociation emerges during a critical time in brain development, a child's thought processes are negatively impacted and they abandon the idea that they have the ability to make a positive impact in their world (McEwen, 2007).

Adolescence is a particularly crucial period of brain development. The critical process of pruning and reorganizing the brain's cortex occurs in adolescence. Essential functions are hard wired into the brain with repeated use and stimulation while other functions are pruned away due to lack of use or stimulation. The cortex is the highest functioning part of the brain, and it is the epicenter for judgment and planning. During adolescence, the cortex is under construction and adolescents use other parts of their brain to manage emotions, and are more vulnerable to stress (McEwen, 2007).

The effects of traumatic childhood experiences are evident in the physical and emotional health of adults. The Adverse Childhood Experiences Study (Filetti et al., 1998), a landmark study conducted by Kaiser Permanente between 1995 and 1997, surveyed over 9,000 middle-class Americans about adverse childhood experiences (ACE) (i.e., psychological, physical, or sexual abuse; violence against mother; or living with household members who were substance abusers, mentally ill or suicidal, or ever imprisoned) and compared their responses to measures of adult risk behavior, health status, and disease. Major findings of this study included the following: 1) ACEs were far more common than previously thought, and 2) ACEs are highly correlated to risk factors associated with leading causes of death later in life (Filetti et al., 1998).

Traumatic life events have been associated with the onset of hair pulling (Boughn & Holdom, 2003; Lochner et al., 2002; Özten, Sayar, Eryilmaz, Kagan, Isik, & Karamustafalijoglu, 2015). Trauma includes emotional, physical, and sexual abuse, as well as other psychologically traumatic events such as childhood traumatic experiences, natural disasters, fire, traffic accidents, physical attacks, sexual assault, war, unexpected sudden death of a loved one, life threatening medical conditions, sudden unexpected

separation from a loved one, domestic violence, and sudden unexpected job loss or serious economic difficulties (Özten et al., 2015). The commonality among all potentially traumatizing events is that there is a violation of one's worldview that threatens one's sense of security. Trauma is often defined in the context of circumstances outside of normal human experience; however, for some people, trauma exposures occur regularly and become a normal part of the common human experience (e.g., sustained discrimination, ongoing chaotic life conditions, and continuous negative feedback resulting from TTM). Not all people experience trauma in the same way. Trauma is not necessarily based on the objective facts, but rather it is subjective due to one's previous experiences (trauma or otherwise), coping capabilities, and currently available resources. This means that two people who experience the same potentially traumatizing event may react to it differently and one may be traumatized whereas the other is barely affected (Storr, Ialongo, Anthony, & Breslau, 2007).

A study conducted by Özten and colleagues (2015) in Istanbul, Turkey found that individuals with TTM and skin picking had significantly higher numbers of traumatic exposures in childhood compared to healthy control participants. The researchers concluded that trauma may play a role in the development of TTM and skin picking. An increase in the duration of time spent hair pulling or skin picking was correlated with fewer symptoms of PTSD. Özten and colleagues (2015) speculated that trauma survivors develop TTM or skin picking as coping strategies to mitigate intrusive thoughts related to trauma, thereby reducing PTSD symptoms.

Several studies report a relationship between sexual abuse and the onset of TTM (Christensen, Mackenzie, & Mitchell, 1992, 1991a; Singh & Maguire, 1989). Green

(1978) reported impaired impulse control among emotionally abused children. Lochner et al. (2002) reported a significant relationship between childhood trauma and TTM among women, with significantly higher scores for emotional neglect and physical abuse being noted for TTM compared to controls.

Boughn and Holdom (2003) interviewed 44 women with TTM and found that 86% of the women were exposed to some form of trauma or violence (i.e., sexual assault, rape, or gang rape) at the onset of their hair pulling. Boughn and Holdom (2003) concluded that the women in the sample population “experienced a disproportionate number of traumatic or violent episodes in childhood, and in most cases, the onset of TTM was correlated with specific episodes of violence” (p. 165). Additionally, Boughn and Holdom (2003) found a strong association between the onset of TTM and exposure to verbal abuse among women in their study of violence and TTM.

Few studies exist demonstrating a relationship between TTM and trauma and/or posttraumatic stress disorder (PTSD) despite their etiological implications (Gershuny, Keuthen, Gentes, Emmot, Jameson, Loh, & Jenike, 2006). One study indicated that approximately 76% of their sample population of individuals with TTM had experienced at least one traumatic experience in their lifetime, and 19% met criteria for PTSD, which was a higher rate than in the general population (Gershuny et al., 2006). They noted that an increase in the number of experienced traumas was associated with a longer period of hair pulling as well as the scalp as the primary pulling site. The authors speculated that, for the traumatized individual, TTM might represent coping, vis-à-vis self-soothing or self-harm (Gershuny et al., 2006). A case study conducted by Corso and McGeary (2008) focused on a 45-year-old male, an active duty military officer, diagnosed with PTSD and

TTM subsequent to deployment to Iraq during the Global War on Terror. They posited a relationship between TTM and PTSD after successfully treating TTM symptoms in one individual using habit reversal therapy (HRT), while at the same time, the individual reported an unexpected decrease in emotional stress and PTSD symptoms (Corso & McGeary, 2008). It is important to note that, although these studies suggest a link between TTM and trauma or PTSD, they are not indicative of a causal relationship. It is possible that an increase in baseline anxiety, despite the cause, may increase risk for developing TTM in some individuals (Duke et al., 2010). Given that everyone experiences traumatic events differently and copes with trauma symptoms in an individual way, their conceptualization of their experience and resulting behavior(s) is very important as it provides deeper insight and understanding of how and why someone developed TTM, as well as what they would like to do about it, and if their conceptualization and understanding may contribute to successfully eliminating the behavior if that is the chosen goal.

### Additional Models

In addition to the plethora of models suggested above, additional perspectives have also been suggested. Some theorize that trichotillomania is a form of addiction much like pathological gambling and that it should be treated as such in some individuals. Grant, Odlaug, and Potenza (2007) presented the case of a woman with a positive family history for addiction who began pulling once a week to relieve anxiety and to experience feelings of pleasure. The participant reported increasing her hair pulling behavior to daily over the course of 10 years in order to produce the same feelings of relief and pleasure. Evidence that opioid antagonists effectively treat TTM in some

individuals suggests that, for some, TTM is more like an addiction (Christensen, 1994, as cited in Penzel, 2003). Additional studies are necessary to further conceptualize TTM from an addictions perspective.

Santhanam, Fairley, and Rogers (2008) studied 38 children who presented with hair loss unexplained by any dermatological disorder and concluded that hair pulling, as a symptom in children, is a heterogeneous condition. The researchers proposed that a developmental model for understanding hair pulling behavior in children and adolescents be utilized due to difficulties in assigning diagnoses under the existing systems and/or qualifying their dysfunction as pathological (Santhanam et al., 2007). This misfit of available explanations and overlaying of models to describe and conceptualize hair pulling speaks to the need that additional studies be conducted to further develop current models of TTM for adults and children, as well as offer new models of conceptualizing hair pulling. Just as there are a variety of models and theories offering explanations of TTM, so, too, are there multiple treatment options.

#### Treatment

No clear guidelines are available for the treatment of TTM. There is a need for large-scale, controlled empirical treatment studies of TTM in order to provide reliable and effective treatments (Keuthen, et al., 1999). In addition, qualitative research is needed to more clearly shed light on the experiences of individuals with TTM themselves in order to more clearly understand the phenomena. Historically, psychoanalytic perspectives were utilized to conceptualize and treat TTM (Aleksandrowicz & Mares, 1978; Buxbaum, 1960; Sperling, 1968). Today, treatment literature is divided into pharmacological and psychotherapeutic interventions. Pharmacotherapy and behavior

therapy are two treatment modalities known to be potentially beneficial in decreasing hair pulling behavior. Many professionals believe that a combination of behavior therapy and pharmacotherapy offers optimal benefits to people with TTM in both the short and long term. Increased attention has recently been given to combining acceptance and commitment therapy (ACT) with habit reversal training (HRT) as an effective treatment for hair pulling. Woods, Wetterneck, and Flessner (2010) reported that ACT combined with HRT works to decrease experiential avoidance and increase treatment compliance, thereby significantly reducing hair pulling.

### Pharmacotherapy

A variety of medications are commonly used in the treatment of TTM, including tricyclic antidepressants (TCAs), serotonin specific reuptake inhibitors (SSRIs), unclassified antidepressants, antipsychotics, and opiate antagonists (Penzel, 2003). A number of pharmacological treatments of TTM have been studied utilizing controlled trials with both varying results and side effect profiles, which further complicates the issue. Several research studies indicated that antidepressant medications with serotonergic properties (e.g., clomipramine and SSRIs) are useful in treating a minority of individuals with TTM (O'Sullivan, Christensen, & Stein, 1999). Clomipramine blocks the reuptake of two neurotransmitters in the brain: serotonin and norepinephrine (O'Sullivan et al., 1999; <http://www.trich.org>). Swedo and colleagues (1989) conducted one of the initial studies focused on the pharmacological treatment of TTM. In a 10-week, double-blind, crossover design study comparing clomipramine (a tricyclic antidepressant with selective antiobsessional effects) to desipramine (a standard tricyclic antidepressant) in TTM, Swedo and colleagues (1989) reported that clomipramine proved

to be the superior treatment. Clinician ratings and trichotillomania-impairment ratings were utilized to determine treatment success (Swedo, 1989). Results from a 4-year follow-up study revealed variable response rates to clomipramine, with less than half of the participants exhibiting symptom reduction (Swedo, Lenaine, & Leonard, 1993). Clomipramine use has been limited clinically due to adverse side effects, but another antidepressant drug, venlafaxine, has been used to effectively treat TTM (O'Sullivan et al., 1999).

Antidepressant medications that block the reuptake of serotonin (SSRIs) have been studied with mixed results (O'Sullivan et al., 1999). Some individuals report a reduction in hair pulling initially with the effect of the medication wearing off over time. Some individuals do not benefit from medication by seeing a decrease in hair pulling but notice a reduction in anxiety and elevated mood (O'Sullivan et al., 1999; <http://www.trich.org>). The results of an 18-week placebo-controlled, double-blind, crossover study of fluoxetine (SSRI) revealed no significant effects between fluoxetine and placebo (Christenson, Mackenzie, Mitchell, & Callies, 1991). Streichenwein and Thornby (1995) studied the long-term efficacy of fluoxetine in a 31-week placebo-controlled study. No significant differences in hair pulling were reported between fluoxetine and placebo (Streichenwein & Thornby, 1995). Additionally, treating childhood TTM with SSRIs is questionable. However, they may be helpful in treating comorbid symptoms of anxiety and depression (Bloch, 2009).

Mixed results in antidepressant trials have given rise to investigating other pharmacological treatment options for TTM. Additional medications considered potentially useful in treating TTM include other antidepressants, opiate antagonists



(Carrion, 1995; De Sousa, 2008), mood stabilizers (Adewuya, Zinser, & Thomas, 2008), anxiolytics (Epperson, Fasula, Wasylin, Price, & McDougle, 1999; Ikenouchi-Sugita, Yoshimura, Ueda, & Nakamura, 2009), neuroleptics (O'Sullivan et al., 1999), and antipsychotics (Van Ameringen, Mancini, Oakman, & Farvolden, 1999; Van Ameringen, Mancini, Patterson, Bennett, & Oakman, 2010). In a randomized, double-blind, placebo-controlled trial of the antipsychotic medication olanzapin in the treatment of trichotillomania, Van Ameringen and colleagues (2010) utilized the Yale-Brown Obsessive Compulsive Scale for Trichotillomania (TTM-YBOCS) and the Clinical Global Impressions-Severity of Illness Scale (CGI) to measure differences in hair pulling between olanzapine and placebo conditions. Results indicated a significant decrease in hair pulling for 85% of the olanzapine group. The researchers concluded that olanzapine is a safe and effective treatment for TTM (Van Ameringen et al., 2010). An earlier study conducted by Van Ameringen and colleagues (1999) assessing the effects of haloperidol treatment, another antipsychotic medication, in TTM revealed significant decreases in hair pulling for 89% of their study population, with 78% experiencing complete or near complete cessation of hair pulling. The researchers concluded that the use of haloperidol alone or in addition to SSRIs might be effective in the treatment of TTM (Van Ameringen et al., 1999). Grant and colleagues (2009) reported a significant reduction in hair pulling severity, with 56% of the treatment group being much or very much improved, in their double-blind placebo-controlled trial of n-acetylcysteine, a glutamate modulator. Additional studies in this area are necessary to replicate findings and provide further direction for the pharmacological treatment of TTM.

Exactly how medications are working to decrease symptoms of hair pulling is

unknown. The heterogeneity of TTM may contribute to this variability in the utility of such medications. These other medications target anxiety, obsessions and compulsions, pruritis, and mood, which may be contributors to hair pulling that are specific to the individual. Additionally, serious adverse side effects (e.g., dyslipidemia, hypertension, gross weight gain, neurotoxicity, delirium, encephalopathy, behavioral activation, tremors, hypothyroidism, and diabetes) (Freeman & Freeman, 2006; Shirzadi & Ghaemi, 2006) may present when taking such medications as antidepressants and antipsychotics (Duke et al., 2010). It is recommended that pharmacotherapy should be augmented with other treatment (i.e., additional medications and/or behavior therapy) if medication benefit is partial. Treatment providers recommend that medication be discontinued if ineffective when treating hair pulling unless there are marked benefits for comorbid conditions. Combining behavioral treatment with medications is considered to maximize treatment response and minimize relapse (O'Sullivan et al., 1999; <http://www.trich.org>).

### Behavioral Treatments

Behavioral approaches to TTM suggest that hair pulling behavior is developed and maintained through classical and operant conditioning (Mansueto et al., 1997). As a result, behavioral treatments are focused on antecedents to pull, associated hair pulling behaviors, and consequences of hair pulling (Duke et al., 2010; Mansueto et al., 1997). Behavioral therapy is an empirically supported nonpharmacological approach to treating trichotillomania (Diefenbach, Tolin, Hannan, Maltby, & Crocetto, 2006; Dougherty, Loh, Jenike, & Keuthen, 2006; Flessner, Penzel, TLC-SAB, & Keuthen, 2010). Historically, HRT has been extensively studied as a potential behavioral treatment for TTM. A recent

review of TTM treatment literature lends support for acceptance and commitment therapy alone and in combination with HRT as effective treatments for TTM.

Habit reversal, a behavioral technique that is oftentimes used to treat TTM, remains the most widely accepted treatment (Keuthen et al., 1999, p. 161). Habit reversal training (Azrin & Nunn, 1973) is a multimodal approach consisting of 13 major components, including competing reaction training, awareness training, identifying response precursors, identifying habit-prone situations, relaxation training, prevention training, habit interruption, positive attention, competing reaction, self-recording, display of improvement, social support, and annoyance review (Azrin, Nunn, & Frantz, 1980). Habit reversal training aims to increase personal awareness of individual hair pulling episodes and engage a competing response to interrupt the hair pulling behavior. Triggers and events associated with hair pulling are identified in an effort to increase awareness of hair pulling (<http://www.trich.org>). A competing response, something that is not associated with hair pulling, such as clenching fists, is a critical element of HRT. Competing responses are employed briefly following an urge to pull or after hair pulling has occurred. Habit reversal training also includes preparing individuals for treatment, maintaining motivation during treatment, and relaxation training (Keuthen, et al., 1999; <http://www.trich.org>). Hair pullers are encouraged to schedule and practice competing responses daily (Azrin et al., 1980). In a randomized group study of TTM, HRT reduced hair pulling by 90% 4 months after treatment compared to negative practice, which reduced pulling by only 68% at a 3-month follow-up (Azrin et al., 1980; Keuthen et al., 1999).

Other behavioral therapy strategies include “stimulus control” procedures and

stress management. Stimulus control techniques are designed to interfere with hair pulling when it is likely to occur (Keuthen et al., 1999). Wearing gloves, hats, scarves, or rubber fingertip protectors, as well as sitting on hands so that they fall asleep are typical techniques utilized by hair pullers to avoid pulling in situations (e.g., watching television, reading, or driving) where it is likely to occur (<http://www.trich.org>). Hair pullers are taught stress management techniques, such as breath control, deep muscle relaxation, and cognitive techniques to modulate stress because “hair pulling often occurs, increases, or re-appears in conjunction with stress” (<http://www.trich.org>). Self-monitoring, punishment techniques, reinforcement techniques, cognitive behavioral techniques, relaxation training, response/prevention, and group behavioral treatment are also successfully used to treat TTM (Keuthen et al., 1999).

Acceptance and commitment therapy (ACT) is a third wave behavioral therapy that uses acceptance and mindfulness skills in combination with commitment and behavioral change strategies to develop psychological flexibility and to help clarify and direct values-guided behavior (Hayes, Strosahl, & Wilson, 1999). ACT promotes “just noticing” and acceptance of private events such as feelings, thoughts, and urges, rather than teaching individuals emotional control strategies as occurs in traditional cognitive behavior therapy. Experiential exercises and metaphors are utilized to foster acceptance, deliteralize language, clarify personal values, and move the individual to take action specific to personal values in an effort to increase one’s personal meaning for life (Hayes et al., 1999).

There is growing support for the efficacy of ACT in treating TTM (Flessner, Busch, Heideman, & Woods, 2008). For example, in a controlled evaluation of

acceptance and commitment therapy plus HRT for TTM, results demonstrated a significant reduction in hair pulling severity, impairment ratings, and number of hairs pulled (Woods, Wetterneck, & Flessner, 2006). Additionally, findings indicated significant reductions in experiential avoidance and both anxiety and depressive symptoms for the ACT/HRT group. Trichotillomania severity significantly correlated with decreased experiential avoidance and increased treatment compliance, suggesting that targeting experiential avoidance may be helpful in treating TTM (Woods, Wetterneck, & Flessner, 2006). Studies combining behavioral therapy modalities ACT and HRT provide preliminary evidence for their independent contributions to symptom reduction in the treatment of TTM (Flessner, Busch et al., 2008). Further, results of behavioral treatment studies suggest combining ACT and HRT to achieve the greatest benefit (Flessner, Busch et al., 2008; Walther et al., 2010).

Caution should be exercised when reviewing treatment literature due to possible sample selection bias (i.e., samples may be biased toward high-functioning and motivated individuals), study design (i.e., lack of randomized group designs), and follow-up (e.g., follow-up studies are limited to 6 months posttreatment) (Keuthen et al., 1999). In addition, generalizability is questionable given that the majority of efficacy studies are case studies with positive outcomes associated with psychoanalytic therapy and behavioral treatments (Keuthen et al., 1999). Further, multiple behavioral techniques are usually administered when treating TTM. Friman, Finney, and Christophersen (1984) reported mixed results when comparing single behavioral techniques to multiple behavioral techniques.

## Breaking the Silence of Trichotillomania

Trichotillomania is a silenced illness. This is not only due to the secretive nature of hair pulling, but also because of its lack of presence and acceptance among public knowledge and behaviors. Not talking about the behavior itself, as well as silencing the emotional self, contribute to increased hair pulling and associated comorbid conditions such as anxiety and depression, as well as to both the internalized shame and the stigma associated with TTM. Silencing the self refers to concealing emotions, thoughts, and needs as a way of gaining and maintaining the approval of others. Women who self-silence are at increased risk of experiencing psychological difficulties (Jack, 1993). Self-silencing as it relates to trichotillomania is limited in the literature. A qualitative study conducted by Casati (2010) demonstrated the impact that silencing the emotional self has on psychological wellbeing and hair pulling. Specifically, half of the women in the study reported that the inability to express their emotional needs resulted in the development of coping strategies such as hair pulling (Casati, 2010).

In feminist theory, TTM can be conceptualized as a coping strategy employed by individuals of marginalized populations to deal with living in an oppressive and patriarchal society (Brown, 1994; Espin, 1994). Supporters of the feminist conceptualization lament that the disproportionate number of women who report TTM (APA, 2000) when compared to men could be indicative of the relationship between women, self-silencing, and/or trauma, given their vulnerability as a population. Additionally, traditional methods of diagnosis, often victimizing/blaming labels, contribute to internalized views of self that may result in hair pulling (Greenspan, 1983; Sinacore-Guinn, 1995).

There is no perfect way to conceptualize and understand hair pulling. This task is even more difficult when medical and behavioral models and treatments do not take into account individual differences among those who engage in the behavior itself. A missing factor in all available models and treatments is lack of participant input and insight into their hair pulling behavior and its associative features. In order to gain a deeper understanding of hair pulling, it is important to invite the hair puller into the conversation of conceptualizing her or his behavior. Including the affected individuals' perspectives of their hair pulling may provide additional clues to this complex behavior and offer a different approach to conceptualizing hair pulling, which may lead to enhanced and more effective treatment.

#### Purpose of the Study and Research Question

A survey of the TTM literature indicates that research is focused using quantitative methods following the medical model to study pharmacological (Dia, 2008; Pittenger, Coric, Banasr, Bloch, Krystal, & Sanacora, 2008; Sharma & Corpse, 2008) and behavioral treatment interventions (Himle, Perlman & Lokers, 2008), as well as potential biological (Aneja & Tierney, 2008; Chamberlain et al., 2008; Katayama et al., 2010) and environmental causes of hair pulling (Flessner, Woods, Franklin, Keuthen, & Piacentini, 2008a; 2008b). The etiology of TTM is not completely understood, and available treatments and research are limited by study design, sample selection, generalizability, and treatment administration (Friman et al., 1968; Keuthen et al., 1999). Qualitative studies are notably missing in the TTM literature with the exception of a few linking hair pulling to trauma (Boughn & Holdom, 2003; Christensen, Mackenzie, & Mitchell, 1992, 1991a; Gershuny et al., 2006; Green, 1978; Lochner et al., 2002; Singh & Maguire, 1989)

and early life events (Casati, 2010). Further, very few qualitative studies of TTM and women only are found in the TTM literature. This lack of information necessitates that qualitative studies be conducted to address the lived experience of women with TTM and the meanings that women with TTM assign to their experiences with this disorder.

The disproportionate number of females with trichotillomania may be due to socially constructed gender norms related to grooming (e.g., it is not socially acceptable for a woman to have a shaved head; APA, 2000), gender differences in personal conceptualization of hair pulling, and/or gender differences in treatment seeking. However, given the associative features (i.e., shame, secretiveness, avoidance in social situations, isolation, and humiliation) (Casati et al., 2000) of TTM, this disparity may be the direct result of the oppression that women and girls are subject to as a result of living in a society where diagnosis and treatment are dominated by the medical model, a model that was historically designed and maintained by men. It is important to study women who pull their hair while understanding the context in which they live in depth and in detail given the secretive and shameful nature of hair pulling (Casati et al., 2000; Denzin & Lincoln, 1994; Marshall & Rossman, 1989; Patton, 2002).

This study is important in that qualitative interviews with women with TTM will allow the research community to glean information about the experience of hair pulling from women who engage in the behavior. Additionally, understanding how women conceptualize and make sense of their hair pulling behavior can further our understanding of the phenomenon, how women incorporate hair pulling into their identity, and how their conceptualization contributes to treatment seeking and success. Using qualitative methods to capture how women conceptualize their own hair pulling is important because



it offers a way to further understand how hair pulling develops for different people, and how it shapes the lives and relationships of hair pullers. In-depth interviews provide non-pullers (i.e., partners, family members, friends, and treatment providers) with personal insights into hair pulling behavior and what maintains the behavior. The extant global hair pulling conversation, including research studies, is missing a personalized conceptualization of hair pulling. A personalized look at the phenomenon at hand may provide information to aid in understanding TTM, as well as providing clarification as to what stands in the way of acceptance, both individual and universal, and ways of addressing hair pulling. The current study addressed the question, “What are the experiences and perceptions of women who engage in chronic hair pulling?”

## CHAPTER 2

### METHOD

#### Methodological and Theoretical Considerations

The literature pertaining to women's experiences and perceptions of their own hair pulling is limited. Qualitative studies examining the phenomenon of hair pulling as it is experienced by women who engage in hair pulling, in addition to how these women make sense of their hair pulling, are nonexistent. As such, qualitative studies in the area of trichotillomania are needed to increase both public and professional understandings of the experiences and perceptions of women living with trichotillomania. An increased understanding of women's experiences with TTM and their conceptualizations as to how and why they engage in hair pulling are necessary, not only to increase awareness of this behavior and to decrease the public stigma of it, but also to address the impact that it has on a woman's mental and physical health, her relationships with self and others, as well as to help guide treatment.

Given the etiological complexities of TTM and the individual differences of the women who engage in hair pulling, it is no wonder this behavior is so difficult to characterize, let alone generalize to every woman who pulls her hair, in order to formulate treatment. Hair pulling treatments are usually retrofitted to the behavior from some other disorder and are not an exact fit. A personalized picture of hair pulling from the hair puller herself helps one to discern the nature of the behavior and to personalize

treatment in an effort to get the hair puller to “buy in” to her treatment. It is common knowledge among treatment providers that an individual has increased success specific to treatment adherence when she or he understands the behavior/problem/condition and its treatment options, and “buys in” to the treatment plan. This study aims to help hair pullers, treatment providers, and support persons better understand the complexities of the hair pulling phenomenon by addressing the role of the hair puller’s conceptualization of her behavior and the impact that it has on the behavior itself. To date, no studies have specifically addressed women’s experiences of hair pulling and how they make sense of it. In understanding their experiences, we are better equipped to recognize how hair pulling affects their lives both physically and emotionally. Once a more complete understanding of hair pulling and its effect on individual lives is available, personalized treatment is possible.

A brief search of trichotillomania on YouTube reveals over one million entries. Many are women’s brief personal video journals about their struggles of living with TTM, suggesting that TTM sufferers have a voice about their hair pulling that wants to be heard and a story that needs to be told. Other entries include public service announcements, news stories, and self-help information about the disorder. The disparity in TTM information available in popular media and academic writing further accentuates the need for additional studies focused on a comprehensive understanding of women’s experiences with TTM, how they make sense of it, and how their conceptualization of hair pulling contributes to self-acceptance and living with the behavior. It is important to understand trichotillomania from the perspectives of individuals who have the condition as a way of identifying possible contributors to its development and maintenance, as well

as to help guide treatment. As such, this study seeks to contribute to the literature by studying how women experience their TTM and make sense of it.

A qualitative approach is the most appropriate research approach to take to understand women's experiences and perceptions of their hair pulling. "Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social and human problem" (Creswell, 1998, p. 15). Qualitative research provides researchers with the chance to grasp participants' meanings of their own experiences. It is through observation and storytelling that this understanding is achieved (Siedman, 1991). Like TTM, qualitative research is multifaceted in that the researcher uses multiple research tools (e.g., in-depth interviews and participants' own language, personal observations, a journal, etc.) to build a complex and holistic picture of the study topic (Creswell, 1998). Qualitative studies are often conducted in a natural setting or in the field, which contributes to a deeper understanding of that which is being studied. In this research study, studying TTM outside of the clinical atmosphere was most helpful in understanding the complexities of the disorder. Interviews for this research were conducted both in person and over the phone. Whether the interview was in person or over the phone, participants chose interview locations where they were comfortable talking about their hair pulling. Example locations include at home, a hotel lobby, poolside, at the workplace, in the car, and in a coffee shop. Researcher observation was not possible for interviews conducted over the phone, whereas it was for those that took place face to face. Conducting the interviews in an environment chosen by the participant contributed to a decreased sense of stress about the interview itself and allowed the participants to open up about their emotional experience

as it related to hair pulling.

Theoretical underpinnings of research both guide and inform the research process. Constructivism and feminist theory provided the framework to study and understand how women with TTM make sense of their hair pulling and construct personal meanings of their behavior in the context of their lives. Constructivist epistemology aims to understand how people construct meanings and actions attributed to their experiences (Charmaz, 2006; Denzin & Lincoln, 1994). Constructivism acknowledges multiple realities specific to each individual's understanding of her experience and concentrates on comprehending the assumptions associated with any particular view (Patton, 2002). What we know and think is true is a construction, our best understanding, based upon and inextricably intertwined with personal choices, development, and goals (Bohan, 1993). Constructionists ask: "*What* do people assume is real? *How* do they construct and act on their view of reality?" (Charmaz, 2006, p. 127).

Feminist theory served as a framework for this study because it embraces sociopolitical ideals of equality and values the voices of women who have often been silenced due to societal, political, economic, and interpersonal factors (Brown, 1994; Espin, 1994; Sue & Sue, 1999). Feminist epistemology, like constructivism, assumes that multiple realities and truths exist. Moreover, a feminist perspective provides a critical analysis of the participants' experiences in collaboration with the participants in an effort to be consciousness-raising and political (Morrow & Hawxhurst, 1998). Feminist multicultural research (Brown, 1994; Espin, 1994) encourages personal empowerment through personal, interpersonal, and sociopolitical change (Morrow & Hawxhurst, 1998),

all the while avoiding pathologizing, which is often victimizing and labeling (Greenspan, 1983; Sinacore-Guinn, 1995).

It was reasonable to approach this research with a constructivist and feminist framework given the multifaceted nature of trichotillomania. The feminist approach served to give a voice to the women about their hair pulling specifically because TTM is a silenced disorder. Both constructivism and feminist theory offered recognition of the uniqueness of each woman's experience and perception of her hair pulling and sought to understand the meaning of hair pulling from both an individual female perspective and from the global perspective of women with TTM.

#### Grounded Theory Research Design

A first step in the qualitative research process is to choose an approach to study the topic at hand. This study utilized a grounded theory approach. Constructivist grounded theory prioritizes study phenomena and asserts that shared experiences and relationships with participants and other sources of data contribute to both data and analysis (Charmaz, 2006). Constant discourse and questioning of meaning is a way to construct meaning and to develop theories about particular phenomena—in this case hair pulling. Analysis of documents and written materials, researcher participation in the setting, direct observation, and in-depth interviewing are four common methods of gathering information that are essential to qualitative inquiry (Marshall & Rossman, 1999).

The inception of grounded theory came about in the 1960s through the collaborative work of sociologists Barney Glaser and Anselm Strauss. Glaser and Strauss were interested in death and dying in terminally ill hospital patients. Their research

focused on how healthcare professionals and their terminally ill patients across hospital settings understood the dying process and their reactions and interactions when faced with impending death (Charmaz, 2006). Their research culminated in the book *Awareness of Dying* (Glaser & Strauss, 1965). Glaser and Strauss utilized a constant comparative method (continually analyzing data at all stages of collection) to analyze dying, which resulted in a systematic way of generating theory from data; grounded theory was born as a result (Charmaz, 2006). Two years later, Glaser and Strauss wrote *The Discovery of Grounded Theory* (1967), which provided research methodology for building theories or conceptual models from the research data as an alternative to using existing theories to test hypotheses (Charmaz, 2006). This groundbreaking work legitimized qualitative research and methods in a quantitative world.

Grounded theory starts with a question and has a reverse approach to conducting the research. Conceptual ideas provide the foundation for hypotheses in grounded theory development. Grounded theory practice involves the following:

- 1) Concurrent data collection and analysis.
- 2) Using data to construct analytic codes and categories rather than hypothesizing from existing theories.
- 3) Constantly comparing data at all stages of analysis.
- 4) Continually developing theory during all stages of data collection and analysis through theoretical memoing.
- 5) Writing memos for category development and refinement, to identify categorical relationships, and to identify gaps within categories.
- 6) Population sampling to aid in theory construction.

- 7) Developing an independent analysis of data prior to conducting the literature review (Charmaz, 2006).

Creswell (1998) stated that a researcher's task when using grounded theory is to develop an understanding of a particular experience and its accompanying circumstances. The circumstances are how individuals "interact, take actions, or engage in response to a phenomenon" (Creswell, 1998, p. 56). This study utilized a grounded theory approach because the purpose of the study was to develop an understanding of how women experience and conceptualize their hair pulling. Using a grounded theory approach for this study was useful in that it helped to identify various elements associated with women's perceptions of their hair pulling behavior.

A grounded theory approach requires that researchers set aside theoretical biases and preconceived notions specific to the topic to allow theory to emerge (Creswell, 1998). A comprehensive review of the research literature was conducted for this study without preconceived hypotheses specific to TTM and hair pulling. As such, the literature revealed a bias toward an externalized understanding of TTM, leaving a gap in the literature whereby understanding the hair pulling phenomenon is explained from those who engage in the behavior. A study utilizing grounded theory offers an opportunity for others to understand TTM from those who experience it.

It is important for qualitative researchers using a grounded theory approach to be aware that it is an analytical approach to research with well-ordered steps in data analysis (Creswell, 1998). To this extent, the following steps were taken when analyzing the transcriptions of participants' interviews:

- 1) Initial coding [line-by-line analysis of interviews].



- 2) Focused coding [connecting initial codes to form categories for further exploration].
- 3) Theoretical coding [development of theory by connecting categorical codes to tell a coherent analytical story] (Charmaz, 2006).

Coding is explained in detail in the data analysis section of this chapter.

Additional considerations that must be taken into account when utilizing grounded theory include knowing when the amount of information collected is sufficient for category and theory development, and understanding that the goal of the research is the emergence of a theory (Creswell, 1998). Transcriptions were reviewed extensively over multiple sittings until it was determined that no new information was available, thus achieving saturation.

The data analysis section of this chapter contains detailed information on saturation.

Emergent themes from this study are presented in the results section.

## Research Design

### Participants

All qualitative research sampling for this study was criterion based and purposeful in that each participant was chosen for an in-depth study of her information-rich experience. The purpose of this study was to learn about the experiences and perceptions of women who engage in hair pulling. The women in this study were required to meet DSM-IV-TR diagnostic criteria for TTM. Women, ages 18 and older, were recruited to participate in this study. Other inclusion criteria included the TTM DSM IV-TR diagnostic criteria of 1) “recurrent pulling out of one’s hair resulting in noticeable hair loss; 2) an increasing sense of tension immediately before pulling out the hair or when attempting to resist the behavior; 3) pleasure, gratification, or relief when pulling out the

hair; 4) the disturbance is not better accounted for by another mental disorder and is not due to a general medical condition; and 5) the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning” (APA, 2000, p. 677). It was necessary for women in this study to be able to participate in a 60–90 minute interview, as well as to provide consent. The DSM-5 became available in 2013 after recruitment, sampling, and participatory interviews were completed for this study, which is why DSM-IV-TR TTM criteria were used. All participants of this study met diagnostic criteria for TTM under the current DSM-5, and it was not necessary to recruit additional participants due to attrition.

Information advertising this study was made available on the Trichotillomania Learning Center (TLC) website and was sent to trichotillomania support groups nationwide that are affiliated with the TLC. More than 40 women responded to the advertisement expressing interest in participating in this study. Initial responses came in the form of telephone calls and emails. Initially, I chose participants for their information-rich history highlighting their intense personal experiences specific to hair pulling. Subsequent participants were chosen to participate in the study for category and theory development.

Twenty-two women were interviewed for this study. Four in-person interviews took place in Utah. Additional in-person interviews were conducted at the TLC national conference held during the spring of 2010 in Texas. A total of 6 women participated in personal interviews at the 2010 conference for trichotillomania. Telephone interviews were scheduled with participants when travel was not possible and at a time that was convenient for the participants. Additionally, telephone interviews were scheduled with

the participants when they were not able to attend an interview for 1 to 2 hours. Twelve women were interviewed over the phone for this study.

Twenty-two participants provided demographic information. The following information was gleaned from the 20 demographic screening questionnaires and from two interviews. Participants ranged in age from 20 to 61 years old, with a mean age of 34 years. Eighty-two percent of the participants identified as Caucasian or White. One participant identified as Hispanic/White (4%). The ethnicity of 14% of the study participants was unknown. Participants live in varied geographic locations across North America: East (18%), Midwest (36%), North (9%), South (14%), and West (23%).

The average reported age of onset for hair pulling was 12 years old (range=3–40 years). When asked about the number of years that they engaged in pulling, the women's responses ranged between 2 and 49 years, with an average of 22 years. All of the participants reported noticeable hair loss as a result of pulling. When asked, "Do you feel tension right before you pull or when you are trying to resist pulling your hair?" 82% of the participants reported yes; 95% percent of the participants informed that they experience pleasure, comfort, and/or relief as a result of hair pulling. Hair pulling was diagnosed as trichotillomania for 70% of the participants. Sixty-eight percent of the participants reported experiencing significant distress resulting from hair pulling. Primary and secondary sites for hair pulling varied across participants. Many participants reported pulling from multiple areas for both primary and secondary pulling sites. Primary sites included scalp (71%), eyebrows (29%), eyelashes (24%), pubic region (10%), and face (10%). Secondary hair pulling sites included pubic region (30%), legs (20%), scalp (20%), face (10%), arms (5%), all over the body (5%), and nose (5%). Thirty-five percent

of the responders to the questionnaire informed me that they do not have a secondary hair pulling site.

The average time gone without engaging in hair pulling was 11 months ( $N=20$ ) with a range of 0 days to 24 months. The majority (95%) of the participants responded that they pull their hair without thinking about it. Over half (55%) of the women reported that they engaged in focused hair pulling. Approximately 20% of participants pull their hair at a specific time of the day. Out of the total number of participants, 76% reported rituals associated with their hair pulling. One third of the participants have a known family history of hair pulling or trichotillomania.

### Sampling

Initially, purposeful intensity sampling was utilized due to its focus on information-rich cases that highlight intense personal experiences of the participants in order to understand the phenomenon of interest (Patton, 2002). In this study, the phenomenon of interest was the personal experiences of women who engage in chronic hair pulling. Participants were recruited by request on the website of a national trichotillomania support organization. I used intensity sampling to select a small number of rich cases to provide in-depth information and knowledge of TTM at the beginning of this study.

Theoretical sampling is the data collection process of collecting data while coding and analyzing the data to determine what new specific information needs to be collected in order to develop an emerging theory (Charmaz, 2006). Theoretical sampling was utilized to gather preliminary data that were coded, and categories were formed, which revealed promising abstract tools for additional analysis (Charmaz, 2006). In order to

“elaborate and refine” categories of emerging theory, theoretical sampling aimed to gather additional data focused on the category and its properties (Charmaz, 2006, p. 96). When no new categorical properties emerged from the data, theoretical sampling was complete. Specifically, categories were saturated with data and subsequently sorted and/or diagrammed to integrate emerging theory (Charmaz, 2006). Theoretical sampling provided direction for the analysis and kept me from becoming stuck in the data. Theoretical sampling involved only conceptual and theoretical development. Theoretical sampling “is *not* about representing a population or increasing the statistical generalizability of results” (Charmaz, 2006, p. 101).

Saturation in theoretical sampling was achieved when fresh data no longer produced fresh insights nor revealed new theoretical category properties (Charmaz, 2006). Charmaz (2006) explained that theoretical saturation of categories is the goal of grounded theory and should be approached cautiously so as not to prematurely claim saturation as a result of closing out a category early through uncritical or limited analysis. Sample size is achieved through grounded theory theoretical sampling when categories are saturated and, “this logic supersedes sample size—which may be very small” (Charmaz, 2006, p. 114). Therefore, participants were added to the study to reach redundancy (Hill, Thompson, & Williams, 1997) and theoretical saturation (Charmaz, 2006; Patton, 2002). Participants were recruited for this study based on the rule of “redundancy plus one” (Patton, 2002). Achieving saturation requires that no new information can be extrapolated from the data to produce new categories. For example, if nothing new is learned from the 10th interview, an 11<sup>th</sup> interview is conducted for assurance. If new data emerge, a 12<sup>th</sup> interview must be conducted. If no new information

is learned from interview 12, saturation has been achieved, but data from a 13<sup>th</sup> interview must be collected to reach redundancy (Patton, 2002). This method of sampling was applied to each category that was produced through theoretical sampling.

### Recruitment

Women were recruited to participate in this study with the help of the Trichotillomania Learning Center (TLC). The TLC is a nationally based nonprofit organization that works to improve the quality of life of children, adolescents, and adults with trichotillomania through information dissemination, education, outreach, alliance building, and support of research into the causes and treatment of this disorder (<http://www.trich.org>). Participants were recruited nationally.

A recruitment flyer providing a brief description of the study, eligibility criteria, limited personal information about me, and contact information, was posted on the TLC website along with a demographic screening questionnaire for potential participants.

Eligibility requirements included the following:

- 1) meets DSM-IV-TR trichotillomania diagnostic criteria,
- 2) female and 18 years old or older,
- 3) willing to talk about experiences related to and your thoughts about your hair pulling in a 60–90 minute interview, and
- 4) willing and able to provide consent.

Interested individuals completed the questionnaire and returned it to me directly by email. To round out the variety of the study sample, I initially contacted specific women interested in participating in the study. Further, once theoretical sampling began, the recruitment information changed to adapt to the categories for which further collection of

data was necessary. Study participants were contacted personally to have the study explained to them, as well as to provide an opportunity for their questions to be asked and answered.

### Consent Process

Verbal consent to participate in this study was obtained from each participant at the time of initial phone contact or during the in-person interview. During the in-person interview, the consent process included an explanation of the study, detailed review of the consent document including study procedures and expectations, and risks and benefits of participating in the study. Potential participants were given ample time to review the study, ask questions, and have their questions answered. The participant signed the consent document, and a copy of the signed document was provided to the participant prior to starting the interview. I provided detailed information about the study to potential participants who interviewed via the telephone prior to the interview. Participants had a chance to ask questions about the study and have them answered prior to the interview. Consent forms were either emailed to participants or sent using the United States Postal Service (USPS). Study participants returned their signed consent form to me via email or through the USPS. Women who requested their consent form through the mail were sent an addressed stamped envelope along with the consent form to return the signed consent form to the study office. A copy of their signed consent form was returned to the participants to keep for their records. The original was kept on file. Interviews were scheduled once I received signed copies of the consent forms. Consent information was revisited with each participant when scheduling interviews in an effort to discuss the study and address any of the participants' additional questions and concerns. All

telephone interviews took place after participant questions were answered and consent was obtained.

### Sources of Data and Data Collection

#### Sources of Data

Researchers often use more than one method of data collection, known as methodological triangulation, in an effort to increase trustworthiness and decrease bias within the data (Lincoln & Guba, 1985). However, triangulation is not limited specifically to methods, but can be applied to data, investigators, theories, and environment (Creswell, 1998). Just as a detective gathers evidence and witnesses to solve a mystery, triangulation aims to gather pieces of the research mystery. In order to achieve triangulation in this study, I conducted in-depth individual interviews, participated in direct observation of interviewees while engaging in the interview process when possible, used a demographic screening questionnaire, and analyzed written materials. Additionally, field notes, a self-reflexive journal, and an audit trail were kept to enhance the data.

#### Data Collection

In-depth interviews. Participant interviews were the primary source of data collected for the purposes of this study. Siedman (2006) explained that the purpose of using in-depth interviews is to understand the experiences of others and their meanings of their experiences. According to Siedman (2006), hypothesis testing, evaluation, and seeking answers to questions are not goals of in-depth interviews. Semistructured, in-depth individual interviews were conducted with the participants of this investigation.



This type of interview was purposefully chosen in an attempt to construct the meaning of a phenomenon (i.e., hair pulling) that is shared by women with TTM. In-depth interviews provided me with the participants' original words, unique thoughts, and memories, which were more valuable than a researcher's reconstruction of a participant's story.

Potential participants contacted me after viewing the study advertisement flyer. I introduced the study as a conversation that I would like to have with women who pulled their hair. I offered personal anecdotes of my experience with hair pulling, and why I thought that this study was important. I explained why I thought it would be helpful for the TTM, mental health, and medical communities to understand hair pulling from the participant perspective. The women and I discussed how individual differences are overlooked in favor of a medical model approach to treatment when trying to understand the behavior. I asked the participants questions about who they are, their interests, and about their families, because I believe that hair pulling and/or a diagnosis of TTM does not define the person. Most of these women agreed that hair pulling was only a part of their identity. Another way that I built rapport with the women when introducing the study was to talk about where they are from and to discuss my personal travel experiences across North America as it related to their geographical location. I shared personal information with the women and engaged in active listening during the interview process. I provided positive feedback and validation of their emotions and experiences with TTM. I offered the women the choice of an in-person or telephone interview, which took into consideration their comfort level of discussing their experience with hair pulling as a way of rapport building. In addition to the above-stated rapport building methods, I made direct eye contact when conducting in-person

interviews.

Each interview was scheduled for the duration of 60–90 minutes. Study participants who were local to Utah met at prearranged locations that were convenient to the participants (e.g., their homes, library, etc.), as long as the my safety was not in jeopardy. Meeting locations were conducive to audio taping (i.e., quiet locations) the interview. Interviews at the National TLC Conference in Texas were conducted in various locations that offered privacy throughout the sponsoring hotel, but did not compromise the safety of the participants or the researcher (e.g., a quiet seating area in the lounge away from people and conference activities). Telephone interviews were scheduled with participants when travel was not possible and at a time that was convenient for the participants and me. I interviewed participants over the telephone in the privacy of either my home or business offices.

Interviews were semistructured, yet followed a guided approach in that specific questions related to past and present experiences of hair pulling were addressed so as to approach the data in a systematic and comprehensive manner (Patton, 2002). Given the emergent design of qualitative research, it was important to remain flexible during the interviewing process. Therefore, interview questions were meant to be guidelines in an effort to build conversation with the participants and see where it allowed them to go related to content (Charmaz, 2006; Patton, 2002; Wertz, 2005). Charmaz (2006) suggests that “how, when, and what questions yield rich data” (p. 33). Semistructured guided interview questions included:

1. When did you first start pulling your hair?
2. What is hair pulling like for you?

3. What do you think about your hair pulling?
4. How is your hair pulling the same as or different from when you first began pulling?
5. How do you feel about your hair pulling?
6. What else should I ask you to better understand your experience of hair pulling?

Participant checks. Participant verification of findings is an important and expected practice in grounded theory (Charmaz, 2006). Participant checks are an additional way of validating participants' personal experiences by providing opportunities for them to voice comments and concerns specific to the emergent themes and categories based on their interviews. Follow-up interviews were scheduled with participants as a function of member checking. Participants were asked at a follow-up interview if the major categories developed during the initial data analysis fit their experience. If not, further discussion took place to fill out a category or create new categories (Charmaz, 2006). Participant checks were in alignment with a feminist perspective in that they promoted an egalitarian relationship, acknowledged individual expertise based on individual experience, and allowed for the research process to capture the essence of what it is that the participants discussed so that my constructed meaning reflected as closely as possible their perceptions and experiences.

Demographic screening questionnaire. A demographic screening questionnaire (Appendix B) was administered to all the participants of the study for the purposes of gathering specific demographic information (e.g., age, age of onset, primary site of hair pulling, and race). The demographic screening questionnaire also addressed variation in

the amount of time that the women have been pulling (e.g., 2 years, 10 years, 20 years, etc.). Questions related to the DSM-IV-TR diagnostic criteria for trichotillomania were included in the questionnaire, worded so that participants could understand them. The questionnaire requested additional information about primary and secondary sites of hair pulling, length of time the individual has gone without pulling, automatic and focused styles of hair pulling, rituals associated with pulling, and family history of hair pulling. This demographic screening questionnaire was made available to individuals who engage in hair pulling through the Trichotillomania Learning Center's (TLC) website ([www.trich.org](http://www.trich.org)). The questionnaire is included in Appendix A. Although the questionnaire was available on the TLC's website, some women who were interested in the study requested to receive the screening questionnaire via email or through the US Postal Service (USPS). I responded to these requests by emailing or mailing the questionnaire, and the questionnaires were either returned to me by email or through the USPS.

#### Field Notes, Journal and Audit Trail

One of the most important elements of qualitative research is researcher reflexivity (Corbin & Strauss, 2008). Corbin and Strauss (2008) suggested that qualitative researchers envision themselves in their study and reflect on how they identify with both the study topic and the context in which the information is obtained. Reflexivity is necessary to ensure that integrity and study quality are maintained (Lincoln & Guba, 1985). As such, I kept a self-reflexive journal.

A self-reflexive journal is an important aspect of qualitative rigor that details the researcher's values, assumptions, and biases as they relate to the research. The self-

reflexive journal was used to record and process my reactions and feelings associated with participant responses, as well as to record personal thoughts and feelings as they related to the research. The utility of this journal came from the process of sorting information to form categories and construct meanings. Researcher sensitivity, my awareness of personal biases and my ability to overcome selective inattention, to increase perceptive sensitivity, and to practice self-discipline contributed to my reflexivity (Lincoln & Guba, 1985).

Field notes can be an important source of information, specifically descriptive data regarding the intricate details of the interview setting, the interviewer's notable observations, as well as the interviewer's own feelings and reactions to her experience of the interviewing process that are recorded in the field notes (Patton, 2002). Field notes are also a place for interpretations and working hypotheses to be recorded. In an effort to collect data from multiple sources, I kept field notes during the interviewing and analytic processes. My field notes contained analytic and self-reflective memos to aid in the capture of my personal reactions to participants' disclosures, as well as questions, thoughts, and speculations about the data and emerging theory. My decision-making and reasoning process (Lincoln & Guba, 1985) were recorded in the field notes located in my self-reflexive journal. Additionally, an audit trail describing the historical sequence of the research process for additional rigor was kept during the research process. The audit trail includes interview dates, times, and descriptions of circumstances; it tracked the analysis and writing processes, in addition to documenting evolving categories and themes.

## Data Management

I used a digital recording device (i.e., iPod Touch) to record individual interviews and follow-up interviews whether they took place in person or over the phone. I used computerized word processing software to transcribe the recordings. In an effort to become familiar with the data, I personally transcribed half of the interviews. In the interest of time, I hired a professional transcriber to transcribe the other half of the interviews. The professional transcriptionist signed a confidentiality agreement (see Appendix B). I provided the transcriptionist with audio files of the interviews on a USB drive. In turn, she saved the transcriptions on the same USB drive and returned the transcribed interviews and audio files to me upon completion of the transcriptions. The transcriptionist did not keep copies of the interviews or transcriptions per our confidentiality agreement. I reviewed all transcripts along with their audio recording to ensure that there were no discrepancies between the transcript and the audio recording. Demographic information gleaned from the questionnaire was included at the end of each transcription. Hard copies of the transcripts were printed so that coding, analysis, and results could be examined by hand. Although computer programs were available for analysis, I chose to immerse myself in the data to better understand the participants' experiences and the qualitative research process by analyzing the data manually.

I used small envelopes to store data (e.g., quotes/text according to individual participants) specific to the different codes. Large envelopes held information related to categories. All information (e.g., quotes/text, demographic data) from each individual was color coded to differentiate information on an individual level. I kept a master outline of data, codes, and emerging themes. I used color codes as a visual record to help

keep the information intact. The self-reflexive journal containing personal thoughts, field notes, and an audit trail were kept with the transcriptions and other analysis materials. I kept all data related to this study together in a locked file when not in use. After the transcription process was complete, no other individuals had access to the transcribed interviews, analyzed data, or to the digital recordings of the interviews other than me.

### Researcher as Instrument

Awareness of my role as a researcher and my relationship with the participants in terms of power structures was essential to creating a working relationship. As a researcher, I discussed my role and expectations, as well as limitations. The participants and I, as the researcher, discussed our working relationship and roles. It was important to keep this dialogue going throughout the interview process. Creswell (1998) asserted that it is important for qualitative researchers to understand their role as a research instrument in a qualitative study, with specific attention being paid to the biases that the researcher brings to the subject. Morrow (2005) specified that “making one’s implicit assumptions and biases overt to self and others” is standard practice in qualitative inquiry (p. 254). Further, it was important to remember that I was a researcher and not a therapist when conducting the interviews. I recognized that offering support and validation for the participants’ experiences was important, and that conducting the interview in a therapeutic manner was inappropriate. If the participant requested information specific to therapy and/or resources available for hair pulling, I directed her to the TLC website where there are numerous national and local resources listed including therapist information.

### Taking Leave

Participant checks by way of follow-up interviews served as a way for participants to make sense of and add to the interpretations that I made specific to their experiences. This information contributed to the analysis and theory construction. Official contact with participants ended with the follow-up interview. Time was set aside for closure during this meeting. I verbally thanked participants for sharing their experiences and expressed my appreciation for their involvement in my research process. Participants were offered a copy of their individual transcripts and/or a copy of the dissertation upon completion if they wished to have copies. Participants were given the opportunity to tell how the research and interview process impacted them.

The women expressed excitement about the research and the meaningfulness of this project. Some told me that they had never told anyone their story. Others said that it was nice to talk with someone who understood hair pulling. Some women were very open in relating their experiences, while others were shy and hesitant. “Cathartic” describes how others felt about the interview process and sharing their individual story. All of their women were interested in reading the final write-up. I thanked all of the women for taking the time to participate in this study, and their response was to thank me for conducting this research.

The process of analyzing data and writing this body of work has taken several years. During that time, several study participants have contacted me via email to ask about the progress of the study. I responded by sharing a bit about my process and explaining my commitment to completing this dissertation. I acknowledged the



participants' role in the success of this work, and reiterated my intention of providing the completed work to all participants who were interested in receiving a copy.

#### Method of Analysis: A Grounded Theory Approach

The aim of qualitative data gathering and analysis is to be systematic and flexible (Marshall & Rossman, 1995) in an imaginative and meticulous way (Polkinghorne, 1994). Analysis begins early through coding, a labeling system for data meant to help separate, sort, and synthesize data (Charmaz, 2006). Meaning units, or sections of text (e.g., transcript or written materials), are identified and assigned preliminary code names. This process is accompanied by writing memos, which are analytic notes about the codes and comparisons, as well as additional ideas about the data that come to the researcher while conducting the research (Charmaz, 2006). Through studying the data, writing memos and codes, and constant comparison of the data, ideas are formed that give rise to tentative analytic categories that contributed to the construction of theories (Charmaz, 2006). Additional data are collected specifically to support or challenge existing categories and give rise to theory construction (Charmaz, 2006). Theory is constructed by cycling between data collection and theory accommodation until the theory is saturated (Charmaz, 2006; Polkinghorne, 1994). Erickson (1986) described this cycle of data collection and theory construction as an evolving relationship. Detailed frameworks of the grounded theory approach have informed how theories are constructed by being grounded in the data from which they derive to reflect the participants' subjective reality (Charmaz, 2006; Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1990).

## Data Analysis

*Constant comparative* methods were used when coding data in grounded theory (Glaser & Strauss, 1967). Coding was used to define what was happening in the data and to determine meaning. Initial coding (i.e., line by line) was utilized in the beginning of the study to explore theoretical possibilities within the data (Charmaz, 2006). This allowed me to immerse myself in the data. During the initial coding, I reviewed each transcript line by line and assigned different codes to each line such as age of onset, gender roles, anxiety, self-esteem, and abuse. A more focused coding was employed later on to use the most significant earlier codes to categorize the data (Charmaz, 2006). Examples of focused coding include accountability, awareness, and acceptance. Theoretical coding was utilized to highlight possible relationships between categories that were formed in focused coding (Charmaz, 2006). Theoretical codes help to tell a coherent analytic story (Charmaz, 2006). For this study, when taken together, the codes of accountability, awareness, and acceptance combine to create a bigger picture and the theoretical code associated with the hair pulling struggle as it relates to identity development and integration.

I wrote memos to keep records of ideas and questions that arose during data collection and analysis to help propel the research in a positive direction. Memos provided the core of the grounded theory (Charmaz, 2006) for this study. Theoretical sampling, as discussed earlier, was used to further develop categories for theory construction.

In order to understand and to become familiar with the data, I constructed individual outlines highlighting core categories for each participant, as well as a general

overarching model for all participants. This process involved identifying salient categories for individuals and then matching them to the overarching outline. An analytic journal, follow-up interviews, and meeting with a peer to discuss my research were essential in making sure that I did not leave out any information when creating the models. The overarching outline was used to write the results.

Sufficient time and exposure to data were necessary for analysis (Moustakas, 1990). Data analysis required multiple sittings with the same information in order to move beyond surface information (Polkinghorne, 1994). Immersion in the experiences of the participants through the process of data collection, analysis, and reanalysis helped to construct a well-integrated theory that adequately reflected the experiences of women with TTM.

#### Trustworthiness

Criteria used to judge the quality of a study are deemed rigor or trustworthiness (Guba & Lincoln, 1994). This study employed various standards for trustworthiness in order to produce a viable study of good quality. Analytic rigor was comprised of the following components: regular consultation and meetings with advisor, regular meetings with a peer researcher that provided a context for peer debriefing, keeping a self-reflexive journal, maintaining an audit trail, and participant checks.

A self-reflexive journal and audit trail were used to maintain accountability throughout the research process. Both were kept throughout the study. These, along with conversations with my advisor and a peer researcher, helped to expose my personal values and assumptions, as well as contribute to methodological, analytical, and ethical reflection. Additionally, consultation provided support and direction specific to

theoretical development. Debriefing provided an opportunity to acknowledge my biases and how they might be contributing to my research.

Attending to disconfirming evidence and conducting disconfirming case analysis are important aspects of trustworthiness. It is necessary to look for adequate evidence, a variety of evidence, disconfirming evidence, and discrepant case analysis in order to enhance rigor and avoid evidentiary inadequacy (Erickson, 1986). Participant checks were conducted to provide verification of the data, researcher's meanings, and themes, thus contributing to trustworthiness (Charmaz, 2006; Lincoln & Guba, 1986; Moustakas, 1990). Participant checks were conducted with research participants through follow-up phone call interviews to discuss questions specific to their interview or to discuss emerging themes that stemmed from the data.

Trustworthiness “is *not* about representing a population or increasing the statistical generalizability of your results” (Charmaz, 2006, p. 101), but rather to gather *thick descriptions* (Geertz, 1973) or rich, contextualized descriptive accounts about oneself as the researcher, the participants, and the context so that others can determine whether the study is transferable (Lincoln & Guba, 1985).

### Ethical Considerations

Trichotillomania is a very sensitive research subject. This is due to several factors including the emotional impact of hair pulling on individuals who engage in the behavior, the secretive nature of hair pulling, a lack of understanding from others (e.g., family, friends, and society in general), and potential consequences of the behavior itself (e.g., noticeable hair loss, infection, isolation, lack of social contacts). Given the incredibly

sensitive nature of hair pulling, it was imperative that I conducted the study in an ethical and respectful manner.

Treatment of participants followed the contextualized-consequentialist model of ethics because it is a continuation of a feminist ethic and requires an egalitarian relationship between researcher and participant that is noncoercive, nondescriptive, and built on trust and mutual respect (Denzin & Lincoln, 1994). This model assumes that researchers are committed to personal accountability, caring, the value of individual expressiveness, the capacity for empathy, and emotional sharing (Denzin & Lincoln, 1994). Specific ethical concerns that I addressed from the framework of this model are discussed in the following paragraphs.

Disclosure of personal information by participants is imperative in the qualitative research process. As a result, several precautions to ensure the confidentiality of the research participants of this study were taken, including explanation and discussion of possible risks to participation in this study, explanation and discussion regarding the limits of confidentiality, and explanation and discussion of data collection and storage procedures. After the initial contact denoting interest in participating in this research study, participants were asked to sign a consent form highlighting their rights as a research participant and were given a copy of their signed consent form. Additionally, participants were given the option of choosing a pseudonym to help maintain their confidentiality. Choosing a pseudonym offered the women a sense of control over their participation in the study. All written and electronic documents were labeled with pseudonyms to maintain confidentiality, with the exception of one source document that matched pseudonyms to identifying information. Identifying information was not used

electronically. Study-related materials were kept locked in a file cabinet when not in use to further maintain confidentiality. Discretion was used when contacting participants through phone calls to ensure confidentiality and privacy. In addition, the professional transcriber was required to sign a confidentiality agreement. She agreed to delete/destroy all study-related material once she finished transcribing the interviews.

Risks to participants were expected to be minimal. Participants' sense of vulnerability and distress may have increased due to the associative features (i.e., shame and secretiveness) of TTM. When necessary, I advised participants of appropriate resources to address their issues if they manifested as a result of participating in this study. Participants were given information regarding local support groups for TTM and were directed to the TLC website for additional resources and therapist information specific to their geographical location when they indicated a need for additional resources to address their personal issues.

Potential benefits of participation included increased understanding of and insight into their hair pulling behavior as a result of being able to tell their stories to an interested and empathic listener. Knowing that this research could potentially add to the theoretical knowledge base of TTM was also a potential benefit of participation. Another potential benefit of participating in this research was the shared experience with other women with TTM of participating in the study, as well as sharing emotional, physical, and situational similarities.

Validation of participants' experiences is an important aspect of qualitative research. Validation often comes in the form of self-disclosure by the interviewer. Specifically, an interviewer may connect with the participant over a particular

experience, and appropriate self-disclosure may offer the participant encouragement to continue reconstructing in a more personal way (Siedman, 1991). Because the nature of hair pulling behavior is sensitive, secretive and often shameful for many women with TTM, I was forthright and self-disclosed appropriate personal information in an effort to build rapport with the participants and to validate their experiences. Personal disclosure also helped to promote an egalitarian relationship between participants and myself, which is consistent with my feminist orientation.

The findings of the study are presented in the following chapter. Major themes, categories, and subcategories emerged from the analyses of the individual interviews, follow-up phone calls, and participant feedback. An outline provided in the following chapter serves to organize the themes, categories, and subcategories for the reader. To become better acquainted with the women who participated in the study, a brief depiction of each participant is provided as an introduction to her story, which allows the reader to immerse herself or himself in the participants' stories and related results.

## CHAPTER 3

### RESULTS

#### Introduction to Participants

Twenty-two women participated in the study through individual face to face or telephone interviews and follow-up conversations with the researcher. The average age of the participants was 34 years old (range=20–61 years old), and the average age of onset for hair pulling was 12 years old (range=3–40 years old). The women interviewed reported pulling for an average of 22 years (range=2–49 years). Most of the women identified as Caucasian or White (82%). One woman identified as Hispanic/White (4%), and the ethnicity of the remaining 14% was unknown. The majority of the women (72.72%) were the first-born child in their families. Middle children and the youngest in their families made up 13.64% and 13.64%, respectively, for this study population. Twenty-one of the women lived across the United States with all geographical areas (i.e., North, South, East, West, Midwest, Northeast, Northwest, Southeast, and Southwest) being represented, and 1 participant lived in Central Canada. Of the participants, 11 were employed at the time of the interview, 7 were unemployed due to being fulltime mothers, 1 participant was retired, and 4 of the women were full-time students.

Brief overviews of the women are presented in the following pages to aid the reader in becoming familiar with the women's narratives. The sketches primarily provide demographic information and relevant facts about the participants' family (e.g., birth



order, family dynamics and relationships, familial roles and expectations, and power dynamics within the family). The onset of hair pulling is presented in the context of surrounding life events. Reasons that participants chose to take part in this research are offered in this section. Specific details of the participants' lives emerge in subsequent sections of this manuscript. The women are presented in the order in which they were interviewed.

### The Participants

#### Kierra

Kierra was the first person to participate in this study. She met all DSM-IV-TR criteria for TTM, but had never received an official diagnosis. Her primary site of hair pulling is her scalp, and she ingests the hair after she pulls it. She is 27 years old and has engaged in hair pulling for 20 years. She experienced a lot of stress and anxiety at home at the onset of her hair pulling because her parents were recently divorced, she moved in with her grandparents, and her mother started dating a new man. Kierra attended counseling to address her TTM and stopped pulling for close to a year. She had only told five people in her lifetime about her hair pulling, including me. She was happy to share her story with me despite the awkwardness, because "I am trying to integrate it a little more because I'm trying to get rid of it."

#### Emily

Emily heard about this study through her support group and contacted me about participation. Emily received an official diagnosis of TTM when she was in high school. Her primary sites of pulling are eyebrows and eyelashes. Emily is a 20-year-old college

student who was born and raised in a large city located in the Eastern United States. Emily began pulling her hair between 10 and 12 years of age. She associated the onset of hair pulling with puberty. She attended therapy in high school, and has gone two weeks without pulling. When discussing her feelings about participating in this study, Emily said, “I’m really happy that someone is writing about it so there will be publications on such a personal level out there.”

### Celeste

Celeste found out about this study through her local support group and contacted me. Celeste began hair pulling at age 16. She has been pulling for the past 10 years and has gone 18 months without pulling before starting again. A therapist officially diagnosed Celeste with TTM. Her primary hair pulling site is her scalp and she examines her pulled hair before discarding. Celeste is a 26-year-old graduate student who identifies as both Hispanic and Caucasian. Celeste said, “I am happy to help whenever I can” when discussing her reasons for participating in this study.

### Nancy

Nancy contacted me about participating in this study after reading about it on the TLC website. Nancy is 22 years old and has pulled for 13 years. Her hair pulling onset coincided with the breakdown of her parents’ marriage and their subsequent divorce. Her eyebrows, eyelashes, and her pubic region are her primary pulling sites. Nancy pulls in cycles going for months without pulling and pulling daily for months at a time. She was officially diagnosed with TTM when she was in high school. Her hair pulling style is

both focused and automatic. She has several OCD tendencies specific to and independent of hair pulling including symmetry, perfection, checking, and issues with odd numbers.

#### Jennifer

Jennifer learned about this study through her local support group and contacted me about participation. Her therapist officially diagnosed her hair pulling as TTM. Her primary and secondary sites of hair pulling are her scalp and her hair pulling style is automatic. She plays with her hair before and after pulling. She first attended therapy when she was in high school to treat major depression but she did not find it useful for hair pulling. She is 26 years old and started pulling at age 3; however, she only became aware of her pulling at age 6. She associated the onset of her hair pulling with the stress she felt of wanting to please others. She expressed her happiness to participate in this study and said, “I’m glad I can help, because if I can help just one person not pull their hair...I really hope that this does help.”

#### Marie

Marie heard about this study at her local support group meeting. She meets DSM-IV-TR criteria for TTM and was officially diagnosed by her therapist. Her primary site of pulling is her scalp and she examines and plays with her pulled hair before discarding it. Marie is 31 years old and began hair pulling at 8. Her parents fought often during her childhood, but remained together. She has OCD tendencies such as perfectionistic thinking. She was happy to participate in order to increase awareness about TTM because “a lot of lives have been traumatically affected by having TTM.”

### Anne

Anne contacted me about the study after reading about it on the TLC website. Anne's therapist gave her the following diagnoses: TTM, depression, anxiety, and OCD. She is a 31-year-old female who has pulled her hair for 23 years. Her primary site of hair pulling is the scalp and she pulls in an automatic style. She ritually runs the pulled hair between her lips to feel its texture. Four months is the longest she has gone without hair pulling. The onset of her hair pulling occurred around the time that a babysitter started sexually abusing her and her sister.

### Misty

Misty joined the study after hearing about it through her local support group. She is a 35-year-old woman who began hair pulling at age 4 following the death of her younger sister. Her scalp and eyelashes are primary pulling sites with the pubic region as a secondary site. Her pulling style is automatic and focused. She was officially diagnosed with TTM as an adult when participating in a research study. Misty wanted to participate in this study to help the cause in any way that she possibly can due to its debilitating nature.

### Heather

Heather joined the study after hearing about it at her support group. Her therapist diagnosed her with TTM when she was in her teens. Her primary and secondary sites for pulling are her scalp and her pulling style is both automatic and focused. She examines and bites the root and plays with the hair before discarding it. Heather is 32 years old. She had her first incident of pulling at age 3 and started pulling regularly by age 11.

Heather was excited to participate in this study in order to increase awareness and understanding of TTM.

#### Elizabeth

Elizabeth heard about this study through her support group and contacted me regarding participation. She is a 29-year-old who has pulled her hair since she was 8 years old. She began pulling around the time that her parents divorced. Her primary site of hair pulling is her scalp, and her secondary site is her pubic region. She engages in automatic and focused hair pulling, and examines and ingests pulled hairs. Elizabeth meets all of the DSM-IV-TR criteria for TTM, but has not been officially diagnosed. The longest period of time that she has gone without pulling was 2 years. Elizabeth wanted to help others understand their own experiences by participating in this study.

#### Tia

Tia contacted me to participate in this study after learning about it from her support group. Tia is a 31-year-old woman who has engaged in hair pulling for 23 years. Her primary sites of hair pulling are eyelashes and eyebrows. Her hair pulling onset coincided with oral surgery. Her hair pulling style is both automatic and focused. A therapist officially diagnosed her TTM when she was 16 years old.

#### Cat Girl

Cat Girl learned of this study through local support group. She is a 61-year-old woman who meets all DSM-IV-TR diagnostic criteria but has not been officially diagnosed with TTM. She began pulling at age 12 and she has pulled her hair off and on for 49 years. She associated the onset of her TTM with her “pretty negative childhood.”

Cat Girl's primary pulling sites are eyebrows and eyelashes. Her hair pulling styles are automatic and focused without rituals. She recently has been pull free for 4 months. Cat Girl participated in this study because she wanted to increase others' awareness of TTM.

#### Liz

Liz was introduced to this study at her local support group meeting and contacted me to participate. She is a 28-year-old woman who started pulling her eyelashes at age 13. She switched to pulling her eyebrow hair at age 18. She attributed the onset of her TTM to puberty and a difficult adolescence. She was officially diagnosed with TTM by a therapist when she was in junior high school. The longest period of time that she has gone without hair pulling was 2 years. She wanted to participate in this study to help individuals with TTM by increasing community awareness of TTM. Liz requested that I not quote her directly.

#### Cathy

Cathy read about this study on the TLC website and contacted me about participation. She was 26 years old and had pulled her eyelashes and eyebrows for the past 15 years. She associated the onset of her hair pulling to her "traumatic middle school years" and her mother's remarriage. She was never officially diagnosed with TTM, but she meets all DSM-IV-TR criteria for the disorder. Her hair pulling style is both automatic and focused. Cathy attended individual therapy and a support group, which she did not find helpful at the time. Cathy went 6 months without pulling her hair. Cathy said that told two people in her life about her hair pulling aside from her therapists, the women in the support group that she briefly attended, and me. Cathy participated in this

study to help others, to give back to the TLC community for providing her with free therapy in the past, and to help find a cure for TTM.

#### LoGo

LoGo, a 56-year-old woman who pulled her hair for 36 years, contacted me to participate in this study after hearing about it from her local support group. She started pulling hair from her scalp when she was 20 years old. Her hair pulling onset coincided with a stressful period of her life when she struggled with her sexual orientation and coming out as lesbian, and individuating from her abusive mother. She met DSM-IV-TR diagnostic criteria for TTM, but had never been officially diagnosed. Her scalp is her primary site of hair pulling with her eyebrows and pubic area as secondary sites. Her pulling style is both automatic and focused. She examined and saved kinky hairs. She attended individual therapy and participated in a support group because of her TTM. She participated in this study to help “shed some light on it [TTM].”

#### Jade

Jade was asked to participate in this study at the TLC annual conference in Dallas. She is a 25-year-old woman started hair pulling at age 15 when she was physically very sick with a thyroid condition. Her primary sites of pulling are scalp, face, and pubic region, with legs and body as secondary sites. She used automatic and focused styles of pulling, and had only stopped hair pulling for a period of 1 week in the last 10 years. A therapist officially diagnosed her with TTM, and she attended individual therapy and a support group.

### Patches Rapunzel

Patches Rapunzel participated in this study from the annual TLC conference held in Texas. She is a 50-year-old married woman who has pulled her hair out for 37 years. She started with her eyelashes, moved to her eyebrows, and then on to her scalp. Patches Rapunzel's scalp is her primary site for hair pulling, but she also pulls from her eyelashes, eyebrows, face, legs, and pubic region. Her hair pulling style is both automatic and focused and twirling the hair and examining the root are her routine rituals. Her hair pulling onset coincided with a series of stressful events including her parents divorce, starting high school, and having a man expose himself to her when she was alone. When she was in her late 20s, a therapist officially diagnosed her with TTM. She stopped pulling her hair for a period of 1 year after receiving intensive therapy. Patches Rapunzel explained that she was happy to be interviewed for this study because she wants to increase awareness of TTM and help others like herself.

### Cheryl

Cheryl participated in this study from the annual TLC conference in Dallas, Texas. She is a 58-year-old woman who began hair pulling at age 12. Cheryl attributed the onset of hair pulling to two events: witnessing a girl in her class pull out her eyelashes and experiencing her "first awareness of losing control" associated with a schoolmate's accidental death. Her hair pulling commenced in the context of growing up in a physically and emotionally abusive household with a "functional alcoholic" father. She was officially diagnosed with TTM 10 years ago when she first attended therapy. Her primary sites of pulling are scalp and face and occasionally from her pubic region. Her pulling styles are automatic and focused and she did not engage in rituals. She expressed



satisfaction in participating in this study because of the potential impact that it could have on the TTM community as far as furthering our understanding of the disorder and those who suffer from it.

### Melissa

Melissa was interviewed for this study at the annual TLC conference in Dallas. Melissa is a 26-year-old woman who had one episode of pulling her eyelashes out at 6 years old around the time of her parents' divorce. She started pulling hair from her scalp around the time that her stepfather moved in with her and her mother when she was 9 years old. For the past 17 years, she has pulled her hair her primary pulling sites: scalp, face, legs, and pubic region. Melissa attended therapy intermittently since she began hair pulling. Melissa participated in this study because she wanted to help others.

### Beth

Beth is a 42-year-old woman who participated in this study while she attended the annual TLC conference in Dallas, Texas. Beth's experience with hair pulling is unusual, in that her introduction to it came at the age of 40. She experienced multiple life changes at the onset of her pulling, including her first sustained pregnancy, finding out that her husband of several years was gay 2 weeks before her due date, divorcing her husband, moving to a new town, starting a new job, and becoming a single mother. She pulls from her head exclusively and has pulled every day for 2 years. Her style of pulling is both automatic and focused, and she examines and plays with the hair before discarding it. She was officially diagnosed with TTM. She expressed her wish to find others like herself who developed TTM later on in life as a way of understanding her experience with TTM,

as well as to help others understand their own hair pulling experience, as her reasons for participating in this study.

#### Amanda

Amanda, a 29-year-old woman, participated in this study while she was attending the annual TLC conference held in Dallas, Texas. She began hair pulling at age 11 and has pulled for 18 years. She started pulling her hair when her grandmother and cousin were hospitalized with illness and injury, respectively. An OCD specialist officially diagnosed her TTM after months of misdiagnoses. Her hair pulling style is both focused and automatic. She pursued multiple treatments for her TTM, including medication, therapy, and support groups. When asked about her reason for sharing her story with me, Amanda replied, “I know there are so many people with so many experiences. I’m happy to tell you about it because it is interesting and people need to know the shape of it, of different people. I want to know what it’s been like for other people because it’s been a totally different journey for other people.”

#### Robin

Robin contacted me to participate in this study after hearing about it through her local support group. She was concerned about telling her actual age and hinted that she was in her mid-30s. She started pulling her eyelashes out at 8 years old. Her hair pulling commenced during a stressful time for her family when her parents were emotionally unavailable to her. She was officially diagnosed with TTM as a teenager. She attended therapy and support groups, and took medication for her hair pulling. Her primary sites of hair pulling are her eyebrows and eye lashes. Her hair pulling style is both automatic and

focused. She stopped pulling her hair for 4 months on three separate occasions in the past. Robin explained her reason for participating in this study. She said, “I would love to be able to help others with their struggles, whether it’s hair pulling or picking or nail biting.”

All of the women who participated in this study initially contacted me after learning about the study through the TLC website and/or their local support group. Participants were asked to join the study based on their information-rich histories specific to their hair pulling experiences. Some of the women were placed on a waiting list and asked to participate later in the analysis process to gather more detailed information about their TTM and how they conceptualized their behavior and made sense of it in an effort to round out themes and potential theories. What follows is the conglomeration of the women’s hair pulling experience.

### Introduction to the Findings

This study investigated how women experience and perceive their hair pulling. The findings of this research were revealed through the use of grounded theory analysis as their stories were woven together. My attempt to understand the experiences and perceptions of TTM through the stories told by the women who engage in chronic hair pulling emerged from the study data, which were organized into four main themes and associated categories and subcategories (Figure 1). Power and control prevail as a pervasive thread throughout all four of the main themes and subsequent categories and subcategories. The role of power and control in the lives of the participants, how their sense of it has affected their lives and shaped their hair pulling behavior, as well as how they perceive their own personal power specific to having control over their TTM, is

Theme	Category	Subcategory	Secondary Subcategory
<b>Theme I: Taking Root: The Inception Of Hair Pulling</b>	A. Traumatic Life Events and Hair Pulling Onset	1. Abuse 2. Divorce and Rocky Relationships 3. Medical Trauma 4. Death	
	B. Power and Control	1. What! I'm Not in Control? 2. Help Me, Hair Pulling!	a. My Best Friend
<b>Theme II: Hair Pulling, We've Got A Problem</b>	A. Others' Conceptualization of Hair Pulling as a Problem	1. Problem Solving 2. Treatment Readiness	a. Medical Treatments b. Therapy c. Ignoring Hair Pulling
	B. Impact	1. I'm Pulling My Hair, I'm So Crazy! 2. Self-esteem	a. Shame b. Hiding and Silencing
<b>Theme III: The Struggle</b>	A. Awareness		
	B. Accountability	1. It Takes a Village 2. Accountability Strategies 3. Treatment: Participating for Change 4. I'm Not Pulling My Weight Here	
	C. Acceptance Is Work	1. The Struggle 2. It's Me	a. It's Me, But Not Really Me b. The Battle Against the Pulling a. Empowerment b. Empathy
<b>Theme IV: Power Play: Reclaiming Their Narrative</b>	A. Making Sense of Me	1. Biological 2. Emotion Regulation and Managing Stress	a. Neurobiological b. Genetics, Illness, and Anxiety c. Addiction
	B. Trichotillomania: A Journey of Personal Empowerment		

Figure 1. Themes I-IV

presented with each major theme. Their hair pulling represents part of their journey of personal empowerment, and their stories are waiting to be told.

The first major theme, *Taking Root: The Inception of Hair Pulling*, focuses on the onset of hair pulling in the context of a trauma experience. Nineteen of the 22 participants described experiences such as abuse, divorce and relationship problems, medical conditions, and the death of a loved one or of an acquaintance as events that shaped their hair pulling behavior. Power dynamics relative to the women's trauma experiences are central to their perception of power and control as it relates to their hair pulling.

The second theme, *Hair Pulling: We've Got a Problem*, focuses on others' conceptualizations of the participants' TTM and how this influenced their hair pulling path. This section looks at the charted course of hair pulling for the women when others defined their behavior and outcomes. Power dynamics in the context of outsider conceptualization are presented in this section. Finally, the impact that the

conceptualization of their hair pulling by others has on the women's TTM, as well as their social and emotional experiences, are explored.

Awareness, accountability, and acceptance are the focus of *The Struggle*, the third theme. The women presented at varying stages of awareness of their hair pulling, holding themselves accountable and accepting their TTM. Ways that hair pullers utilize their relationships with others to increase their personal awareness of their behavior, and how it connects to accountability and control over their hair pulling, are explored in this theme. The role of personal power and control over hair pulling increases as the women move toward integrating TTM into their identities.

The fourth theme, *Power Play: Reclaiming Their Narrative*, focuses on how the women made sense of and understood their hair pulling and how their personalized conceptualizations of TTM shaped their hair pulling journeys. Reclaiming their narratives empowered the women of this study to understand their hair pulling in the context of their personal experiences and to decide the role that TTM played in their lives. The analysis that I engaged in highlights the role that power and control play in the development and maintenance of TTM. It culminates in the development of an empowerment approach to understanding TTM through the exploration of the hair puller's conceptualization of TTM in the context of her individual experience.

Themes are discussed in more detail on the following pages under Themes I through IV. To illustrate the themes and categories, quotes are excerpted from the women's interviews. An organizational table for each theme showing its categories and subcategories is presented at the beginning of each theme.

### Theme I: Taking Root: The Inception of Hair Pulling

The first major theme, *Taking Root: The Inception of Hair Pulling*, focuses on the women's initial experiences of hair pulling and the context in which their hair pulling commenced. Each of the women was asked, "When did you start hair pulling?" The follow-up question was, "What was happening in your life when you first began pulling your hair?" These two questions elicited varied responses as to when the women started to pull their hair, but with similar contextual events that demonstrated why hair pulling took root. Two categories emerged to describe this overall theme: *Traumatic Life Events* and *Power and Control* (Figure 2).

#### Traumatic Life Events

Traumatic life events and prolonged exposure to adversity without the means to cope were common occurrences in 19 of the women's lives at the time that their TTM commenced. In discussing this connection, a shared experience of trauma wove through their stories. For the purposes of this study, traumatic life events referred to both physical trauma experiences and other severely distressing events that overwhelm a person's ability to integrate emotions related to the experience and may have long-term emotional and physical consequences (APA, 2013). Four types of traumatic life events emerged: abuse, divorce and dysfunctional relationships, medical trauma, and death of a loved one or an acquaintance. Stress and anxiety are inherent in trauma experiences, and the women's stories indicated that they commonly experienced stress and felt anxious.

## Theme I: Taking Root: The Inception of Hair Pulling

- A. Traumatic Life Events
  1. Abuse
  2. Divorce and Rocky Relationships
  3. Medical Trauma
  4. Death
- B. Power and Control
  1. What! I'm Not in Control?
  2. Help Me, Hair Pulling!
    - a. My Best Friend

Figure 2. **Theme I: Taking Root: The Inception of Hair Pulling**

### Abuse

In describing the circumstances surrounding the onset of hair pulling, the women provided a discernable connection between the onset of their hair pulling and experiencing abuse (e.g., experiencing rape and sexual abuse, witnessing physical violence and emotional violence, experiencing physical and emotional abuse). Nine women shared explicit information about their abuse experiences.

Sexual abuse and trauma occurred at hair pulling onset for several of the women. Trusted male friends sexually abused two women when they were young girls, and a third participant had two encounters with a lewd man at a bus stop. Anne recalled her hair pulling onset. She said,

There was a male babysitter who sexually abused my sister. He tried to get me to participate in that, as well. I just remember that he wanted to do something that I didn't think was appropriate, and that I said, "No." Then he moved on to my sister, and raped her repeatedly. She was six....I just found an outlet at that point....I started pulling out big clumps of hair at first.

Prior to the onset of her hair pulling, Patches Rapunzel "had never seen an erect penis," and she experienced these violations by two strangers at her bus stop as "very stressful."

All of these women had experienced multiple stressors at the time including discovery of the abuse by their families, the birth of sibling, living with a special needs sibling, frequent moving of house, and a parent living away for extended time periods. Robin remembered the stressors that she encountered at the onset of her TTM. She said, “I had some sexual abuse issues with a neighbor. I’m a middle child of seven, and I had an older sister that’s deaf with special needs. I had emotional needs that I don’t think were met by my parents.”

Emotional and physical violence were present in the homes of some of the women ( $N=7$ ). Several participants described their familial environments as “dysfunctional,” “stressful,” and “invalidating.” Their experiences included physically fighting with a parent, being a parent’s emotional “scapegoat,” living with parents who had “psychological problems,” and moving out of their parental home and in with relatives.

Cheryl’s story of growing up in a “traditionally dysfunctional family” characterized by “emotional and physical violence” directed at her, her mother, and siblings, best exemplifies the experiences of the other participants who were physically and emotionally abused at home. Her father as “an alcoholic with an explosive temper” who “could turn on a dime and hit you.” At the same time, her mother was emotionally unavailable; and Cheryl said, “I never felt warmth from her.” It was in this dysfunctional context that Cheryl first started hair pulling.

I remember sitting in class and watching a girl twirl her hair. I tried it but did not find it satisfying. I immediately started to feel around my head for course and curly hairs and I pulled them out. It was a feeling of phenomenological bliss...a feeling of, like, satisfaction and pleasure, and I didn’t stop. It was stressful, confusing, and oddly satisfying at the same time.



Growing up, LoGo's mother was emotionally abusive and unavailable toward her and her sister, and her mother limited physical touch to times when LoGo needed medical attention. Her mother did not model coping skills to deal with difficult situations and change, and her mother avoided emotionally charged situations as a way of protecting herself. LoGo and her sister were not allowed to express emotions that would upset their mother. LoGo began pulling hair from her head when she was in her early 20s at a time when trying to individuate from her controlling mother and move out on her own.

I was about 20-something--my early 20s, and I remember, like, the first memory of it--I was, um--it was kind of a stressful time. I was moving from LA where I grew up... up to Santa Barbara to finish college there.... It was stressful leaving....It was a big change.... I felt like I needed a change, and I need to leave....it was just, like, this whole thing of, like, I have to get out of here....maybe it was traumatic. That struggle of I've gotta go--I've gotta go.

### Divorce and Rocky Relationships

Many of the participants grew up in households where parental fighting was the norm, and some of their parents divorced. These women associated the onset of their hair pulling with the anxiety and stress that they experienced specific to the instability of their parents' relationships (e.g., fighting, divorce, and reuniting), moving house, visiting a parent after the divorce, learning that one parent was abusing the other, estranged relationships with a parent, and to the addition of a stepparent. Six of the 22 women informed me that they plucked their first hair around the time that their parents divorced, and two connected their hair pulling to the arrival of a stepparent. Another woman started pulling her hair when she was in the process of divorcing her husband.

Nancy's earliest memory of hair pulling was pulling from her eyelashes at the age of 9.

My parents were having marital problems right around that age, so, you know, some fighting going on in the house and that sort of thing. They sat us down and told us what the word divorce means and all that kind of stuff. So, that's kind of when that started happening.... I really just attribute it to that--seeing my parents' fights.

Her parents lived together as a "family" after their divorce, and they instructed Nancy and her siblings to hide their divorce. She said, "They would tell us stuff to keep it hush-hush. It was a very sore spot in the family. We never talked about it."

Multiple women whose parents divorced related that the divorce was not discussed within or outside of the family. As such, they discovered hair pulling to manage the stress associated with the ambiguity specific to their parents' dissolved marriage. Kierra best described hair pulling as an anxiety management tool.

Things weren't really child-centered, they were more on my dad or the conflict. When I look back, there was something about the stimulation and trying to control some aspect of my appearance that seemed important. I think that's the big reason of why it took root and why it continues.

In LoGo's experience, not only was divorce never discussed, she had never witnessed her parents fight with each other and she was blindsided by their divorce. She said, "It was extremely traumatic because they maintained a façade....He just left us a note. It was horrible. It was really fucked up." Interestingly, LoGo did not start hair pulling at this time, but rather pulled her first hair 8 years later when she experienced a lot of stress related to the cognitive dissonance that she felt about moving out of her mother's house.

Several women all had estranged relationships with their fathers after their parents separated. They shared a common story in that they had little control over their home life because their mothers made decisions about if, when, and how often they saw their fathers. For Cathy and Melissa, the introduction of a stepfather into their lives led to their

hair pulling. Cathy's parents' divorce was messy, and she and her mother fled in the night and she lived in fear that her father would find them. She started pulling her hair out 3 years later when her stepfather moved in. Like Cathy, Melissa's hair pulling also took hold when her stepfather moved in. They did not get along because they were both vying for her mother's attention, and they fought with each other a lot, which strained her relationship with her mother.

I remember pulling out my eyebrows.... I pulled most of them out.... And then, I kind of moved to my head. And it was around that time, around 9 years old, and that's where it really started. It took hold.... I guess around the age of 9 was when my step--when my mom met my stepdad, and he moved in with us. So there was a lot of family upheaval stuff.

Two women experienced betrayal at the onset of hair pulling. For Patches Rapunzel, "finding out that your dad is an abusive man" was stressful. Knowing that he was abusing her mother, her "great protector," increased her stress. She said, "Those are the kind of things that were going on when I was 13. So, I'm not really surprised that when I found hair pulling, I found some comfort in it."

Beth felt betrayed by her husband and was extremely stressed and anxious as a result. At the time, she was 2 weeks away from giving birth to her first child when she discovered that her husband of several years was gay, which ultimately led to their divorce.

In the course of starting hair pulling, you could say I found out my husband was gay, asked him to leave, divorced him, started seeking a new job, moved, purchased a new house, became a mother, became a single parent... I believe that all of that happening in such a short time, that that is when I began pulling my hair out.

Divorcing her husband was a painful decision for her because she loved him, and she knew that he would face discrimination where they lived because of his sexual orientation. At the same time, she had to make a choice that would be best for her and her

newborn. In the end, Beth's choice of divorce was less traumatizing than the stress of living a secret life.

### Medical Trauma

Health problems and medical procedures can be very frightening for children and adults, especially if the problem is acute. The onset of hair pulling for Jade and Tia was accompanied by the sudden onset of a serious medical issue. Jade's hair pulling commenced when she was very sick with a thyroid imbalance; and she was not aware of how her health affected her behavior. She explained,

I got off my Synthroid, and I didn't realize I had done it. I got really kind of sick; so a number of things, as far as my nervous system, went wrong that year. I started having digestive problems. I couldn't eat a lot of things. My nervous system was just totally out of whack. I was pretty sick. So, yes, it's not surprising that I picked it [hair pulling] up that year. I suppose it could be considered very traumatic.

Tia underwent an emergency surgery to remove a cyst from her mouth that had grown to the size of a golf ball within 2 days. She said, "It wasn't life threatening. It wasn't cancerous. It was just this freak thing that happened." She did not remember feeling scared or worried at the time, but she surmised that undergoing surgery at such a young age and with short notice may have been an internally traumatizing experience for her, and hair pulling was her way of coping with this experience. She said, "I thought that I was the only person in the world who did this, and I felt very, very alone."

### Death

Two women in this study experienced a close relative's death at the onset of their hair pulling. At the time, both of the women felt "alone with the grief" and "stressed." Misty was 4 years old when her 2-year-old sister died. Her parents emotionally and

physically distanced themselves from Misty. Within days of her sister's death, she started pulling her hair out.

I was four years old. I rolled my hair into a ball, and then I pulled it out. It just gradually got worse. It got more involved. Like, then the fingernails, and then more hair pulling, and then, you know, finding the pokey ones, and then getting those out. Then it just got bigger, and bigger, and bigger, and worse, and more time spent on it. It just snowballed.

The tragedy of her sister's death affected her whole family. Her mother went into a deep depression, abused alcohol, and refused to touch Misty for years. Her father "was very cold, and still is, and very, very abrasive, and standoffish." She explained that her father is afraid of being close to her for fear that she, too, will die.

Amanda's elderly grandmother was in the hospital, and it was "touch and go" for a while; and, at the same time, her cousin died after being in a "major traumatic motorcycle accident." It was during this time that she began pulling her hair. She remembered her first pull.

I was watching this crazy movie. I wish I could see it again because I really remember it and associate it with pulling my first hair... I remember the movie being really weird and that I was interested in it, and that I pulled some hair. My cleaning lady, who was also my babysitter, and a lovely lady, she saw me doing it and she goes, "Oh, I do that sometimes."... I just remember that, and then it was always kind of like when I was watching a movie or reading a book that I started kind of pulling around a barrette or a bow.... I just remember being alone a lot during that period. I remember feeling, yeah, a lot of tension in my family over worry. It was a pretty stressful time, and... there was a lot of alone time.

Misty's and Amanda's lives spiraled out of control after their family members died, and in Amanda's case, her parents refocused their attention on her to help her with her TTM. Misty's story is vastly different in that she experienced a multitude of subsequent traumas. She spoke of her difficult and stressful life.

I've been through a lot in my life already. I went through a bad divorce... and it was really tumultuous, and I was homeless. I've been abused, and I've also been raped,

and had a kid at an early age. Just recently, it's been the worst because of this economic stuff. Finally, I have a husband, I got a house, I'm rebuilding my life, and I finally got on the right track; and then, all of a sudden, I got laid off. I've been laid off, and no money coming in, and the husband's hours are getting cut here and there now. It's like finally when I'm rebuilding my life, I'm finally starting to breathe--now this shit's happening, and, you know, everything is stopping. We had to give some stuff up and walk away from different situations. The house almost got put in foreclosure, and then my dog passed away. It's like, Oh My God! You know? What else is going to hit?

### Power and Control

The category, *Power and Control*, relates the women's perceptions of the power they felt and the control that they had in their lives at the onset of their hair pulling. Their descriptions fall into two subcategories. The first, *What! I'm not in Control?*, refers to the women's first awareness of losing control or their lack of control in their lives. The second subcategory, *Help Me, Hair Pulling!*, highlights the ways in which the women used their hair pulling for control.

#### What! I'm Not in Control?

Connecting the inception of hair pulling with their first awareness of how much control they had in their lives is the subject of this subcategory. Five women associated their hair pulling onset with losing control. Events that coincided with their increased awareness include the death of a classmate, learning that her father was abusing her mother, experiencing control-related shifts in their relationships with their mothers, and having no control over personal secrets. Two of the women began hair pulling while they were in the process of leaving a relationship.

At the onset of hair pulling, multiple women experienced a loss of innocence at their first awareness that they could not always be protected from harm. Patches

Rapunzel referred to herself as “a naïve child” when thinking back to when her hair pulling began. Similarly, Cheryl’s first awareness of how little control she had in her life came to her when a schoolmate drowned at sea. She described her experience:

We grew up with lots of rules and you followed the rules. There was this feeling of horror and almost repulsion about the fact that this [death of a schoolmate] had occurred, and it was real strong. I was obsessed with this like, “How did this happen?” because it didn’t fit my worldview.... I remember just having this feeling of horror like, “Things like this can happen to you.” So, like my first awareness of losing control, I don’t know. Those two things are associated in my mind--thinking about that and sitting behind that girl in class. I mean literally thinking--his younger brother was in my class, and I think we had just finished talking about the fact that they were going back stateside, and all of the sudden, I see this girl doing this thing, and I think, “I can do that, too.” I think those two things are connected.

Periods of change occurred concomitantly with hair pulling for several of the women. Beth and LoGo both faced the difficult decision to leave a significant relationship, and it was during their process of gaining control in their lives that they both started hair pulling. Beth’s first awareness of how much control she had in her relationship with her husband came when she noticed her hair pulling and took control of it by researching hair pulling on the internet.

When I first realized that I had pulled, I was actually stopped. I had washed my car, and was getting out to vacuum my car. I noticed hair to the left of my driver’s seat right between the door, lots of my hair. I remember looking down and thinking, “Oh my god, look at that hair!” Not connecting that it was mine, and my first thought was that. Then, I immediately realized, “Okay, you’re the only one that drives your car. That’s your hair!” Then I connected that with it and I was like, “Oh my god!” It was like that was my ah ha moment, and when I got home, I immediately went to my computer and I just Googled hair pulling because I absolutely had no idea why I’d done it.

By taking the initiative to learn about hair pulling, Beth became aware of her lack of control in her marriage. Shortly after, she left her husband because she “could not live that lie.”

LoGo experienced a power shift in her relationship with her mother when she moved out. Her hair pulling commenced in conjunction with the dissonance that she felt about leaving her mother's home, particularly because she was "not allowed to upset my mother," and moving out was upsetting to her mother. As such, TTM proved a way for LoGo to gain control and focus on her own needs and not her mother's.

### Help Me, Hair Rulling!

The stories presented by the women suggest that hair pulling offered help and self-care. Eight women described how hair pulling directed others' attention toward them in the context of stress and trauma when, as young girls, they were otherwise going unnoticed. For 3 women, TTM provided a physical way of emotionally distancing themselves in relationships. Hair pulling allowed other women to physically attend to themselves through touch and by creating physical symptoms on which to focus. One woman described hair pulling as her way of physically managing her energy and allowing her to sit still. Hair pulling served as a best friend for most of the women in this study.

Hair pulling offered multiple women a way of garnering attention from parents and others when stressful events were overshadowing their existence and needs. Parents of 4 of the participants were wrapped up with the traumatic stressors happening in their families, and hair pulling got their attention. Most parents "freaked out" when they discovered their daughter's hair pulling. Trichotillomania focused parental attention on Cat Girl at a time that she felt invisible and unvalued in her family. Cat Girl purposefully made her appearance "terrible looking" to show her mother that she was in control. She said, "She's a big appearance person. So, my appearance was very important to her. So,



guess what? I found something to make my appearance terrible looking.” Cat Girl’s parents punished her because of her hair pulling.

Hair pulling and the resulting hair loss redirected Amanda’s parents’ attention away from her grandmother’s illness and her cousin’s death, and back to her. They were concerned about her. She said:

My parents started watching me, they started noticing I was doing it.... they’d peek in at night and I’d be pulling. I was pretty severe starting in the 5<sup>th</sup> grade probably as a reaction to, you know, the stress of being found out, and there was a lot going on in my family at the time....It was a pretty stressful time in my family. We were a really close family, my parents were doting. I just remember being alone a lot during that period.... I remember feeling a lot of tension in my family over worry, over, my mom is a very anxious sort of person over that sort of thing, and so it [hair pulling] just got worse. Then, it all kind of shifted toward me and this hair pulling problem.

Trichotillomania helped 3 women to emotionally distance themselves from other people. Nancy said that she amended her social interactions to relieve her discomfort over her hair pulling. Tia added to this when she explained that she did not open up with her close friends to tell them about her TTM.

I think it’s sort of prevented me from having even closer friendships with people... I think this just makes me so much more guarded. I know that I physically try to back up because I don’t want to be so close where people are gonna notice.... I try to do everything in my power to not make people notice it. I probably don’t have very good eye contact.

Some women found TTM to be a physical way to attend to themselves and their experiences. LoGo identified multiple ways that hair pulling helped her. She said, “Basically, it ended up that I was trying to make myself uglier.... It’s like, why would you court more attention?... I just wanna be invisible and anonymous.” Through TTM, she created moods and physically took care of her emotional self. She wondered if there was a connection to not receiving much physical touch when she was younger.

There wasn't a whole lot of physical touch in my house growing up, and I'm not real comfortable with- I'm not very physical...I don't know what all is involved there, but one of the few times my mom was physical and would touch me, was if I had a fall and needed medical care or something. It's not like I- thank you, God, I'm very healthy, and it's not like I became a Munchausen, but that just struck me recently. Like, I wonder where, you know, what that- why that need to create situations where I need to be taking care of myself in that way.

During intense periods of illness when her body systems were “out of whack,” Jade pulled her hair to provide tangible symptoms to explain her illness. She explained that the physical sensation of the hair coming out was both pleasant and painful, and that she often pulled because she wanted a “sharp sensation.” For Jade, pulling too much from a particular area overly sensitized that area, causing everything to hurt and feel good simultaneously; and she wanted to “repeat that physical sensation over and over again.”

Cheryl also used her TTM in a physical way to calm her body and to help her sit still. She theorized as to how pulling organized her excess energy.

I remember taking a test once, and it was like a hundred arithmetic problems in three minutes. Well, it was easy. It was like four and six is ten, but it wasn't easy for a third grader. I remember going like this [shows hair pulling] when I was taking it and the teacher coming by and saying, “Calm down.” I didn't think anything bad was going on. I was really into the test because I was going to be the first one done, So, that's what I mean about the energy. I often think that what maybe is, again, this sort of— it's not so emotional as it is focused. This whole thing about not having any direction about what to do with it. You know?...I sort of feel like the idea of having random energy, not emotions, but psychic energy that was never addressed.... That's my theory about myself. I don't think of it as emotion, I think of it as focus. Psychological energy—organizing it.

### My Best Friend

A subcategory, *My Best Friend*, includes the women's perceptions of what their hair pulling offered them at the onset and what it continued to do for them throughout their hair pulling tenure. Seventeen of the women identified multiple ingredients that help make a best friend and attributed these ingredients to hair pulling. They described these

aspects of hair pulling as a source of “nurturance and validation,” “a way to feel normal,” “comforting,” “soothing,” “a stress reliever,” and “a favorite book.” Several women referred to TTM as a longtime “best friend.” Elizabeth’s perception of her hair pulling as a best friend highlights the important role that hair pulling plays in these women’s lives.

It’s also kind of my best friend, because it’s the one—it’s like a person, and it’s the only person in my life that I can trust, countless times, again and again. It will comfort without judgment. One hundred percent acceptance, you know?... I feel like I have really latched on to pulling because it fulfills a deep emotional need for comfort that I don’t get anywhere else. And, I honestly don’t think that I could get the same feeling from anything else. It saves me from any--like, it’ll talk me down from any bad place. It’s just so reliable. It’s always there for me, and I can access it any time I want, essentially. So, yeah, it’s kind of like a best friend.

### Theme II: Hair Pulling, We’ve Got a Problem

The second theme, *Hair Pulling, We’ve Got a Problem*, highlights others’ conceptualizations of TTM as a problem. The women were asked, “What is hair pulling like for you?” and “What do you think about your hair pulling?” and “How is your hair pulling the same as or different from when you started?” Two categories emerged: *Others’ Conceptualization of Hair Pulling as a Problem and Impact* (Figure 3). The women’s charted course of hair pulling was influenced by how others defined their behavior, treatments that they received, and the impact that others’ reactions had on their TTM.

#### Others’ Conceptualization of Hair Pulling as a Problem

“We do not see things as they are, we see them as we are.” -Anonymous

One constant among these women’s experiences is the perception by other people that hair pulling is a problem; this perception was often accompanied by the message that

Theme II: Hair Pulling, We've got a Problem

- A. Others' Conceptualization of Hair Pulling as a Problem
  - 1. Problem Solving
    - a. Medical Treatments
    - b. Therapy
    - c. Ignoring Hair Pulling
  - 2. Treatment Readiness
- B. Impact
  - 1. I'm Pulling My Hair I'm So Crazy!
  - 2. Self-esteem
    - a. Shame
    - b. Hiding and Silencing

Figure 3. **Theme II: Hair Pulling, We've Got a Problem**

something was wrong with the hair puller. They were punished and yelled at for their hair pulling. Their peers called them derogatory names because of TTM, and they were ignored because of it. Their stories further highlight how little power many of these women had in their lives, in their relationships, and over their hair pulling. Their TTM was framed by others as a problem in need of a solution. Attempting to solve the problem of their hair pulling led to medical treatments and medications, psychological therapy, or ignoring the hair pulling entirely.

### Problem Solving

More than half of the women ( $N=13$ ) had parents who addressed their hair pulling as a biological or medical problem that required treatment. These well-intentioned parents did not include their daughters in the discourse of conceptualizing hair pulling as a medical problem and choosing treatment. Their parents took them to their family doctor. As such, hair pulling was diagnosed as ringworm, female pattern baldness, dermatitis, hormone imbalance, a nervous habit, boredom, under-stimulation, sleep

problems, depression, anxiety, fibromyalgia, and addiction. The women were neither in control of how their hair pulling was conceptualized, nor were they in control of treatment choices. Being excluded from these decisions contributed to their lack of control over their hair pulling and to their treatment readiness.

### Medical Treatments

Amanda's parents conceptualized her hair pulling as a medical problem and went to great lengths navigating the medical system to help her. She is representative of several of the women in the study whose parents took them to multiple doctors for various treatments, searching for answers and a cure for TTM. Amanda said of her experience:

She [mother] really started to pursue some treatment with our family doctor first, who birthed me and was a family friend, and so we went there. We went to the doctor, and he looked at my head, and I guess I kind of pulled in a horseshoe-shaped pattern on the top of my head. He thought it might be ringworm. I knew all along what I was doing, but I was just ashamed. I didn't want to tell. So, he treated me for ringworm. I remember going back when that didn't work because I had also, with the pulling, irritated my scalp so I was getting some dermatitis or something like that. It looked pretty bad, so they were thinking of fungus, you know, all this kind of stuff. We tried all this different kind of stuff--shampoos and things. I went to two dermatologists over the course of that summer, and then, maybe more in the fall. I knew all along, but I wasn't ready to tell. I knew all along that here I was going to the doctor's for something I didn't need to go to the doctor's for, but I didn't want to tell my parents, "I'm pulling my hair out." So, I went to one dermatologist who thought it might be some sort of dermatological thing. Then, we went to one in Oklahoma City.... There was an older man, who first did a biopsy of my scalp. Yeah, a small section of skin right there, and I don't remember thinking, "Oh my gosh, I've got to tell them." You know, I just remember being like, "Well, they'll find something out." He did. I don't know if he ever processed the biopsy or what, but he came back in and he talked to my parents first. I think I was in the room, and he said, "I think she's pulling her hair out, and you guys need to talk about it or watch her because maybe she's not even aware of it." I kind of thanked him for that. I was aware of that. I was very conscious I was doing it. It was like, "Oh good, maybe I can kind of pretend I don't know I'm doing it."

Other parents, like Amanda's parents, pursued medication treatments for their daughters. Under a physician's guidance, 9 women took prescribed antipsychotic and antidepressant medications for hair pulling that had little or no effect and sometimes had serious adverse effects, including personality changes, increased anger, increased symptoms of anxiety and depression, emotional lability, apathy, nausea, cognitive slowing, and confusion. Celeste had a serious adverse reaction to taking Seroquel, and her experience is exemplary of the bad reactions experienced by the other hair pullers who took prescribed medications. In recounting her experience on the "crazy antipsychotic drug," she said, "It totally knocked me on my ass. I couldn't even talk or pick up my orange juice that morning." In the case of Jennifer, she thought that taking medication made her hair pulling worse. She explained:

I actually think it [medication] made my hair pulling worse. I don't think that antidepressants help with hair pulling at all, because, well, I pulled when I was stressed or relaxed, but the medicine makes you so relaxed, you're just like, "Who cares! I'll just pull my hair out." That is how I felt. I couldn't stop.

Of the women who took medication for hair pulling, none of them found it to be helpful and discontinued taking it after experimenting with several. Several parents pursued psychological treatments for their daughters when medication proved to be ineffective.

### Therapy

Where some parents sought out medical professionals and drug treatments for their child's TTM, other parents looked to psychologists and counselors to fix their daughters' hair pulling problem. Thirteen of the women attended therapy to address their

TTM. Multiple women saw a therapist after medication treatments failed. For some of the women, attending therapy came after a decade of hair pulling.

From the beginning, Emily opposed all forms of therapy because her father was a therapist. After 6 years of pulling and struggling to stop, she approached her parents about taking medication. Her parents sent her to a psychologist who treated her with cognitive behavioral therapy. She said:

When I was in my senior year, I realized what it was, and I realized that I wasn't gonna get any help on my own. So, at the time, I actually decided that I wanted to go on medication. Um, but instead of going on medication, my parents found, um, just a therapist who doesn't prescribe.

Two women met with school counselors to discuss their hair pulling and their responses to their treatment were mixed. Anne found her guidance counselor to be mildly helpful. She said, "The first school counselor got me down to just one at a time. That was my first big milestone." However, she believed that by reducing her hair pulling from pulling out clumps of hair to pulling one at a time strengthened her desire to pull, and "it really took off after that." Conversely, Amanda found meeting with her counselor to be "isolating" and "ridiculous."

When Robin was 17 years old, her mother decided that her hair pulling was a problem that was not going away, and she took her to therapy. After being in therapy for many months, Robin attributed her TTM to her personal "issues of not being able to accept other people's love and not having my emotions validated." Unlike Robin, who found therapy to be helpful in addressing the underlying issues that contributed to her hair pulling problem, many of the other women's initial experiences in therapy were unsuccessful, which may be attributed to how much control they felt that they had over their hair pulling and to how ready they were to attend treatment.

## Ignoring Hair Pulling

Several of the women's hair pulling went untreated when they were children, because their parents did not know how to approach it and instead, ignored it. Nancy spoke of her experience of feeling that she, along with her hair pulling, went unnoticed by her parents.

My parents ignored it for 8 years. Back then, it was just something that I had, and something I did, and something my parents noticed, but not necessarily me...I started seeing a therapist in August 2005. I had just graduated high school, and I was going into college. That's kind of when they saw that I was at really a low point with it, and they were just like, you know- I don't know if they realized, like, hey, she's been doing this since she was a little kid. Let's, like, not ignore this anymore, and they sort of pushed me to finally go talk to someone about it.

Jade's hair pulling was initially ignored because of her other medical problems and her depression. Her mother acknowledged that her hair pulling was a problem when she was at a very low point with her nutrition and her depression. She said, "That was the year it got bad enough for my mom to say, 'Yes, okay, something's wrong. This is not normal teen problems.'" Her parents waxed and waned in their acknowledgment of her TTM and their support of her treatment. At the time of the interview, her parents were continuing to ignore her hair pulling and were treating it as the "pink elephant in the room." They paid her TLC conference fees but did not discuss it, because they largely believed that it was something that she would give up when she was ready to let it go.

Anne's parents, like others, didn't know how to react when they first discovered her hair pulling. They ignored it for some time, and then they lectured her about it, and every time they saw her pulling, reminded her not to do it. When the lectures and reminders were ineffectual, her parents punished her. She said, "Nothing would make me angrier than them pointing out that I was pulling my hair. They're interrupting my only



coping mechanism, and I needed a different coping mechanism.” Anne’s parents thought of her hair pulling as a problem and either ignored it or punished her for doing it, but they never took her for treatment.

Six of the women attended therapy for the first time as adults. They had spent many years hiding their hair pulling from others. Cheryl viewed her hair pulling as a problem, and she felt it necessary to keep it a secret from others. After many years of seeing the flyer for the TLC Conference, Cheryl decided that she needed to attend the conference, because she was through ignoring her TTM. Unlike Cheryl, Patches Rapunzel could not keep her hair pulling a secret from others because she pulled out most of the hair from her head. She believed that her hair pulling was a problem, and one that she thought was hers alone. She learned that hair pulling affected “millions of people” and not just her when she was 25 years old. After 15 years of intensive pulling, Patches Rapunzel sought help utilizing an intensive treatment program.

### Treatment Readiness

Twelve women hesitated to accept treatment when they first attended therapy. For the majority of these women, therapy was someone else’s solution for their hair pulling problem. Emily “was against going to a therapist” and did not want to stop hair pulling when she first started. Cathy is representative of multiple women in this subcategory. She said, “I was not ready for therapy at the time and did not find the therapist helpful. I don’t think this lady knew anything about it. She just had me do breathing exercises, and obviously that did nothing for me.”

“My mother made me go” was how Celeste described her entry into therapy. For Amanda, attending treatment during the summer when her friends were getting together

without her was particularly difficult for her.

I was a kid. I was really young. I didn't want to be going there every week in the summer. I didn't have the discipline at the time to do all those techniques; and, really, I wanted to be a busy sixth grader, have a social life, and go to all these events and boys and stuff like all my friends were doing. While here I am, already kind of a total nerd, at the psychiatrist in the middle of the summer, which, at the time, was something to do. Now, looking back on it, I wasn't ready to work on it. You know, it was kind of my parents forcing me into something.

Two other women talked about their readiness to do the work in therapy. LoGo recognized her role in creating change. She said, "I am sabotaging my success by not trying hard enough." She understood that by not putting in the work, she never truly knew if she failed at treatment. Similarly, Celeste was aware of the effort she put into treating her TTM. She told her therapist, "I'm not trying very hard, and I don't know what my deal is." In being challenged by her therapist, she understood, "I'm not pulling my weight here or holding up my end of the bargain." Celeste took a break from therapy after learning this about herself.

When they were girls, many of these women were dragged from appointment to appointment searching for medical solutions for their hair pulling problem. This epic search for the holy grail of treatments was outside of the girls' control. Ultimately, the treatments that were chosen were ineffective in resolving their hair pulling because these treatments did not address the issues underlying the behavior, mainly the lack of control that the women had in their lives. Medications and other treatments prescribed to treat TTM did not effect a change in the behavior or address contributing factors to hair pulling and ended in what appeared to be treatment failure. The women's hair pulling was viewed by others as a problem that was within the hair puller's power to fix. Because the women continued to hair pull, they were shamed for their TTM because they were not

able to control it. They were described as “crazy.” The girls internalized these messages at a young age and at a vulnerable time in their development, which resulted in low self-esteem and feelings of shame and self-loathing. Ultimately, many of the women chose to keep their hair pulling a secret and to hide their hair loss from the world.

### Impact

#### I’m Pulling My Hair Out I’m So Crazy!

Why would someone voluntarily pull out their own hair out? They must be crazy. This is a message that extends back in history to Hallopeau who combined the Greek words *thrix*, *tillein*, and *mania* to name hair pulling. Hallopeau did a major disservice to all hair pullers by adding “mania” to a word that described hair pulling, because the name itself inferred that the hair pulling was a form of “madness,” thereby perpetuating the belief that people who pull their hair are crazy. Interestingly, Hallopeau made up the word after he was unsuccessful in treating his patient for hair pulling.

For years, many of the women heard others describe their hair pulling as “crazy,” “weird,” “not normal,” and “bad.” Marie posited that hair pullers’ experiences of shame and low self-esteem are connected to past perceptions (theirs and others) of hair pulling because of the many ways that hair pulling is associated with mental instability and being crazy.

I think of all the ways it’s used—”Oh my god! I’m so angry! I’m just going to pull all my hair out.” There’s cartoon pictures of crazy people ripping their hair out of their heads because they’re going crazy. It’s sort of always been sort of this crazy thing that only crazy people do.

Eight of the women mentioned that they felt “crazy,” “different,” and “alone” because of their hair pulling. Jennifer described her first understanding of her hair pulling

using the term “crazy.” She said, “It was so crazy, like, ‘I’m pulling my hair.’” Amanda summed up how hair pulling made her feel in comparison to her schoolmates, “I’m an idiot. I’m crazy, and I’m different than all of you.” Heather normalized her hair pulling, “I’m crazy like everyone else.”

When she discovered that many people pulled their hair out, Patches Rapunzel was relieved to know that she was not alone.

I stopped resisting, and so then it got worse because it was a relief to know I wasn’t crazy, and that millions of people did this. That was shocking and very unbelievably sense of relief that I wasn’t by myself and that I wasn’t crazy, too. I just thought, “Well, even though I feel pretty normal, other than pulling out my hair, but who pulls out their hair?” Apparently, millions do.

### Self-esteem

Trichotillomania affected the women’s self-esteem. Multiple women described how their hair pulling contributed to their low self-esteem, feelings of shame, and hiding their hair pulling and hair loss from others, which led to additional feelings of isolation and further contributed to the downward spiral of hair pulling and self-esteem.

Hair pulling offered a visual by which the women could condemn and chide themselves. In referring to her looks, Nancy described the connection: “It’s been something that’s kind of like an eye sore.” Mirrors were a reflection of their self-esteem. Tia said, “I don’t feel like I’m not necessarily a very good person on the inside, and I don’t really like what I see on the outside.” A few women who believed hair pulling was “integral to self-esteem issues” described their TTM with hatred and disgust. Anne said, “I hate it. I despise it. I hate the way it makes me look. I hate that I feel like it’s in control of my life.” Patches Rapunzel offered a portrait of self-loathing that she directly associated with her TTM.

I actually hated myself because I was pulling out my hair. I was hard on myself. . . . I was very self-hating because I felt that I shouldn't be doing this, and it disgusted me that I did. . . . I don't like myself, so I'm not going to let anybody else find out what kind of crappy person I am, and reaffirm that I'm not worth anything.

The women were "confused" about the dissonance that they felt toward hair pulling and the negative way that others reacted to their TTM. Mellissa offered this description of her internalized beliefs:

I definitely felt all these things like "I must not be a good person" or "there's something terribly wrong with me," or "defective" or like "is anyone ever going to love me because I pull?" and all this stuff. I felt it really affected my self-esteem.

The women described feelings of revulsion because hair pulling was viewed by society as being abnormal, yet they found TTM to be helpful. Elizabeth highlighted the dissonance that she felt in the following statement.

If I've been doing well and I haven't been pulling, and when I do pull-- I just feel disgusted and disappointed with myself. I can be very unforgiving, too. . . . I just described it as a best friend, and then it makes me feel disgusted about myself.

LoGo's sense of dissonance stemmed from recognizing that she ultimately did not feel good about herself. She referred to her self-esteem struggle as being on a path to self-love.

It's so disgusting. I'm so sad. I mean, it's like, it's pitiful. I think it's an indication that I don't feel very good about myself, which is kind of true. It's like I do and I don't. I'm hyper-sensitive to criticism. I think it comes from a lack of really believing in myself and trusting myself and just really loving myself. It's really just this path I'm on, but trying to, like, just, you know, love myself.

## Shame

A second factor highlighted by the responses to what the women thought about their hair pulling, how they experienced hair pulling, and how it differed from when they first started, was shame. The women described a number of different hair pulling

experiences associated with shame, including the discovery of their hair pulling, being perceived by others as different, personal disappointment, hiding hair pulling, and living with their hair pulling secret. Six women identified “being discovered” for their hair pulling as a shaming event. Anne responded to being discovered pulling with anger that is “immediately coupled with the shock and humiliation of being discovered because it’s so shameful.” Nancy’s parents punished her when they found her hair pulling. She explained her experience of being discovered, punished, and shamed.

I remember getting in trouble for it a lot. My parents would, they would see me—not see me doing it, they never saw me do it, actually. But, they would see the results afterwards and they would kind of, like, I mean, I got in trouble for it. I got grounded. I got put in my room. I got yelled at. So it—it definitely took on a shameful sort of feeling for me at a very young age. Like, almost instantly, as soon as they found out about it, because they just didn’t know what it was. They didn’t understand what it was....[Shame is] definitely something that I experienced as a child growing up having to be like, not ridiculed by my parents, but questioned about it constantly. You know, sent to my room about it. Pointed it out, and I’d feel bad, and I’d feel self-conscious.

A few women connected their shame with being perceived as different. Amanda described her experience of being singled out as different.

I felt pretty freakish. It caused me a lot of heartache. I’d always been a perfect model student, and suddenly they’re sitting there yelling at me, “bald eagle...” I’d stop getting invited to all the slumber parties that I had always gone to before, and it was, like, the mothers who were, like, “Something is wrong with Amanda.” I felt that from the mothers of my classmates and my friends more than anything.... I’m going to be a social pariah.... It was like, well, you don’t look like everyone else, you don’t look right. You’re going to have to cover it up. That was really cruel of people. They should have been a little more insightful to see that this girl’s dealing with something.

Wanting to fit in contributed to Nancy’s experience of shame.

I really had a huge weight of shame then, even through high school. Kids are terrible and you just wanna be cool, and you wanna look like everyone else, and you wanna be pretty, and you wanna have guy friends and maybe a boyfriend. I guess during those years it was worse.

Several women described experiencing shame at the onset of their hair pulling when they were young girls and attributed it to their feeling that something was wrong with them. Cheryl's description of her initial experience of shame and how it continues to impact her best describes the overall feeling that the other women had that something was wrong with them.

I have to say that, when it first started happening, I felt a lot of shame. I felt like there was definitely something psychologically wrong with me.... There is something essentially wrong with me, that I'm defective, that I am disgusting. I am repulsive. I thought that people would have those feelings towards me, that they would not want to be around me, almost as if they might get it or something....I feel helpless, sadness, I guess. I guess it's kind of a sadness. Worthlessness. Pulling proves—it's an obvious physical proof of the problem.

LoGo described shame a daily struggle. She said:

With that shame piece, I really need to spend more time really addressing this. I really haven't, because it—I get busy, and then it's like, oh, I'll deal with it. But, you know, when I saw this, and I was pulling this together for the questionnaire, and everything, it really helped spur me back on to keep addressing it because it's ongoing. It's every fucking day.... I'm hurting myself. So, that adds to that feeling of shame, like, god, what's wrong?

Elizabeth felt that something was wrong with her because she did not have control over her hair pulling, and her appearance.

I feel ashamed about pulling, like I'm weak. I'm ashamed of my lack of self-control. I'm just ashamed of having this disorder, even though it's not my fault....I feel ashamed of how I look, because I feel I'm an attractive person, but my hair has just been the thorn in my side of, like, about my looks.

Three women associated shame with guilt. Liz said that she internalizes embarrassment and guilt over hair pulling and beats herself up because of it, which leads to additional guilt and shame. Tia's experience echoed Liz's. After pulling her hair out, Tia "sometimes feel that immediate relief, but then immediately after that, it's the guilt and that sadness. It's like disappointment in myself, and why do I keep doing this?" Beth

described her shame cycle, “It’s that vicious cycle of shame and embarrassment, and then anger at yourself for doing it, and fear that someone’s going to find out. Then more shame and fear.” For Marie, “a lot of the shame comes with keeping it to yourself.”

### Hiding and Silencing

Hiding hair pulling altogether and employing techniques to cover up the results of TTM is directly related to the women’s low self-esteem and sense of shame. Ultimately, the women responded to outsiders’ conceptualizing their hair pulling as a problem by internalizing this message and viewing themselves as not normal and not accepted by others, which resulted in their covering up their hair pulling and keeping silent about it.

Hiding and self-silencing changed the course of these women’s lives.

Jennifer’s earliest experience of hair pulling taught her to hide her TTM.

I remember, like, pulling my hair on the school bus coming back from school. I was, like, “Look what I can do!” I just grabbed a chunk of my hair and just yanked it out, and I was just appalled, like, “Oh my goodness! I just pulled a huge chunk of my hair out.” It was so weird, and I stuffed it in my backpack and ran home. I threw it out, like I wanted to hide it.

The women felt a sense of burden in keeping their hair pulling a secret. Celeste who had “a few semitraumatic experiences of people discovering” her hair pulling, went to great lengths to keep her head covered.

There’s a point where the fillers just don’t stick to your head anymore. That’s when I started wearing a scarf. Most of my friends and professors never knew me without one on my head...I felt like I couldn’t ever take it off, and it was hard to hide from [my roommate] what was under the scarf.

Some women were limited in their choice of hairstyle because of bald spots, and they could not wear ponytails. Others wore wigs and scarves or cut their hair to hide hair loss. For Tia and several others, “hiding hair pulling was an extra burden.” They who hid their



hair pulling and loss from their family and friends would “wake up earlier than everyone else to get into the bathroom first,” “put on my face,” and wear hair pieces and false eyelashes. Cathy described her experience of hiding her TTM.

I started buying false eyelashes and trying to wear those, and that was just hard, because those are not meant to replace your eyelashes. They’re meant to compliment the ones you already have. When you don’t have anything there, there’s nothing to attach to a lid. I know all the false ones by now because I’ve tried so many different ones. That was difficult. After college, it got even worse. It became extensive because I’d have to buy these false eyelashes and the glue, and with my eyebrows I have to buy the filler pencils. Every time I would go to the store to buy them, I would think, “This is a really silly expense that I don’t need to be spending my money on, but I can’t stop pulling so I have to buy the stuff.”

Keeping hair pulling a secret for many years was not uncommon among many of the women in this study. Misty’s experience best describes this type of hiding because she kept her hair pulling secret for over 30 years—including from her husband. She started attending a TTM support group, and the women in the group were the first people that she told about her hair pulling. That support group met one Saturday a month, and she likened attending the support group without telling her husband about it to cheating on him. “I joined the trich group, and then what was I supposed to tell him? James would think I’m cheating on him every Saturday. So I—it had to come out.” Misty was married to her husband for over 6 years before she told him about her TTM and described it as a burden being lifted.

I kept it really private, and of course kept it covered up, and only pulled alone. It took thirty years to actually come out and tell strangers that I have it. Then, I told my husband, like, three years ago. It is like a burden lifted off of you because you’re, like, phew, these people finally know and I don’t have to hide it because the husband was starting to tell me, “Why don’t you wear your hair down?” and “I like it that way.” How can you explain it? You can’t. And, you’re having your hair up in the shower, and he walks in, and it’s like, “god, now I can’t wash my hair.”

Keeping their hair pulling a secret from family was a shared experience for many

of the women. They hesitated to tell family “for fear of being judged” and because TTM was “mortifying” and “a weird thing to do.” Tia mentioned the hurdles to revealing her hair pulling secret.

I’m very close to my family, and so it’s really been really hard not to be able to open up about it even more with them, and at all with my brother and sister-in-law. ... I’ve just been having a hard time, even still to this day, getting over that hurdle of the shame, and the guilt, and the embarrassment.

Hiding hair pulling and keeping it a secret takes a toll on the emotional self and relationships, and it impacts social interactions and life choices. Both Cathy and Elizabeth “shy away from makeovers with friends.” Elizabeth recounted her avoidance of intimacy in social settings.

I’ve avoided parties. My friend had this cool party where they were gonna do henna tattoos, and there was some type of hair styling aspect to it. I had to make up some excuse to not go hang out with my friends and go get all this cool stuff done. It sounded like this awesome party that I would not have wanted to miss; but, because I was afraid someone would see my hair, I didn’t go.... I think it’s like a combination of feeling shame already, and then wanting to avoid further shame.

Amanda literally ran away to boarding school, Montana, and Mexico in an effort to hide from herself, her peers, and her hair pulling for most of her teenage years. She recalled her experience:

Really, what I wanted to do was run away, everything else was me finding ways to market it. I have to get out of this small town, and then I have to get out of this boarding school. Everything, always was closing. Just people, and their cruelty, and myself, and my shame at being awkward and goofy. I was like, that’s not really me. I felt like that’s not really me, that was like the way I’m dealing with you people because I’m not feeling confident, but inside of me is a very confident person who has a lot to say and a lot to give that you’re not seeing because I don’t have hair, which kind of cripples me, you know?

In Emily’s case, hair pulling changed her intended path in life. She explained:

I wanted to be an actress. That was like my little childhood dream. I remember thinking, “Oh well, I don’t actually know if I could do that because what happens when the makeup artist realizes that they have to pencil in eyebrows all the time?”

Will the cameras catch that? Will people know?” I remember thinking about that when I was younger. You know, maybe I can’t do whatever I want because of this.

### Summary

Seen and not heard—this is how hair pulling was approached by many of the women, their parents, and partners. Some of the women were not allowed to acknowledge their hair pulling, and they were encouraged to keep their hair loss hidden. A few women did not talk about it as adults. They hid their hair pulling and presented the perfect image on the outside, leaving a mess on the inside. This was a setup for shame. Being singled out and chastised or punished for their TTM shamed them. Many of the women were taken to numerous doctors to fix their hair pulling problem. In turn, the women internalized the message, “something is wrong with me,” at a young age. Believing that something was wrong with them negatively affected self-esteem and relationships with parents and friends, and it set the women on a path that was difficult to navigate—especially as it started at such a young and vulnerable age for many of the participants. The women’s belief that something was internally wrong contributed to their belief that they had little or no control over their hair pulling. This led to many years of struggle for the women to accept their hair pulling and to understand how TTM fit into their lives.

### Theme III: The Struggle

The third theme, *The Struggle*, highlights the evolution of the women’s hair pulling and their struggle to understand their behavior and accept it. The women’s answers to two main questions: “How is your hair pulling the same or different from when you first began hair pulling?” and “How do you feel about your hair pulling?” as

well as the follow-up question, “What do you get from hair pulling?” provided the basis for this theme. The participants’ perceptions of their TTM and their hair pulling experiences illuminate their process for accepting their TTM and integrating it into their identities. Three categories within this theme emerged: *Awareness*, *Accountability*, and *Acceptance is Work* (Figure 4).

### Awareness

At the time of the interviews, all of the women were aware that they pulled their hair. Some had consciously pulled for years and others were newly aware of their TTM. Jade remembered her first awareness of hair pulling, “I remember my dad asked me why I was pulling my hair out, and I said I wasn't, because at the time I really wasn't doing it on purpose.” Patches Rapunzel’s experience was similar to several others’ experiences in that she was aware of her TTM starting with her first pull. She said:

I started with my eyelashes. You know how if you get something in your eye, you feel it there and you want to try and pull out whatever is up there? Well, I pulled out some eyelashes with it, and that amazed me for some reason. I started checking to see if all my eyelashes were loose- as loose as that. I thought, “Man, those eyelashes came out easy.” So, I checked all of my eyelashes. Some of them were ready to come out and came out, and then that’s how it started. From then on, I just wanted to keep pulling. When I had no more eyelashes, I started on my eyebrows. After that, I started on my scalp.

Several of the women’s understanding of their TTM was associated with their emotional awareness. Kierra recognized this connection:

I think that one of the things about me is that sometimes I have a hard time connecting with my emotions, but I have a lot of them, so it's hard for me to sometimes put them into words or connect with how I'm feeling. In some ways, it's like my hair pulling is connected to that, to those issues, so it's hard to know what's really going on with me until that's happening; and then, even then, there are different reasons. I think that the helplessness, that's a feeling that makes me feel like, "Well, I'll just keep doing it. Obviously, I can't stop anyways." So, just feeling really helpless, or I'm just stuck in the anxious mode where I'm feeling anxious, but I just don't know

### Theme III: The Struggle

- A. Awareness
- B. Accountability
  - 1. It Takes a Village
  - 2. Accountability Strategies
  - 3. Treatment: Participating for Change
  - 4. I'm Not Pulling My Weight Here
- C. Acceptance is Work
  - 1. The Struggle
    - a. It's Me, But Not Really Me
    - b. The Battle Against the Pulling
  - 2. It's Me
    - a. Empowerment
    - b. Empathy

Figure 4. **Theme III: The Struggle**

what to do about it, or just, I need to release some kind of energy, and it comes out that way. So a lot of times for me it's general dis-regulation, and those are the times that hair pulling will happen for me.

Awareness presented them with the choice: to pull or not to pull? Emily said, "Now, there's rarely a time when my hand goes up that I don't know it's up." Cat Girl attributed her emotional awareness to her TTM. She said: "I've become more aware of my feelings, and where I'm at.... It's the awareness that's making me know that I feel bad," It was "feeling bad" that led her to pull her hair.

Nancy attributed her increased awareness of her pulling to slowing down her process of hair pulling from urge to pull by sitting with a feeling, and trying not to judge herself for her TTM.

You definitely have an awareness of when you're pulling, when you're thinking about it; what urges feel like. I've really been able to hone in on that in recent months especially, just sort of slowing down the process from urge to pull, and, like, really sitting with that feeling and analyzing it. Since I've gotten older. It's just a bigger part of my life, because I understand more about it now.

Conversely, Heather was aware of her hair pulling, but she was not always aware in the moment. She paid no attention to her emotions before, during, or after she pulled, and she allowed herself to pull freely. She said, “I don’t pay attention to [emotions].” She now recognized that her emotional disconnect and lack of awareness of her hair pulling in the moment was a problem for her. She explained, “I don’t really think about it. There’ll be times where I’ll just do it and not know I’m doing it, and that’s the problem. I don’t know why I’m doing it, and that’s hard for me.”

Awareness of their hair pulling was the initial step toward understanding their TTM and the role that it played in their lives. Awareness offered the women a choice: continue pulling or try to stop. This choice was not fluid, and it was a struggle for many of the participants, but it moved them toward taking responsibility for their hair pulling.

### Accountability

Taking ownership of their TTM and actively working to change their behavior helped the women to be accountable for their pulling. Personal accountability represented a shift in their sense of the control that they had over their pulling. The participants identified that they wanted to change their behavior and used multiple strategies to accomplish this goal. Personal accountability, for some women, centered on self-disclosing about their hair pulling with family and friends and avoiding pulling in their presence. Asking for help from friends and relatives was a strategy that others utilized when working toward being accountable. Some of the participants shared about their TTM with others and asked that they be able to talk about it when they were having a difficult time, and other women asked friends and family to notify them when they were pulling. Participants limited their hair pulling by number of hairs pulled and reorganized

their pulling sites to increase their control over TTM. The majority of the women in this study actively worked to change their hair pulling through participation in therapy, research studies, support groups, and TTM community events.

Nancy's experience exemplified how she changed her thoughts about her TTM over time and became accountable for her hair pulling. She said:

I used to think that it was, like, something, like, oh, okay this is something that just lives within me, and I can't really control it. You know, and it comes out when it wants, and it goes away when it wants.... I have been trying to work on ownership of that, because if I, sort of, place the blame on this thing or that, I can't control it. There's really no way that I can ever make it better if I'm always just—you know, if I don't take accountability for it. So, if I take accountability for it, and I find ways in which I can control it, then it sort of changes how I'm able to fight it.

### It Takes a Village

Several of the women openly spoke about their TTM with family, friends, and strangers alike. They identified that self-disclosing about their hair pulling struggle was a motivator for them to pull less or not to pull at all. They told others to garner their support and as a way to help themselves be accountable for their hair pulling. Several women viewed their openness about hair pulling with family and friends as a way to gain allies to help them change their behavior and as a way of increasing control over their TTM. In essence, they utilized an “It takes a village” approach to their TTM. In self-disclosing about their hair pulling, the women gained allies who aligned with their specific hair pulling goals. The hair puller and her allies were a team, and with a team, she was empowered to address her TTM. Further, the hair puller shaped others' perceptions of her experience when she self-disclosed; in doing so, she owned her hair pulling.

Elizabeth had greater control over her hair pulling with allies, because she was free to ask for their help without worrying about their reactions. She said, “I think that one of the most positive aspects about telling people is that you've now gained yet another ally in your fight against this, because, once they know, I think that you could ask for help.”

Emily told as many people as she could about her hair pulling, because she held herself accountable to control her pulling in their presence.

I have found that the most helpful thing for me is to tell as many people in my life as I possibly can, because then, when I'm with those people, I will not pull. I know that they know, so I'll be watching myself.... I just tell whoever I'm with this is the reason beforehand, so I just don't have to think about it. I've never had someone have a bad reaction to it when I tell them, so it makes it much easier, and it just really prevents people from doing anything.

Similarly, Celeste decided “it's in my best interest to have allies” to tell others about her hair pulling rather than let them come to “different or worse conclusions.” Nancy found that being open about her TTM with the people in her life motivated her to want to stop pulling. She said, “That accountability piece of, like, that they have an actual awareness of it, you're a lot less likely to pull. It's a motivator not to pull.”

Marie and Patches Rapunzel made public their struggles with TTM during a class presentation and in a series of articles for a local newspaper and a support community. Marie presented on the Hoxb8 gene in a graduate course of her peers and gave a personal account of her behavior. The class and her professor responded positively to her presentation. She spoke enthusiastically of her experience and its impact on her hair pulling in subsequent years.

It was really liberating to be able to just tell a bunch of people my age my deepest, darkest secret and have them just be fascinated and just talk to me about it. Over the



course of the next couple years, it became less about controlling what I could or couldn't do, and more about making me a stronger person because I was able to let go of my insecurities and not be selfish; not focus on me me, me all the time, but focus on helping others and losing who I was in living my life.

Patches Rapunzel gained a sense of control in sharing her experience. She explained:

I wanted to feel like I had some control in my life. I concentrated on growing my hair out. I wrote up some stuff that was in the newsletter, too. So, I learned to help myself, because when I went online, there wasn't any real help online from the support groups. Basically, you have to do it yourself, but doing it yourself, what I wrote up, is a lot like what these [clinicians and researchers at the conference] are talking about, which I didn't realize that I was so bang on. Basically, it's changing the way you think about stuff and changing the way you behave. That helped me change my thinking. I started letting [co-workers] know through that article, and then people came up and talked to me about it, which is, like, amazing. I was so incredibly supported by everybody. That was the big surprise. I hid for so long that I thought I would be ostracized. Then, when I did tell everybody—I'm getting tears in my eyes—when I did tell everybody, it was the exact opposite. Everybody wanted to just be supportive....Just the tremendous support was so overwhelming to me that it just shocked me. I guess I discovered that I was more well-liked than I thought.

Jennifer's experience is representative of several women. She was a fascinating accountability paradox, and her experience exemplifies the complexity of individuals with TTM. She struggled with accountability. She identified her TTM as a behavior that was both within and outside of her ability to control. She openly talked about her TTM with family and friends, and she looked to them to help her control her pulling. She wanted her friends and family to point out her hair pulling to her, because she did not believe that she was capable of changing her behavior without their input. When she told friends and family and asked for their help, she said, "Would you tell me if I'm touching my hair?" She vacillated between asking others to hold her accountable by telling her when she was pulling and helping herself to be accountable by being aware of her pulling and working to not pull. She worked on being accountable with her therapist and her support group.

I actually think that with the counselor that I saw, I really wanted it to work for myself and for her. I wanted us to be successful. With the support group, we set goals; and it's something like you want to be able to go back and say, "I met my goal." or "Three days of the week I didn't, but you know the other few I did." I want to be accountable and successful at not pulling my hair. I feel like I need help to not pull my hair. I don't feel like I can do it on my own. I couldn't just make up my mind not to do it. I need help. I needed support from the ladies that are in the support group and through a counselor. I'm the one who's not pulling my hair, but I needed some direction.

Jade was at an accountability crossroads, and she talked about taking ownership of her hair pulling. She said:

I'm at this lovely point where I know everything that would fix it. I just haven't quite gotten to the point where I'm ready to institute the fixes.... I'm getting restless with myself, so it's a good time to start putting the different tools into place and practicing them.

Multiple women kept their TTM to themselves and self-disclosing to only a few people created a barrier to taking ownership of TTM and being accountable. Tia recognized that she "might gain control over hair pulling if I let more people know about it," but she was "not ready to take that step." Similarly, Kierra struggled to control her hair pulling, and she had only told five people outside of her immediate family about her TTM. She said, "It's super secretive; and just recently, I think, I'm trying to integrate it a little more, because I'm trying to get rid of it."

Two women had told only two people about their TTM, struggled to be pull free, and related their hair pulling to "God's will." Both of the women used prayer to address their pulling. Liz believed that God gave her hair pulling to make her a better person if only she could overcome hair pulling. Cathy experienced a brief period of nonpulling when she was in college. She explained:

I definitely attribute it to—I was just praying all the time, and I felt like that time of my life was the strongest and closest I've ever been to God. My relationship was very

strong at that point, and I feel that had 100% to do with it, because, since then, I have definitely not been as strong in my faith or anything. I think that's a huge factor in it.

### Accountability Strategies

The women employed a number of other strategies outside of self-disclosure that helped them to be accountable for their hair pulling, including limiting their pulls to a specific number per day and containing their pulling to a certain area of their body where hair loss was less noticeable. Other helpful strategies included, but were not limited to, pulling with the nondominant hand, holding worry beads or stress balls, bandaging fingers, wearing acrylic nails, shaving, avoiding triggers to pulling, and keeping company. The use of such strategies put the women on an accountability path to help them to control their hair pulling.

Three of the women limited the number of pulls that they allowed themselves each day in an effort to control their hair pulling. One woman delayed pulling her first hair of the day for as long as could and had more success in controlling her pulling throughout the day the longer she delayed. Two women tracked their number of pulls per day. Celeste described her process as, "I'm always making deals with myself all day."

Similarly, Anne granted herself a certain number of pulls each day and called these "graces." She described her accountability process:

It was actually a pretty effective technique to do that because it was like giving myself permission. I called them "graces." I gave myself four graces a day. I was keeping track of how many I pulled a day. I was just writing it down in a little journal, and the first four I would put in a little box that was called a "grace." I would just be like, "Okay, it wasn't a failure. It's still within my first four. I'm okay." So my goal was to keep it to those four or less every day.

Targeting a particular spot or evenly distributing their pulling were strategies that many of the women used to control their hair pulling. One woman pulled only the hair

from behind her ears “to minimize hair loss in a particular area.” Another pulled from thicker areas. Kierra concentrated her pulling in particular areas to keep from losing hair in an area that she preferred. She explained:

I’m trying to manage the hair loss, so I’ll focus it in areas I don’t prefer; and I will pull in those areas; and after a while, I’ll build more of like a relationship with that area because I’m trying to keep from being totally bald.... So, I will go through periods where I try to focus and control it.

Most of the women in the study utilized a variety of strategies throughout the day to control their hair pulling. The strategies that they employed included pulling with their nondominant hand, holding worry beads at night while watching television, squeezing stress balls, and wearing white gloves, finger guards, bandages, and fake nails that were “not able grasp the hair.”

Nancy described her accountability process:

Right now, I’m journaling, and I have my Outlook email send me reminders, and it’s randomized throughout the day. It’ll send me a reminder to do sort of a check in with myself, and when that reminder pops up on the screen, no matter what I’m doing, I’ll stop with the computer, and I’ll pull a little notepad from the side, and I’ll just write about my day.... I do it twice a day to check in with myself and be mindful of my pulling again.

Shaving offered some of the women an effective solution to manage their hair pulling. Melissa explained:

When I shaved my head, I was like, “This is what I’m doing about it” because I don’t have the urge to pull when my hair is this short. It was a really good remedy to just shave it, because I have to be able to get my hands around it in order to pull.

Ironically, others often mistook a shaved scalp as an indicator that the hair puller was unable to control their pulling.

Wearing hairpieces, scarves, and hats provided a barrier to hair access, which was enough to keep some of the women from running their hands through their hair in search

of a curly hair to pull. Elizabeth often took showers to relax and because she pulled less when she was calm. Also, she did not feel the urge to pull when her hair was wet and slicked back. She said that she was “unable to differentiate between the curly and straight hairs when they were wet”; therefore, she did not pull her hair out.

Several of the participants held themselves accountable for their hair pulling by refraining from pulling in the presence of others, including their partners and family. Kierra and Elizabeth spent as much time as possible with other people to keep themselves from pulling. Elizabeth explained:

I’ll avoid situations where I know I’ll pull. For example, I am a scientist, and I have an office, and I work in a lab. But I try to stay out of the office, because when I’m sitting at my computer, I tend to pull. So what I’ll do is, I’ll just work in the lab all day wearing gloves so I can’t pull.

Elizabeth also read blogs by others struggling with TTM in an effort to manage her pulling. She related to their struggles and identified with their pursuit of accountability, and she limited her hair pulling because she felt a kinship with them.

At times when her hair pulling was intense and she did not feel that she was in control of it, Kierra instituted her own form of aversion therapy for hair pulling. She paired pulling with smelling ketchup, because she loathed the smell of ketchup. Her technique worked to control her TTM. She said, “I’ve tried to do aversion things where if I pull a hair, I hate ketchup and I can’t stand it, so if I pull, I have to go smell ketchup; and that actually worked for a while.”

#### Treatment: Participating for Change

Therapy, research studies, support groups, and TLC conferences were activities that the participants engaged in for accountability. Many of the women participated in

more than one form of treatment, simultaneously and over time, to address their hair pulling. Being actively involved in their change process contributed to helping themselves to be personally accountable for their pulling. Being accountable for their TTM gave the women a new vantage point to understand the role that TTM played in their lives and increased their sense of control over their hair pulling to effect a change.

Robin participated in multiple forms of therapy over the past 15 years. Her goal was to “explore all available avenues to battle” her TTM. So far, she found ACT to be the most helpful. She discussed the impact that practicing ACT has had on her life and her hair pulling.

It’s an eight-step thing, and that, I think, at least for me, has given me the most clarity and the most clear path of being able to get it under control. It’s definitely something that has to be applied every day and until you do get the patterns down. It’s worked because you have to remember, I’m changing thought patterns that I’ve had for my entire life.

Many of the women found ACT to be a useful form of treatment. They identified with sitting with their emotions, accepting themselves along with their hair pulling, and “refraining from judgment” of self. Kierra credited the work that she did in therapy with helping her to “pull it together” and to be accountable for her hair pulling. She worked hard to be accountable for her pulling when she was not in therapy by using CBT strategies, and Emily was aware of her limitations.

At school, I do give myself some leeway, and I understand at the heart of the semester, I can’t really work on it. So, as of right now, I’m aware. If I feel I have a little less—not such a stressful day, I will wake up in the morning and say, “Okay, today make it a better day, because you have that chance”; but overall, I will probably start consciously working on it again as soon as the semester is over.

By allowing herself a break, she retained control of her hair pulling and had an accountability plan in place for when the semester ended.

Many of the participants regularly attended and participated in a support group, an activity that they all found helpful in encouraging accountability for their hair pulling. Most women helped themselves to be accountable in the group. One woman described her support group as a “wonderful tool and support” because “I needed their help to help quit.”

In discussing helping herself to be accountable, Nancy said, “We try to refocus how I think about it and put the accountability back on me.” Celeste also led a support group and felt a sense of accountability to herself and the members of her group. She said, “In terms of letting people down, I feel like having the support group—we all hold each other pretty accountable.”

Elizabeth recommended support groups to everyone as “the most helpful way of being accountable for your hair pulling.” Elizabeth reached out to friends from her support group at times when she felt stressed and was concerned that she might pull her hair. She said:

I’ll call someone from my support group to say “Hey, I wanna pull, I’m feeling stressed.” I just needed some support, and then we don’t even really talk about pulling necessarily, but it’s just talking to them and kind of touching base that makes me feel a little stronger.

Attending the annual TLC Conference is something that many of the participants have been doing for years. Some started attending with their parents and siblings when they were younger, and others were relatively new to the conference. All of the women who attended the conference spoke of it as a community of support and inspiration for them. It was a chance for them to meet with others who identified with their struggle, and they developed lasting relationships while there. The conference also provided the

women with information on the most recent treatments and access to research and community professionals.

Amanda, Beth, and Cheryl were first-time attendees at the annual conference. Amanda described her experience as one of “just an overwhelming amount of support just being here.” Cheryl had been aware of this conference for a few years, but she did not identify herself with this community until recently. She recognized that her attendance at the conference was her commitment to herself and to changing her hair pulling. She said:

I don't do much environmental modification, that sort of thing; but I'm more motivated now. I think coming to this conference was clearly a commitment and a way to do something different, because I've been seeing this conference in the newsletter for a couple of years, and it seemed like something other people did; and then, this year, it just clicked with me. It's like, “I've got to be there. That is me.”

### I'm Not Pulling My Weight Here

Several women acknowledged that they did not put forth the effort to change their hair pulling behavior. LoGo, Celeste, and Jade discovered that they were not actively working to mitigate their hair pulling, despite having a personal goal of eliminating TTM from their lives. LoGo stopped attending therapy because her last therapist minimized her hair pulling, which offended her. She said, “She minimized my behavior, and that kind of pisses me off.” As she continued to talk during the interview, LoGo revealed that she “did not try as hard as [she] could” in treatment, because she was afraid that she would fail and never be able to control her hair pulling. Her admission that she did not try in therapy was her move toward accountability and understanding her hair pulling.

Similarly, Celeste recognized that she did not try in therapy. With the help of her therapist, she understood her role in treatment and the impact that it had on her TTM:



I had this one session with my therapist, and I'm, like, I'm not trying very hard, and I don't know what my deal is. He was, like, "So basically what you're telling me is that you could—or I could take you out of therapy—or, like, there's like no point in you coming if you're not trying." And I was like, "Wow! You know, yeah, I guess I'm not pulling my weight here."

Cathy attended only a few support group meetings. Upon finding out about the group, she was excited to join, because, "It was the first time that I found an outlet where I could fit in." Her excitement turned to disappointment when she did not relate to the women in the group and felt that she did not fit in. She wanted a "more authentic group experience" of openness and sharing with these women but found them to be "very reserved." Ironically, Cathy wanted an authentic experience with the members of her group when she herself struggled to be authentic with the group. Cathy looked to the women in her support group to hold her accountable for her hair pulling instead of looking to them to help her be accountable. She wanted her support group to do the work for her rather than doing her own work to change her hair pulling and to be in control of it.

All of the participants struggled with taking ownership of their hair pulling at some point on their journey. Helping themselves to be accountable for their TTM was more than identifying what needed to be done. It required that the women clarify how and why it was to be done and to work to change their behavior in order to help themselves. The women participated in a variety of treatments, some of which challenged them to work to be accountable for their TTM. Accountability required continual vigilance of their hair pulling and a shift in understanding the role that it played in their lives. Personally effecting a change in their lives by actively working to control hair pulling helped the women to be accountable for it. In becoming personally responsible for their

behavior, hair pullers determined the importance of hair pulling and examined the ways that it impacted their lives. Taking ownership of hair pulling led the women on a path toward acceptance of their TTM and integrating it into their identity.

### Acceptance ~~K~~ Work

A third category, *Acceptance is Work*, emerged from the data and revealed the complexities associated with accepting hair pulling. The women worked continually to identify with their hair pulling and to control it. Their work was made difficult, because others conceptualized their hair pulling as a problem. The presumption that something was wrong with the hair puller centered on the behavior and her ability to control it, not on the underlying cause of the behavior. As such, the women struggled to accept their TTM, because they did not want to accept that they had a problem that they struggled to control. Integrating hair pulling into their identity empowered them to take control of their hair pulling and to determine the role that it played in their lives, which resulted in the women living more authentic lives.

### The Struggle

Accepting their TTM was a struggle for the participants, because they were embracing themselves and disowning themselves at the same time. Integrating hair pulling, a known problem, into their identity, when they did not want the stigma of having a problem associated with them, was a cornerstone in the women's struggle to accept TTM. Nancy best explained her dissonance when she described her experience as "a process of accepting who you are and, at the same time, fighting who you are." Outsiders conceptualized hair pulling as a dichotomous problem: hair pulling was bad

and not pulling was good. This framework forced the women to choose to work on their TTM or to not work on it. Being forced to choose ignited an internal fight to control their hair pulling. Self-acceptance was further complicated by outsiders' perceptions of TTM and their acceptance of the hair puller. Others viewed hair pulling as problematic in that the hair puller was not in control; and, when they were not in control of their TTM or not trying to control their pulling, others did not accept them, which further contributed to the women's struggle to control and accept their TTM. It was difficult to accept their hair pulling as a part of themselves when others did not accept them because of their TTM.

It's O e, Dut P ot Teally O e

Understanding how hair pulling fit into their perception of self was challenging for the participants. TTM was a part of them, but it was not the only part of them. The women did not want to be defined by their hair pulling, which was often the case. They knew that they were “strong,” “accomplished,” “successful,” “loving,” “good,” “friendly,” “smart,” “empathetic,” and “passionate,” yet, they also felt as if they were a “freak” or “crazy,” because that is how others viewed them due to their TTM. Therein lay their struggle—the women grappled with being hair pullers despite all of their other wonderful attributes. Six women spoke of their endeavors to incorporate TTM into their identity.

Elizabeth explained her struggle this way:

I desperately wish I could give it up and have it not be a part of my life. I mean, if I found a magic lamp and got a free wish that would be it. I don't wanna pull my hair out anymore. I know- maybe that's kind of sad, because there's so many other things to wish for, but that is my one wish in life, is that I don't want this. I don't want this disorder. I mean, it's made me who I am, too, but I just wish it would stop. I desperately wish it was not part of my identity, but it is, and so I just kind of have to accept it. Um, well, I don't have to accept it, but for my sanity I do.

Heather struggled to accept that she was both a “very strong person” and a hair puller. She viewed hair pulling as “weak” and wrestled with identifying with it.

I'm not a weak person. I'm a very strong person. We all have little issues, so I can't pinpoint anything. That's what doesn't make sense to me. To me, it's not a typical- when you think of somebody who's strong... to have [TTM] is, to me, almost the opposite in a way. That's what I can't figure out. That's why I can't pinpoint anything, and that's- that's the most struggle. That's what I struggle with the most.

Nancy felt that she was “split into two halves”; and each had her own opinion of her hair pulling. She described this split and her process of identifying with her two halves in a poem that she wrote titled, *The Beast Within*. She maintained a self-image of both a hair puller and a nonpuller, and accepting both identities was a difficult process. She said, “While I do acknowledge that this is something I will probably have to struggle with my whole life, I do believe it’s something that I can maintain or manage.” Cheryl’s process was similar.

Cheryl spent decades refusing to fit hair pulling into her self-perception. She intellectualized her behavior and thought of it as, “Well, it's me, but not really me.” She operated from the mindset of “this is something that I do, and not who I am” for years, which contributed to the disharmony that she experienced in accepting hair pulling as part of her identity.

Kierra experienced intrapersonal discord in accepting her hair pulling as a part of her identity, because TTM did not fit with how she perceived herself to be now. She associated her hair pulling with anxiety that she felt in the past and struggled to understand the role that hair pulling played in her present life.

I have more dissonance around it now. Like then, it was just like something I did, but I think I'm more dissonant around it now; and it feels more also like it's weird, because at that time it's like it's a part of me that I have to hide. It's something that's really weird about me. It's really strange, but it's this part of me, and I've got to keep it

close. That reflected more how I felt globally about myself then. Now, I've done a bunch of work. I understand my anxiety. I don't internalize it in the same way. I've done a lot of work, so it's more like a thing that doesn't fit with who I am anymore. It's like an old skeleton or something that just won't go away. I don't feel those same ways about myself anymore, but it's still there. It feels more automatic or entrenched, but those pathways are so ingrained. I can almost just feel my brain wanting pattern completion in all those areas, and I can just feel it.

### The Battle Against the Pulling

A defining part of the women's path to accept their TTM was their "battle against the pulling." Having control over their hair pulling meant that they were "normal" and others would accept them; therefore, they could accept themselves. Self-acceptance was made difficult when others did not accept the women for who they were: hair pullers. As such, the women waxed and waned in their fight to control their hair pulling, and this provided a continual source of disappointment for the women and reinforced the notion that hair pulling was a problem. "Fighting who you are" to control her hair pulling was a constant theme for Anne. She described her struggle: "I feel like it's very much a part of who I am, not the pulling, but the battle against the pulling and the constant losing."

In their "battle against the pulling," several women questioned whether they had the power to stop pulling their hair. Jade asked, "Do I want to stop?" "The most obvious struggle" for Melissa was, "Can I stop or not?" She explained that she benefited from TTM, which contributed to her struggle to accept herself as a hair puller. She said, "I want to have hair; I want to look normal; I want to be functional and all this stuff versus the really strong urge to do it because it has benefits for me." LoGo described her experience:

It is a struggle. I have the intellectual capability to read through something and learn

about it and change something. But, for some reason, this one is, like, I don't know yet what it's doing for me that I'm so resistant to giving it up. Acceptance is work and that is the struggle.

Jennifer's struggle involved constant self-talk. She said:

I'm constantly just telling myself, "You don't need to. You don't need to. You don't need to. Put your hands down. Put your hands down." Just thinking like, "Your hair's growing back. It's not going to grow back if you pull it out."

Beth, who had pulled for the shortest period of all of the women in this study, had trouble controlling her hair pulling. She said, "It's a struggle every day. When I take that towel off my head in the morning and I sit down and I start looking for that thing, it's a struggle." She had not integrated TTM into her identity, which may have been due to the short period of time that she had pulled her hair. As such, if she were to stop pulling her hair, she would not experience a loss of identity. She said, "I don't feel like I'd be giving up my identity at all."

Jade's attempt to control her hair pulling was multifaceted. She explained:

The struggle is wanting to quit. I know there are times when I'm not happy with it, and I'm still not trying to quit at those times. So I get unhappy with that more than anything. I'm unhappy when I look up and realize I have done nothing at work for three hours because I have been pulling. So that's a struggle, and self-image is a struggle, but it's not just the hair pulling.

Robin haggled with herself for control over her hair pulling. She justified her pulling with various excuses, including symmetry. Her fight to accept TTM as part of her identity waged a battle with her urge to pull her hair and her want to stop herself from pulling.

Sometimes I'll justify my actions. I'll be telling myself, "You shouldn't do this." And I'll say, "Yeah, but this side is uneven and this side doesn't look right, this isn't going to work, this isn't going to match," so I'll even it out. I'll have a bunch of justifications lined up for me to use if I need to. But a lot of the time after I start pulling, I'll stop myself and say, "Let's not go down this road." Sometimes it turns

into a little battle, where I want to stop, but the urge is there, and it doesn't go away. I'll fight it for a while and then pull a couple, or I'll bite my nails instead.

Three women understood that self-acceptance was related to having control over their hair pulling. Liz worked to be mindful and accept her hair pulling. She had a difficult time controlling her TTM when she rejected hair pulling; when she accepted it as a part of her identity, she had periods of nonpulling. She described these periods of nonpulling as "glimmers of hope." Moving between periods of pulling and nonpulling and accepting herself as a hair puller was the struggle for Liz.

Nancy and Celeste understood their struggle to be something that was lifelong and manageable. In their journeys of self-acceptance, they used hair pulling and their struggles for control over it as a way to empower themselves. Nancy said, "I try to use it as a way to empower myself rather than something that brings me down." Celeste, too, accepted hair pulling as a part of her identity. She recognized that being able to control her hair pulling was at the core of her self-acceptance.

### It's Me

Integrating hair pulling into their identities was the ultimate form of self-acceptance for the women in this study. Many recognized that their struggle to accept their TTM was their largest barrier to identifying as hair pullers. Understanding the role that TTM played in their identities changed how the women perceived themselves. Four women accepted their hair pulling and did not believe that they were defined by it. For them, hair pulling was not who they were; it was something that they did. Five participants owned their hair pulling and recognized that hair pulling was a part of them, but it was not the only part of their identities. Three women accepted their hair pulling

and questioned who they would be without it. One participant accepted herself as a hair puller, but she chose to spend her time focusing on something other than her hair pulling.

Several women identified as hair pullers; however, they did not believe that their TTM defined who they were as women. As Emily said,

It's something that I feel is like definitely a huge part of who I am at this point, because it's just so ingrained in the things that I do and how I behave. I would say that hair pulling, to me, is something that I have to deal with. It's an annoyance, but I try not to let it be the thing that defines me.

Despite accepting TTM as part of her identity, Misty and LoGo would be happy to give up. Misty said, "It's a part of me; but, yeah, I mean, it would be a good thing to give up. It would be a good part of me that I would... good riddance to bad rubbish, you know?" She refused to be defined by her hair pulling. In response to being asked if her hair pulling defined her, she said, "No, absolutely not! I am who I am. No, it's just something I do. It's not who I am." Similarly, LoGo did not see herself as a hair puller in spite of accepting it as a part of her identity. She said, "I don't feel like if I gave up, you know, it's my identity. It hasn't become how I see myself. It's part of what I do."

Nancy identified with her hair pulling, and it was a way for her to understand herself. Hair pulling was only a part of her identity; it did not define her, but at the same time she could not imagine her life without TTM.

It's hard for me to admit that it'd be a big piece of the way I identify with myself. It is like my other half, because I have to deal with consequences of my actions. I make those actions, and I make those decisions, and I have to deal with it. If I woke up and I just didn't have trichotillomania, I wouldn't feel like the same person. I don't know what life would be like for me to do that. In some ways, it's tied with how I experience life, but I don't know if it's necessarily who I am as a person.

The women who accepted hair pulling as a part of their identities presented themselves as hair pullers to others. They recognized that hair pulling was very much a



part of their identity; if they were no longer pulling, it would be like missing a part of their identity. Tia explained, “I can’t imagine not having it. It would be like I’m losing a part of myself.” Emily daydreamed about who she would be if she stopped hair pulling:

It's such a big part of me. On times when I go for two weeks without pulling, I start to think about what it would be like if I never pulled again; because I don't know myself, really, without hair pulling.

Similarly, at times when she was not pulling, Jade asked herself, “Why aren’t I pulling? That’s what I do. It very much becomes your identity.” Patches Rapunzel asked herself, “If I’m not a hair puller, what am I?”

After many years of struggle, the women accepted their hair pulling as part of their identities. Robin said:

I've always treated it as this separate monster that dwells inside me, but I will have nothing to do with it, and that's not the case. It is part of me. I have to acknowledge it, and I think that's the only way that you can, because we all have to live in harmony with our bodies, with whatever we deal with. I feel like this is something that is a part of me, and it always will be a part of me, most Likely; but I am not a victim to it. It’s just another aspect of who I am. It’s just another layer of me.

Amanda described how she finally identified as a hair puller and told her parents.

I finally got to a point after high school, and after a lot of experiences and a lot of work and talk with my mom and dad, that, you know- this is me. This is what it is. I’m not hiding it. I don’t wear a wig ever, never have, that just didn’t feel right to me. Felt like I would be hiding and lying about something that’s pretty integral into who I am.

Melissa recognized that much of her self-acceptance struggle stemmed from her hair pulling being thought of as a problem, the focus that was put on her behavior, and her ability to control her TTM when she was younger.

I think the biggest struggle, and I don't know when it kind of occurred... but the struggle was accepting myself—that I have so much other stuff; that this isn't the whole thing. A lot of focus when I was a kid was all on the hair. There's one thing wrong with you, and that just becomes the entire thing your parents want. The entire day is focused on, “Did you pull today?” I've come to recognize that it is this

behavior that sort of fit a need of my life, and there's other things that I can do. It's not inevitable that I'm going to give in to it. I can certainly resist the urge, and I'll survive, and I'll live. Nothing bad's going to happen. It's a part of me, but not like—it isn't all of who I am. It's not like my identity. It's not like the entirety of my identity.

Heather said:

I don't know if I would feel like I would lose anything, but it is part of my life, because it has been for so long....There are so many other things that I would prefer to be spending my time and energy on. So, I'm not, by all means, saying I'm giving up. I just don't—it's just a part of my life, and it's been a part of my life.

Marie's self-acceptance of her hair pulling was different from the others in that she identified her TTM as having a genetic etiology. This was something that she could not help. She said, "It's not something I did to myself. It's something I have." She explained that she experienced a positive change in her pulling identity when she was in her late teens, because she stopped letting her TTM control her self-image and her life.

She explained:

It used to be a lot more a part of my identity in a negative way. It stopped me from doing a lot of things growing up. It controlled a lot of what I was, because it was an insecurity, and so it held me back. Around 18 or 19, I decided to let go of that and to be okay.

Support groups were a powerful tool for self-acceptance and identity integration, because hair pulling was normalized in the group. Acceptance in the group was not based on whether the hair puller could control her behavior—it was based on the mutual understanding of the group members' common experience. This understanding helped decrease the shame that the women felt and increase their self-esteem while contributing to self-acceptance and integration of hair pulling into their identities. Women who participated in support groups valued their support group friends, because they were accepted by them, and in turn they accepted themselves as hair pullers. Their shared focus in the group was on the individual goals and not necessarily on the cultural norms

of controlling hair pulling, which stemmed from the idea that hair pulling was a problem. As discussed earlier, several of the women participated in support groups and recognized how powerful it was to be a group member with others who self-identified as hair pullers. Experiences of two women exemplified the power of group acceptance and were representative of many of the participants' paths toward identifying as hair pullers. Elizabeth was a member of her support group for more than 6 years. She explained that her membership in the group was based on friendship. She and her friends accepted one another as hair pullers, and they supported one another in their struggle to accept their TTM and understand its place in their lives.

I attend the group now truly for friendship and to support others. I guess for service, in a way, because I really care about all of them, and I want them to succeed or at least be able to live with themselves happily.

Anne identified herself as a hair puller when she was with other hair pullers, because she related to their experiences. Her TTM was normalized in the context of others who pulled, because they had a mutual understanding of each other's experience. She was accepted, and she accepted herself.

When I'm talking to someone else who has hair pulling, it feels like a part of my identity, because I relate to them through it. When I'm reading about it, about other people's experiences on the TLC site or on one of those things, I feel like I can understand where those people are coming from, and then it feels kind of like that it's hard to let go.

Conversely, a few did not accept hair pulling as a part of their identities. Cat Girl said, "I don't want to be identified by my pulling. I don't want it to be part of me. I want it to stop." Jennifer summed her thoughts, "I don't think I'd be losing anything from not pulling, because it's not really who I am. I do see it as separate." These 3 women were not

ready to include TTM into their concept of self, and it had an impact on their control over their hair pulling. Their struggle continued.

### Empowerment

Five women identified their struggle with TTM as an empowerment tool that contributed to self-acceptance and identity integration of TTM. Robin said, “I feel like doors are opening, and I feel empowered by myself.” LoGo explained that reclaiming her hair pulling was a way to empower herself. She said, “I guess that if you empower it, it would change, like reclaiming it somehow. So it kind of takes away some of that shaming piece about it.” Nancy was empowered by her TTM in that she believed that it made her a stronger person.

It's something that's a part of my life. I don't really know what it's like not to—I don't want to say be normal, but I don't know what it's like to not have pulling urges and to not think about pulling. I've grown in how I feel a little bit, and it helps me be a better person, because it makes me work harder to be like everybody else. I think it gives me a little something extra....I try to sort of use it as a way to empower myself rather than something that brings me down.

Elizabeth and Cheryl were empowered when they took responsibility for their hair pulling. Both recognized that TTM was something that they had and that they had the power to improve this aspect of themselves. Elizabeth explained:

It's just a disorder. It's something that's not my fault, but I also have a stake in improving my situation. I still have to take responsibility for it. Just accepting that alone has just made a huge difference, because I don't blame myself, but I also need to feel kind of empowered by it and do something, because no one's gonna change this for me. I think just trying to make myself feel empowered has a really strong deterrent to that hopeless feeling.

Elizabeth also empowered herself by self-disclosing to others about her hair pulling.

Cheryl believed that there were things that gave her power in her process of accepting hair pulling and integrating it into her identity. For many years, she was not

aware what gave her power over her hair pulling. After she “stopped feeling sorry for [herself],” she empowered herself to change her situation, because she now saw hair pulling as her choice to change.

I just said, “Well, this is just something I have, like somebody who has a stutter or somebody who has some other kind of disorder or affliction.” I guess I felt victimized, and then I just sort of said, “It's there. It doesn't have to change my life.” Now I feel more like it's there and there are things I can do to minimize its power. I'm more able to see the option of it being a choice.

### Empathy

Eight hair pullers identified with others who struggled in some capacity. An empathic concern for others emerged from their experiences with TTM, and they felt a connection with disabled individuals and mentally ill people given the difficulties that they themselves faced.

Marie said, “It does feel like I'm able to relate to other people--I think I can relate to people with disabilities better.” Tia thought, “I think I just pick up on if somebody else is uncomfortable or distressed in some sort of way, because I can relate.” Anne described how her struggle with TTM helped her to identify with others.

It has been kind of my defining struggle for a very long time. I can't say that all of it has been bad that's come from it, because it has helped me to be able to relate to a lot of people who have had issues that I wouldn't have been able to understand on that level, you know? People who have not figured out how to get over their social attraction problems and just never quite fit in, and they laugh at the wrong thing, or maybe they're a little bit socially disabled. I understand how that feels. I feel like part of it was because of these issues that I've had. So, to me, that feels like a blessing, because I feel like I can help people like that and be a bit more compassionate.

Cathy and Elizabeth were more empathic toward individuals who struggled with addiction and other mental health issues associated with control because of their hair pulling experiences. Cathy put it this way:

It helps me kind of understand other people better if they're dealing with something like an addiction or something that, you know, they can't necessarily control. I think it helps me kind of empathize with them a little better. Instead of just writing someone off for being weird or not being able to stop smoking or something like, you know, anything.

Elizabeth described herself as having empathy for addicts because “I really feel like this is an addiction.”

Both Kierra and Heather believed that their journeys with hair pulling led them to want to help others. Kierra determined that she “probably did have some aptitude to work with people and help people heal with whatever their own stuff was.” Heather connected to others’ difficult experiences and found that she changed the way that she interacted with people. She said,

If there's a reason I have it, maybe it's for this. Maybe it's to try and help other people. I look at people differently now. I treat them differently because I've had to go through with that, things that most people won't ever go through.

Nancy found beauty in others that may have been overlooked. She explained how her struggle with TTM helped her appreciate individual differences.

I can look at someone who's, like, a cancer patient, let's say, who doesn't have a lot of hair on their head or their face area, and I think, “Oh that person is beautiful.” I can see past that, because I know what someone looks like when they don't have hair in those areas. So, I'm able to see beauty past what maybe a common person would see it as.

Empathizing with others helped the women accept their hair pulling. They visualized themselves in another’s situation, recognized themselves in someone else’s struggle, and understood the difficulties that person faced. In empathizing with others who struggled for control over their behaviors and had issues that were sometimes conceptualized as “not normal,” the women empathized with their own struggle, they accepted others and accepted themselves. Having self-empathy enabled the women to

perceive their hair pulling as something other than a problem, which led them to conceptualize their TTM in a way that made sense to them.

### Summary

The women struggled for awareness of their hair pulling. Their struggle included helping themselves be accountable for their TTM through setting goals, establishing a plan to reach the goals, and doing the work to put their plan into action. In helping themselves to be accountable for their behavior, those women who took ownership of their hair pulling did not let others do the work for them. The hair puller's struggle involved understanding TTM within the context of her world and not letting others define it for her. Her struggle involved moving beyond her anxiety specific to wondering if she was good enough to control her hair pulling, wondering if she was going to be accepted by others, and the limbo of being stalled in her struggle for years. The hair puller struggled to accept who she was, TTM and all, when others did not accept her as a hair puller.

As she accepted TTM and integrated it into her identity, she left behind her worry that others did not accept her for who she was. Now that she identified as a hair puller, she wanted to know how she made sense of her hair pulling. She wanted to understand what hair pulling gave her and why she did it. In conceptualizing TTM for herself, she determined what role it played in her life. She now had the power to decide what she wanted to do about her TTM. She personally conceptualized her TTM; and, in doing so, she reclaimed her hair pulling narrative.

#### Theme IV: Power Play: Reclaiming Their Narrative

In the fourth and final theme, *Power Play: Reclaiming Their Narrative*, the women conceptualized their hair pulling in the context of their personal experiences (Figure 5). When the women made sense of and understood their hair pulling, they shaped their TTM journey and determined the role that it played in their lives and the impact that it had on them personally. They were empowered to take control of their TTM experiences and tell their own hair pulling stories. The women's answers to the questions "How do you understand and make sense of your hair pulling?" and "What else should I ask you to better understand your experience of hair pulling?" formed the category: *Making Sense of Me*. These women were experts on themselves and their hair pulling experiences. It is important to know their personal perceptions and conceptualizations of their TTM in order to gain a complete understanding of TTM and how it impacted each of the women of this study. Further, TTM is the hair puller's lived experience, and it is imperative that she has a voice in telling her story.

#### Theme IV: Power Play: Reclaiming Their Narrative

- A. Making Sense of Me
  - 1. Biological
    - a. Neurobiological
    - b. Genetics, Illness, and Anxiety
    - c. Addiction
  - 2. Emotion Regulation and Managing Stress
- B. Trichotillomania: A Journey of Personal Empowerment

Figure 5. **Theme IV: Power Play**



## Making Sense of Me

Just as the women and their experiences varied, so, too, did their understanding of their TTM. Their perceptions of their hair pulling contributed to their conceptualizations of their TTM and to their perceptions of control specific to their hair pulling. In understanding their hair pulling for themselves, the women helped themselves to be accountable for their pulling and accepted themselves as hair pullers. In doing so, they took control of their stories. The women of this study conceptualized their hair pulling in multiple ways that often overlapped. Two subcategories emerged: *Biological* and *Managing Emotions and Stress*.

### Biological

Biological conceptualizations were broken up into four distinct subcategories: *Neurobiological*, *Genetics*, *Illness*, and *Anxiety*, and *Addiction*. Sixty-eight percent of the women in this study understood their TTM to have biological underpinnings. They subscribed to the idea, “This is not who I am. This is something that I have,” as a way of ascribing their hair pulling to their biology.

### Neurobiological

Six women explained their hair pulling as a neurobiological condition and theorized that hair pulling was related to neuropathways. Cheryl attributed her pulling pattern to the firing of specific nerves along the path and indicated that she pulled particular hairs based on a feeling.

I have a theory that it follows nerve patterns or something, because, if I'll start, I'll have a feeling that one hair leads to another, but it's not random. I'm following a pattern. I'll go through and I'll say, “It's not that one, not that one, not that one.” Then I'll get to one and I'll say, “It's that one.” And it'll be more than just the hair. It will be

the whole area, the area of the scalp feels sort of highlighted or illuminated or whatever. Then I'll find another hair nearby, but it's not part of that system.

Cheryl compared her hair pulling experience to shingles, in that they both followed along particular nerve paths. She said,

I think of the analogy as being- what's that thing people get- shingles? You know, and you see it along the nerve path. That's what I understand. It is sort of- there is something very like that because the relief comes from pulling the right hairs, not just any ones.

Anne conceptualized her TTM as a response to overused neural pathways. She explained that she always relieved stress through hair pulling, “which have deep and wide pathways” because she always uses the same path. She likened her experience to “a well-traveled trail in the woods verses a single track trail.” Anne used the same pathways by practicing hair pulling; at this point, it was difficult for her to do it differently, to take the road less traveled. She felt powerless to stop her hair pulling, as well as powerless to control other aspects of her life. Her struggle was circular. She said,

It makes me feel powerless to affect other things in my life that I should be able to affect. I felt like I couldn't control things in my life, because I couldn't control my hair pulling. With this is the symbol of complete lack of willpower. I feel like because I have no willpower against my hair pulling, that I must just have no willpower at all.

Kierra made a similar point about her pulling that was discussed earlier. She thought of her TTM as her “need for pattern completion,” despite having changed her circumstances and recognizing that she was a different person from the one who started hair pulling when she was 6. She had a difficult time believing that she had power to control her hair pulling, because she practiced hair pulling for many years that resulted in “very entrenched pathways.” She conceptualized her struggle for control over her hair pulling as her battle to interfere with her “neurological system’s path to right itself

through pattern completion.” She was in a power struggle with her own body. She described her experience:

There's tension around that [starting/stopping] because, every time, I lapse again. So, probably it will be for the rest of my life, “Well, when's the other shoe going to go off?” And I think that's probably part of the long-term tension around it and wanting to control it, so I think, “Well, maybe I'll just control when it will start again so I don't have to keep wondering when I'm going to break.”

Patches Rapunzel and Melissa experienced their hair pulling as a neurobiological response to coping with stress. Patches said, “There’s a brain chemistry thing going on here, and I need that medication to straighten up that chemistry so that I don’t become a Tasmanian devil. It’s a coping mechanism to deal with stress.” Similarly, Melissa understood her TTM as “my default way to release any kind of neurological stimulation.” She perceived her hair pulling as “a physical manifestation of anxiety, and pulling was the only way to numb it.” Melissa considered herself “in recovery,” meaning that she had not pulled [very much] for a few years. She said,

I absolutely, like, know what it’s like to live as a hair puller, but it’s something that I would rather not be actively doing... I’ve been in recovery for a few years, because about three years ago, was when I first started a shift in my point of view on the place that trich had in my life. Rather than- I started realizing it was something I could live without doing, that I wanted to work on living without doing it... I just started to consider the idea that pulling was something that I could give up, and that that would be okay, and when times are really hard and when stressful things happen, it kind of comes back as sort of a crutch that I rely on to help me through emotionally.

### Genetics, Illness, and Anxiety

Marie and Heather thought of their hair pulling as genetic. Marie said, “It’s something I have.” She did not include shame in her way of thinking about her hair pulling, because it was genetic. As such, “Hair pulling is not at the forefront of who I

am.” Her genetic conceptualization of her hair pulling allowed Marie to “live life fully and enjoy my family, friends, and career.”

Heather attributed her TTM to her genetics, and she lived her life as if she was not a hair puller. She related her hair pulling to a congenital condition that she “fixed” by wearing hair extensions. She said, “I kind of ignore it at this point... I mean, yeah, I have it. It’s like my own little secret, because nobody knows.”

Beth and Jade conceptualized their hair pulling as a symptom of their illnesses. Beth explained her hair pulling as a symptom of her depression and believed that, once her medication was appropriately managed, her hair pulling would decrease. Jade also believed that her hair pulling was an extension of her health problems, and she thought that she would stop needing hair pulling when she improved her health. She attributed her TTM to hormone imbalance, anxiety, and a nutritional problem. She conceptualized her TTM as a biological way of providing emotional support to herself. She explained to me that, when she is healthier, she would not use hair pulling as much. She said,

For me, the goal is to deal with all the other things. If I could just get that stuff under control. It’s one of those almost physical sensations of knowing, just like bone deep, that it would solve itself as soon as I stopped needing it. The less sick I am, the less I need to pull, the less I do pull. I’m at this lovely point where I know everything that would fix it; I just haven’t quite gotten to the point where I’m ready to institute the fixes.

Two participants understood their hair pulling as an anxiety disorder. Emily experienced generalized anxiety and felt a sense of relief after she engaged in hair pulling. She said, “Your anxiety goes away for a little while, and it really does feel like a coping mechanism.”

Anne specifically experienced her hair pulling in context of obsessions and compulsions, and conceptualized her TTM as “compulsive”:

I can tell you that my hair pulling is compulsive. I have obsessive thought loops where I worried that I've angered someone. I'm worried that someone doesn't like me. If I'm in a social situation, I'm constantly thinking that I know what the other person is thinking, and it's always bad.

When thinking about her hair pulling as OCD, she felt powerless to control her pulling, and she felt that it controlled her life.

### Addiction

Nancy battled both sides of herself when it came to hair pulling, and she described this struggle earlier. She comprehended her hair pulling as an addiction and said, "It's similar to a drug addiction." She believed that she would struggle with TTM for her lifetime and that it was something that she could manage. She said, "I believe in myself. I think that I'm just not there yet. I mean, this has been a part of my life for twenty years. I didn't develop this habit overnight, and it's not gonna take a day to put it in some sort of remission."

Kierra, Patches Rapunzel, and Cat Girl also understood that their hair pulling experiences were similar in that there was an addictive aspect to TTM. Kierra experienced her hair pulling as something that felt good to her, whereas Cat Girl recognized that she was not benefitting from her hair pulling. Kierra said, "It just feels like I'm doing something which feels good to me. It feels like I'm doing something, like I'm connecting with myself in some way. It feels addictive."

Patches Rapunzel understood her TTM to have an addictive aspect to it that benefited her and was harmful at the same time. She said,

I think it has a very strong addictive type of quality to it because, the more you do it, the more you want to do it. It's also a really good avoidance tactic. I'm really good at

avoiding. If you're pulling out your hair for hours, you're not doing the laundry; you're not cleaning your room. It's a coping mechanism for stress, but it's also an avoidance thing. It's good and it's bad.

She knew that she could control her hair pulling someday if she worked to control it, as was described in a previous section.

LoGo explained her experience. "It's soothing, and it's serving some function. It is an addiction. It's like a habit, but it's an addiction. It satisfies itself, that cycle of pulling and relief." She attributed her hair pulling cycle to "a lack of really believing in myself, and really trusting myself, and just really loving myself."

Similarly, two women understood that their hair pulling was both a habit and an addiction. Liz experienced her TTM as something that was always present, even when she was not engaged in the behavior. She was a very religious woman and believed that God was in control of everything in her life, and this left her to believe that she did not have any control over her hair pulling. She believed that God "doled out this challenge" for her so that she "will be a better person." As such, she did not experience power in her relationship to her hair pulling and struggled to control it. She thought about her TTM using an addiction model and built in the idea that she would never be rid of hair pulling because it was an addiction. Robin also thought about her TTM from an addiction perspective. She articulated this perception when she said,

It's a behavioral habit issue that I need to be able to get under control because even if, you know, I think it's just like alcoholics. I know they have a tendency to need alcohol, but they can withstand it, they can abstain. I'm an alcoholic to my eyebrows, and I need to be able to abstain.

Elizabeth thought that her hair pulling went further than just being a habit, and she understood her experience to be an addiction.

I think on a scientific or medical level it's definitely a disorder. It's not just a habit. I feel compelled to do it beyond other habits that I have. I have a lot of habits, bad and good, and none of them are like hair pulling. It's something like I feel solidarity with addicts, because I really feel like this is an addiction.

She experienced TTM as a complicated addiction with many faces. "It has so many faces. It's an addiction. It's a disorder. It's a habit. It's a coping mechanism. It's so many different things for me." Elizabeth accepted that her TTM was a disorder without a cure. She said, "I don't search for a cure because there isn't one." Her perception of TTM shaped her hair pulling journey in that she accepted herself as a hair puller and she worked to change her TTM. Elizabeth realized that her hair pulling evolved over 20 years and that she could not change it overnight.

So, I just kind of try to learn to love myself how I am now. I feel negative about it, but I try not to let myself feel negative about me as a person. I believe in myself. I think that I'm just not there yet. I mean this has been a part of my life for twenty years. I didn't develop this habit overnight, and it's not gonna take a day to put it in some sort of remission.

For Celeste and Cathy, who conceptualized TTM as an addiction, hair pulling offered them a way to calm themselves in times of stress. Hair pulling provided psychological relief to Cathy. She said, "I look at it as an addiction. It calms me down. It's like an outlet for stress."

Celeste used a relapse-prevention model to treat her TTM and celebrated her success of decreasing the number of hairs that she pulled each day. She said,

I feel like if I can maintain a low level of pulling- of like ten a day- that that's better than what I could do if I was totally un- not monitoring myself at all, which is, you know, who knows- a hundred in a day. I think that it is something that I'm going to have to deal with every day for the rest of my life. Whether I'm pulling or not, I think that it's gonna be controllable and uncontrollable, and I'm never really ever gonna be completely free of it.

Based on her past experience of being pull-free for 6 months, Cathy believed that she could control her hair pulling because “I really, really do not want to deal with it for the rest of my life.”

### Emotion Regulation and Managing Stress

Many of women understood their hair pulling to be their way of managing their emotions and stress. Several of their stories are highlighted in the previous theme, biology; yet other women thought about their hair pulling solely as emotion regulation and/or stress management without the biological underpinnings. Liz and Amanda knew that they pulled their hair to calm their emotions and relieve their stress. Amanda conceptualized her TTM as “a regulating mechanism.” She explained her experience with hair pulling further and recognized that she felt disempowered because of her TTM.

Pulling it out obviously represents some sort of, you know, helping me deal with things that I don't deal with very well, probably lots of struggles of what I want to do versus what others want me to do. It also represents to me power that I'm taking away from myself when I'm pulling my hair sometimes, because it is a confidence thing, and without hair.... Everybody deals with feelings of inadequacy, low confidence, at some time in their life, but for such a long time, to such an extreme degree, hair pulling and all the problems that go with it, it's like a chronic illness.

Cathy, LoGo, Jennifer, and Tia utilized their hair pulling as a way of managing their stress; and they experienced TTM as “mindless and soothing.” Cathy said, “It provides a sense of relief. It calms me down. It's like an outlet for stress.” Cathy conceptualized her TTM,

It's like a habit, almost, that I don't even think twice about. It's definitely a cycle because it causes bad self-esteem, and then when I do feel bad about myself, I'll tend to pull more or something, because I don't care.

Her cycle resulted in her feeling disempowered to control her hair pulling. She described her sense of hopelessness to control her hair pulling. She said, “I think I'll be taking so



many great strides, and then I'll have a really bad episode. I feel like I've taken 20 steps back for every two steps I've taken forward."

Jennifer conceptualized "hair pulling as a stress response and a way of self-soothing." As such, she approached treatment from a mindfulness perspective "to raise awareness" and utilized relaxation exercises to help her manage her emotions and stress. A continuous stressor for Jennifer was her husband's wish for her to stop hair pulling. He brought attention to her struggle that elevated her level of stress, which she calmed with hair pulling; and then she felt helpless to control her pulling. Further, she asked others to tell her when she was hair pulling, and this contributed to her sense that her hair pulling was outside of her control. She perceived her TTM as a problem that others were pointing out to her and as something that was not within her control. Her perception led to additional stress and hair pulling, a cycle for control that she found frustrating. Despite her frustration, she expressed hope that, with continued work, she would eventually not want to pull. She said, "It's a frustration for me, because I still, like, want to pull; but I know as long as I keep working on it, like, I won't that one day, I will not actually even want to pull."

#### Trichotillomania: A Journey of Personal Empowerment

The purpose of this study was to understand how hair pullers perceived their hair pulling experience and conceptualized their TTM. This is the first study of its kind to include the hair puller in the global conversation about her hair pulling. It is important that the voices of the women are heard and that the hair puller's conceptualization and meaning of her hair pulling are included in the global conversation specific to hair pulling.

The struggle to understand TTM and the roles that it played in the hair pullers' lives was complex for the women in this study—particularly so when hair pulling onset occurred in the context of trauma and when the behavior itself and the resulting hair loss was conceptualized as a problem by nonhair pullers who were unable to change or fix the behavior. Now, hair pulling was a problem, but for whom? Hair pullers utilized TTM as a means of coping, relief, validation, and for self-care in relationships. When hair pulling was conceptualized as a problem, this led to a type of problem solving that was often entrenched in the medical model. Because someone else identified TTM as a problem and the hair puller was not involved in conceptualizing her own behavior, the chosen treatments were ineffective due to poor fit or treatment readiness, and this resulted in a control paradox.

The paradox was that the nonpuller took control of the puller's TTM in choosing treatments with the assumption that the puller would learn to control her TTM. When the hair puller did not learn to control her behavior, the nonpuller relinquished responsibility back to the hair puller and presumed that something was wrong with her because she was not able to control her hair pulling. Hair pullers struggled with this because hair pulling met a need for them, while the nonpuller dismissed this need and instead insisted that she control her pulling because they wanted it to be controlled. This control paradox provided a framework from which all of the women operated, even those who hid their hair pulling from others.

The women struggled for awareness of their hair pulling. Their struggle included helping themselves be accountable for their TTM through setting goals, establishing a plan to reach the goals, and doing the work to put their plan into action. In helping

themselves to be accountable for their behavior, those women who took ownership of their hair pulling did not let others do the work for them. The hair puller's struggle involved understanding TTM within the context of her world and not letting others define it for her. Her struggle involved moving beyond her anxiety specific to wondering if she was good enough to control her hair pulling, wondering if she was going to be accepted by others, and the limbo of being stalled in her struggle for years. The hair puller struggled to accept who she was, TTM and all, when others did not accept her as a hair puller.

As she accepted TTM and integrated it into her identity, she left behind her worry that others did not accept her for who she was. Now that she identified as a hair puller, she wanted to know how she made sense of her hair pulling. She wanted to understand what hair pulling gave her and why she did it. In conceptualizing TTM for herself, she determined what role it played in her life. She now had the power to decide what she wanted to do about her TTM. She personally conceptualized her TTM; and, in doing so, she reclaimed her hair pulling narrative.

In conceptualizing hair pulling for themselves, the women provided a framework to understand their lived experiences with TTM. Figure 6 shows the framework that emerged from the women's understanding of their lived hair pulling experiences. It highlights their journey from others' conceptualization of their hair pulling as a problem to their own empowered conceptualization of hair pulling. This framework emphasizes the women's journeys of acceptance; it indicates their move from feeling little control over their TTM because others are holding them accountable to being in control of their TTM because they help themselves to be accountable for their hair pulling.

## Trichotillomania: A Journey of Personal Empowerment



Figure 6. **Trichotillomania: A Journey of Personal Empowerment.**

## CHAPTER 4

### DISCUSSION

#### Trichotillomania: A Journey of Personal Empowerment

The purpose of this study was to invite the hair puller into the TTM conversation to better understand her perception of her hair pulling and how this informs her conceptualization of TTM and guides her hair pulling experience. Currently, the etiology of TTM is unknown, and existing models do not include the hair puller's understanding of her TTM in conceptualizing hair pulling behavior. Qualitative studies of women and TTM that address their lived experience of hair pulling and their assigned meaning of their behavior are notably missing from the available research. This study aimed to enhance the current TTM literature by providing a new TTM discussion, one that included the voices of the women who engage in hair pulling. This study addressed the overarching question, *What are the experiences and perceptions of women who engage in hair pulling?* The qualitative findings of this study provide an understanding of when and why hair pulling took hold, how others' conceptualizations of TTM created barriers to accountability and acceptance, and how women empowered themselves to conceptualize their hair pulling and to determine the role that hair pulling plays in their lives. Altogether, the findings of this study contributed to the women's perceptions of their TTM experiences and to their attempts to increase their awareness of their hair pulling, help them to be accountable for their hair pulling, include TTM into their self-concepts,

and understand their hair pulling in the context of their life experiences. The findings are discussed in relation to the relevant TTM literature.

### Traumatic Life Events

The first finding of this study included a look at the traumatic life events surrounding the onset of TTM. The genesis of hair pulling for the women in this study coincided with varied traumatic events that they perceived as emotionally overwhelming, stressful, and outside of their control. What became evident from their experiences and perceptions is that their discovery of hair pulling coincided with their conscious and subconscious awareness that they were unsafe. Trichotillomania became an avenue for control in the hair puller's relationships with herself and others.

The connection between traumatic stress and anxiety is well documented in the current literature (de Silva & Marks, 1999; Dykshoorn, 2014; Gershuny, Baer, Radomsky, Wilson, & Jenike, 2003). The current finding of hair pulling onset in the context of trauma is congruent with recent research (Boughn & Holdom, 2003; Ozten et al., 2015). It is also consistent with reported studies linking OCD and trauma (Badour et al., 2012; de Silva & Marks, 2001; Huppert et al., 2005; Lafleur et al., 2011; Nacasch, Fostick, & Zohar, 2011).

This study extends the extant literature by providing additional evidence of a significant relationship between traumatic life events and TTM. In a study of 42 treatment seeking hair pullers, the researchers found that 76% of their sample had an onset of hair pulling with trauma (Gershuny et al., 2006). In the current study, 86% of the women had an onset of TTM in the context of a traumatic life event, which was similar to research conducted by Boughn and Holdom (2003). This finding raises the question of

whether the prevalence of hair pulling onset with trauma is actually higher in the TTM population given the secretive nature of hair pulling, as not all hair pullers seek treatment or participate in research studies. This finding provides additional evidence to support speculation that developing TTM protects the hair puller from developing PTSD (Gershuny et al., 2006; Ozten et al., 2015). While this study did not formally assess for PTSD, anecdotal evidence gathered through interviews indicated that only one of the women who experienced trauma at TTM onset met criteria for PTSD.

Identifying traumatic life events as a homogeneous precipitant of TTM is important in that trauma may be a crucial piece of the hair pulling puzzle. If the hair puller perceives herself or a loved one to be in danger or if she experiences a betrayal (Rachman, 2010) and conceptualizes her experience to be that she is physically or emotionally unsafe, it is possible that TTM develops as a means to contain and soothe her trauma-related anxiety. Additionally, others' negative responses to TTM, resulting in shame, low self-esteem, and isolation, can be further traumatizing for the hair puller. Perhaps trauma, when the definition is broadened, plays a significant role in the development and maintenance of hair pulling compared to previous thought. This is worth considering when treating TTM, given the elusiveness of reliable and effective treatments for hair pulling. Although we cannot presume that TTM is caused by trauma, it is important to understand the role of trauma in the hair puller's life, because healing trauma can empower the hair puller to understand her lived experience and work to change her behavior if this is her goal. The results of this study support a connection between trauma experiences and hair pulling. Additional consideration of trauma in research focused on the nature and treatment of TTM is necessary.

### Hair Pulling Is a Problem

In the present study, all of the women shared the experience of having non-hair-pullers conceptualize their TTM as a problem. As a result, the women internalized this message and believed that something was wrong with them. When TTM is framed as a problem, solutions for TTM in the form of medically based treatments, medications, therapy, and ignoring hair pulling are pursued. When the hair puller does not experience success in a treatment, she experiences low self-esteem, feelings of shame, and hiding her hair pulling. Conceptualizing TTM as a problem created barriers to accountability and acceptance for the hair puller. Ultimately, the hair puller was expected to fix her hair pulling problem by controlling it.

A new finding from this study suggests that TTM, when conceptualized as a problem by non-hair-pullers, negatively impacts the hair pullers' self-worth. Someone other than the hair puller usually conceptualizes TTM as a problem. There are 1136 references to TTM in PubMed.gov alone that identify TTM as a problem, not to mention the various theories (Boughn & Holdom, 2003; Diefenbach et al., 2008; Duke et al., 2010; Flessner et al., 2009; Keuthen et al., 1999; Koblenzer, 1999; Lochner et al., 2002; Özten et al., 2015; Reinhart, 2005; Roos et al., 2015; Stein, O'Sullivan, & Hollander, 1999), books (Penzel, 2003; Stein, Christensen, & Hollander, 1999), websites, and treatments devoted to problem solving and curing TTM. Current literature specific to the impact of problematic hair pulling includes physical impact (O'Sullivan et al., 1996; Penzel, 2003; Rapp et al., 1999), emotional impact (Diefenbach et al., 2005a; Penzel, 2003; Walther et al., 2010), social concerns (Casati et al., 2000; Diefenbach et al., 2005a;



Diefenbach et al, 2005b; Keuthen et al., 2004), and economic repercussions (Wetterneck et al., 2006; Woods et al., 2006).

There are no studies in the current literature that specifically address how others' conceptualization of hair pulling as a problem impacts the hair puller. However, there is well-documented literature specific to the stigma associated with TTM (Casati, 2010; Casati et al, 2000; Penzel, 2003; Townsley-Stemberger et al, 2000) and mental illness (Corrigan, 2004; Overton & Medina, 2008). These references are examples of the current body of TTM research that conceptualizes TTM as a problem and reveals the negative impact that this conceptualization has on the hair puller. Penzel (2003) argued, "I believe that it would be an understatement to say that TTM is, for the majority of sufferers, a disorder of shame, silent agony, inner grief, and isolation" (Penzel, 2003, p. 31). The women's experiences of low self-esteem further highlight the damaging effects of conceptualizing hair pulling as a problem. Non-hair-pullers have a difficult time understanding hair pulling as anything other than a problem, and hair pullers respond by internalizing their conceptualization of hair pulling as a problem and view themselves as less than others in many ways.

The obvious result of such a situation is for TTM sufferers to jump to the conclusion that they are weak and defective human beings and to blame themselves, and for others to also see it as their fault in some way. (Penzel, 2003, p. 31)

Given that the individuals who conceptualize TTM have power (e.g., medical professionals and researchers) and that their conceptualization of hair pulling as a problem that needs to be fixed is generally accepted in society, hair pullers struggle to control their hair pulling when a problem solving framework is applied to understand and treat hair pulling. As such, hair pullers experience low self-esteem, shame, and fears of

discovery that lead to hiding their hair pulling. Their struggle to control their TTM perpetuates a cycle of negative self-perceptions and hair pulling. This is the first study to suggest that conceptualizing hair pulling as a problem contributes to the negative impact and stigma associated with hair pulling.

### Helping to Be Accountable

The women struggled to understand their hair pulling in the context of their experiences and to help themselves to be accountable for their TTM, which increased the control that they had over hair pulling and contributed to acceptance of self as a hair puller. The struggle of helping oneself to be accountable for hair pulling stemmed from hair pulling being conceptualized as a problem. Initial experiences with TTM included others holding the puller accountable for her behavior (e.g., parents taking hair puller to treatment, therapist-directed treatments, other people pointing out when the hair puller is pulling, etc.). The switch to helping herself to be accountable for her hair pulling was difficult, particularly in the presence of someone who conceptualized TTM as a problem for the hair puller in the first place. Hair pullers went back and forth in being held accountable by others versus helping themselves to be accountable in their various relationships. Women who associated with other hair pullers and participated in TTM support groups helped themselves to be accountable for their hair pulling and indicated a greater degree of self-acceptance. This finding is consistent with the current literature (Frost, Pekareva-Kochergina & Maxner, 2011; Hersperger, 2012).

An examination of the literature reveals that the relationship between hair pulling and accountability has not been formally addressed. Further, information and studies on accountability and treatment adherence specific to TTM are missing from both the TTM

and the OCD literature. Of the available literature, the focus has been on therapist-directed treatments such as medications, psychoeducation, self-monitoring/awareness training, stimulus control, and competing response training (Kaplan, 2012), which may not help the hair puller to be accountable for her TTM.

### Empowerment

Helping herself to be accountable for TTM put the hair puller in control of her hair pulling and led to self-acceptance and to identifying as a hair puller. Identifying as a hair puller empowered the women to assign meaning to their hair pulling in the context of their experiences. By conceptualizing their TTM, the women reclaimed their hair pulling narrative and chose the hair pulling path that fit their needs.

Understanding how hair pullers perceive and experience their TTM is an important piece of the hair pulling puzzle. There are two qualitative studies in the literature that capture a hair puller's conceptualization of her hair pulling, but neither asks the participants explicitly how they understood their hair pulling (Casati, 2010; Walderhaug, 2015). Walderhaug (2015) qualitatively assessed the experiences of 8 participants who completed an Acceptance and Commitment Therapy Enhanced Behavioral Therapy for Trichotillomania (AEBT-T) group treatment study for trichotillomania. The participants' subjective understanding of the treatment model was assessed with the goal of understanding their constructed meanings of TTM. Participants conceptualized their TTM as a symptom disorder as well as an expression of underlying psychopathology. This study utilized a thematic approach to analysis that provided the hair pullers' conceptualizations of their TTM in name only, as it did not delve into further detail.

The way that hair pullers think about and understand their TTM experience informs their conceptualization of hair pulling. Given that the etiology of TTM is presently unknown, current theoretical models identify hair pulling as a problem; and consistent, reliable, and effective treatments are unavailable at this time. It is important to invite hair pullers into the TTM conversation to expand the global knowledge of hair pulling and to better understand how hair pulling develops, is maintained, and how it impacts different individuals.

### Summary of Findings

A specific aim of this study was to provide a detailed qualitative examination of the subjective perceptions and experiences of women who engage in hair pulling to better understand how they made sense of their hair pulling and included it in their lives. The findings suggest that there is a journey of self-discovery and empowerment that the women engaged in as they navigated their hair pulling experience. Currently, there are no studies in the extant literature that focus solely on women's subjective experiences with hair pulling and how they make sense of it. This is the first study to systematically examine the women's perceptions and conceptualizations of their TTM.

### Strengths, Limitations, and Implications for Research

A strength of this study is that qualitative assessments of hair pullers' subjective perceptions and experiences are not available in the extant TTM literature. This study provides insight into the hair puller's conceptualization of her TTM and adds to the existing research. Another strength of the study includes the participants. The participant sample included hair pullers who ranged in the number of years that they engaged in hair

pulling (Range 2-49 years). These women provided a detailed level of insight into their hair pulling and spoke to the complexity associated with the behavior.

This exploratory study had several limitations. First, a relatively small sample of participants was included in this study ( $N=22$ ). However, given that the purpose of qualitative research is not to generalize but to explore meanings in depth, the sample size was sufficient to yield thick description of the experiences of women with TTM. Findings should be interpreted with caution when applying them to other women hair pullers. However, it is reasonable to presume that the findings accurately represent all of the women in this study given that all of the themes overlapped their experiences. Future quantitative research including a large sample size could determine whether the findings of this study are generalizable to the larger hair pulling population.

A second limitation of this study is the lack of diversity in the participant sample. The majority of the participants identified as Caucasian or White (82%), 1 participant identified as Hispanic/White, and the race/ ethnicity information was not collected from 3 participants. The inclusion of a predominantly White sample of participants is consistent with the current literature (Ferrão, 2006; Neal-Barnett et al., 2010). A more diverse cultural look at hair pulling across races/ ethnicities is missing from this research, which makes it uncertain as to whether these findings will apply to ethnically diverse hair pullers. This is an additional area of research to be explored in the future.

All of the participants of this study were women. It is known that the prevalence of TTM is higher in women compared to men (Christensen & Mansueto, 1999), which is why I chose to interview only women. It is unknown whether the findings of this study can be applied to a male population with TTM. A future area of research would be to

include male hair pullers in the TTM conversation to understand their perceptions, meanings of hair pulling, and experiences with TTM.

Socio-economic status of the participants was not assessed, and the study included mostly middle to upper class study participants due to their connection with the TLC. While it was certainly not my intention to exclude anyone from participating in this study, it is possible that certain races/ ethnicities and socio-economic classes of women were not included in this study due to the recruitment and sampling methods used. Further, most of the women who participated were in some way connected to the TLC and have access to the Internet. Future studies are necessary to determine whether the findings of this research generalize to other socio-economic groups.

Another limitation of this study was that all of the women who participated were willing to talk about their experience of hair pulling. The women's readiness to share their experiences may be an indication of previous treatment, self-acceptance, self-awareness, and acceptance by others. This calls to question how the results of this study generalize to the population. Given the secretive and sensitive nature of hair pulling and the women's willingness to participate, it is thought that their experiences, although unique in a way that everyone's experience is unique, are valuable to the TTM community (i.e., sufferers, family members, and treatment providers) in that they provided a deeper understanding of how women experience hair pulling and conceptualize their behavior. Future research may include hair pullers who have never attended treatment or participated in a research study.

All of the participants conceptualized their hair pulling after exposure to treatment and were influenced by their experiences. It is important to interpret the findings of this

study with caution, particularly when applying them to individuals who have not been in treatment. When attempting to understand hair pulling in the future, researchers may want to include children, adolescents, and adults who have not attended treatment, which may change the hair puller's perception that TTM is a problem.

### Implications for Practice

The findings of this study illuminate several issues that should be addressed when treating someone with TTM. First and foremost, the majority of the women in this study experienced trauma, when the definition of trauma was broadened, at the onset of their hair pulling. It is important to inquire about the experiences of clients that occurred at the onset of their hair pulling and to determine if a traumatic life event was a precipitant of hair pulling. Although we cannot presume that TTM is caused by trauma, it is important to determine if there is a relationship between a past traumatic experience and hair pulling, because a therapist can empower the hair puller to achieve her goals specific to hair pulling and healing the wounds of past traumatic events. Further, trauma can significantly impact treatment choices and effectiveness. Spending time to focus on healing trauma, a hair puller may begin to feel safe enough to work through issues of shame and to develop healthy coping strategies so that she is ready to work on changing her hair pulling behavior if this is her goal. Additionally, the therapist may want to explore how hair pulling is/was utilized as a coping strategy in the context of her trauma. Addressing hair pulling in a nonpathologizing way and exploring how effective a tool hair pulling was in the context of traumatic experiences may help the hair puller understand her behavior in a different less shameful way, why it developed, why it

worked in the past, and why it may no longer be working as a coping strategy in the present.

Secondly, it is important to know the historical conceptualization of TTM that is woven through the hair puller's experience and perceptions of her TTM. Specifically, if hair pulling was conceptualized as a problem for the client, the therapist will want to be mindful of her client's experience and perceptions of her TTM and remain free of judgment when working with individuals who engage in hair pulling so as not to shame or embarrass them. A therapist will want to take a nonpathologizing approach to understanding the role that TTM plays in the client's life. It is important to establish a collaborative relationship with the hair puller to truly understand her lived experience with TTM.

It is important to utilize the client's conceptualization of her TTM to establish goals together that address the client's needs specific to her hair pulling, and reassess these goals as necessary. When treating someone with TTM, it is important to openly discuss the roles of power and control directly with the client to determine how she uses hair pulling (e.g., what strategies is she using to gain control of her hair pulling; TTM is a way of gaining control within her environment). It is important to continually revisit the role of power and control within the therapy relationship to ensure an egalitarian relationship, and to understand both the role of and the power that the therapist has over the hair puller's conceptualization of her hair pulling.

Practitioners may want to explore with the hair puller the impact that conceptualizing hair pulling as a problem has had on the hair puller's sense of control over her behavior. Discussing how allowing others to hold the hair puller accountable



negatively impacts the hair puller in that she is always looking for someone else to control her hair pulling for her. Another helpful therapeutic intervention would be to help the hair puller to become accountable for her hair pulling, which gives her a greater sense of control over her TTM and autonomy over the process of being accountable.

While it is natural for parents to view their child's TTM as a problem given the social, emotional, and economic impact that it has on the hair puller and the family, the problem may lie deeper than the hair pulling behavior. Parents may be utilizing medical and behavioral treatments to address TTM. These treatments stem from the medical model, which focuses on physical causes of behavior and largely ignores the environmental and psychological bases for behaviors. It is possible that medical and behavioral treatments are not addressing the underlying causes of hair pulling. Specifically, by focusing on the outwardly facing symptoms of TTM (e.g., hair loss) and treating the outwardly facing symptoms, the systemic cause (e.g., trauma) of hair pulling may be unaddressed. This is similar to treating hives with anti-itch cream and not attempting to understand the systemic cause of the hives. Psychoeducation specific to TTM may help parents and hair pullers recognize unaddressed emotions (e.g., anxiety) and experiences of the hair puller that may be possible root causes contributing to TTM. Further, providing psychoeducation about hair pulling, conceptualization of TTM as a problem, and associated emotions (e.g., low self-esteem; shame) to parents/caregivers and other family members may be beneficial to the hair puller in creating a continuum of care outside of treatment. Including families could mitigate the effects of stigma associated with hair pulling, as well as the TTM itself. The practitioner should take care

to include the hair puller in making decisions as to what others should be involved in her care.

The findings support the need to consider the multifaceted nature of trichotillomania, as each hair puller has a unique conceptualization of her TTM. It is important for treatment providers to be aware of the multiple treatments available for TTM and to know that there are currently no empirically supported treatments specific to TTM. Including the hair puller in the TTM conversation to understand her perceptions, meaning, and experience of TTM is crucial to understanding her lived experience and hair pulling journey.

### Conclusion

In conducting this research, I have asked myself many times, *What are these women trying to tell me?* They asked me to listen to their stories and to understand their experiences of hair pulling. The women who participated in my research have provided me with the great honor of sharing their personal journeys of empowerment.

This research identifies the collective experiences (i.e., onset in the context of trauma, TTM conceptualized as a problem, the struggle for accountability and acceptance, and reclaiming their narrative by conceptualizing their hair pulling) of the women who engaged in chronic hair pulling, and it illuminates their journeys to empowerment. Self-conceptualization empowered the women in this study to reclaim their hair pulling narrative. In doing so, they recognized that they were the experts on themselves and that they no longer needed others to describe their behaviors and accompanying emotions. They gave their voice to their hair pulling experiences and offered insight into the complex nature of TTM and the role that power and control

played in their lives. Their conceptualizations of TTM, based on their experiences and perceptions of their hair pulling, needed to be heard and provided clear evidence for why it is so important to include the hair pullers' voices in the global TTM conversation.

## APPENDIX A

### CONSENT DOCUMENT

#### **Consent Document** **A Qualitative Study of Women Engaged In Hair Pulling**

##### **BACKGROUND**

You are being asked to take part in a research study about your experiences and perceptions specific to your hair pulling because you are a woman who has been diagnosed with trichotillomania (TTM). Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully, and ask if there is anything that is not clear or if you would like more information. Take time to decide whether you want to volunteer to take part in this study.

The purpose of this study is to understand women who pull their hair while understanding the context in which they live, in depth and in detail, as well as their thoughts, and feelings about their hair pulling. The aim of the study is to make the findings available to others who engage in hair pulling, as well as to service providers who may find this information useful in treating individuals with TTM. A female graduate student at the University of Utah is conducting this research.

##### **STUDY PROCEDURE**

Your participation in this study will involve filling out a questionnaire that asks you demographic questions (e.g., age, age of onset, primary site of hair pulling, and race). The questionnaire asks questions about how long you have been pulling your hair (e.g., two years, ten years, twenty years, etc.). Also, you will be asked questions related to the diagnostic criteria for trichotillomania.

You will be asked to take part in two interviews. The first interview will be scheduled for the duration of sixty to ninety minutes, but may be broken into shorter segments based on your needs. The second interview is a follow-up interview and will last no longer than thirty minutes. Interviews will be conducted either in person or over the telephone. Interviews will be audio taped and transcribed.

You will be re-contacted for a follow-up interview to clarify information that you provided in the initial interview, as well as to provide the researcher with additional information if necessary. Follow-up interviews should last no longer than one half hour. Follow-up interviews will be audio taped and transcribed. The total amount of time it will take to participate in this study is two hours and thirty minutes.

**RISKS**

The risks of participating in this study are expected to be minimal. It is possible that you may feel upset thinking about or talking about personal experiences related to your hair pulling. These risks are similar to those you experience when discussing personal information with others. If you feel upset from this experience, you can tell the researcher, and she will tell you about resources available to help.

**BENEFITS**

There is no promise of any direct benefit to you for taking part in this study. However, it may be that having the opportunity to talk about your hair pulling may result in increased self-awareness and positive feelings about sharing your thoughts and feelings with other people, and the possibility of sharing information that will help others. It may also result in greater clarity about your own hair pulling behavior and the impact that this behavior has on you and your life. Further, participating in this study may help doctors, researchers, and the general public to better understand hair pulling and trichotillomania, which could lead to new and/or additional treatments for hair pulling.

**CONFIDENTIALITY**

The information you share will be kept confidential. Only the researcher will have access to the personal information that you share as a participant of this study.

Each interview will be recorded onto a digital recording device. The digital recorder will be placed in the room near the participant and researcher when the participant is interviewed in person. The digital recorder will be placed near the telephone speaker when the participant is interviewed over the telephone. All interviews will be recorded so that the researcher will have a word for word account of the participant's answers to her questions. An exact account of the interview is necessary for the analysis of this study. The researcher will transcribe each audio recording using the exact words of both the researcher and participant. Transcribed interviews will be kept as individual password-protected computer files on a password-protected computer that will be kept locked in a filing cabinet in a locked office when it is not being used for study purposes.

Audio recordings and computer files of the interviews will be kept in a locked filing cabinet in the researcher's private office while the study is open. Audio recordings will be deleted from the recording device and audio files will be permanently deleted from the computer once the study has completed. Computer files containing the transcribed interviews will be permanently deleted from the researcher's computer at the close of the study. Audio recordings and transcripts will be stored in a locked filing cabinet or on a password-protected computer located in the researcher's private office. Only the researcher will have access to this information.

Your information will be assigned a code name (which you may choose if you wish), which will be kept with your questionnaire, initial interview, and follow-up interview. Only the researcher will have access to this information. In publications, only your code name will be used, and every effort will be made to protect your identity by removing identifying information from quotes, etc., that may be used in publication. Further, audio recordings will not be shared with anyone or published. The only exception to the guarantee of confidentiality is if you share actual or suspected abuse, neglect, or exploitation of a child or disabled or elderly adult. In this case, the researcher must report this to the most appropriate agency in your state.

**PERSON TO CONTACT**

If you have questions, complaints, or concerns about this study, or if you feel that taking part in the research has harmed you, you can contact Missy Dixon at 801-694-7404. Missy is usually available during normal working hours; however, if she is unavailable when you call, you may leave a message on her confidential voice mail. She will return your call as soon as possible. You may also contact her by e-mail at [missy.dixon@gmail.com](mailto:missy.dixon@gmail.com), however, you should be aware that e-mail is not a confidential form of communication.

### **INSTITUTIONAL REVIEW BOARD**

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns that you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at [irb@hsc.utah.edu](mailto:irb@hsc.utah.edu).

**Research Participant Advocate:** You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at [participant.advocate@hsc.utah.edu](mailto:participant.advocate@hsc.utah.edu).

### **VOLUNTARY PARTICIPATION**

It is up to you to decide whether to take part in this study. Refusal to participate, or if you withdraw from this research will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to stop after you have agreed to participate, just inform the researcher. Your interview tape and any transcripts that have been made will be destroyed. Your decision to withdraw from the study will not affect your relationship with the investigator.

### **COSTS AND COMPENSATION TO PARTICIPANTS**

There should typically not be any costs incurred by you to participate in this study. Study participants will not be compensated for their time or participation in this study.

### **CONSENT**

By signing this consent form, I confirm I have read the information in this consent form and have had the opportunity to ask questions. I will be given a signed copy of this consent form. I voluntarily agree to take part in this study.

\_\_\_\_\_  
Printed Name of Participant

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Researcher or Staff

\_\_\_\_\_  
Signature of Researcher or Staff

\_\_\_\_\_  
Date

APPENDIX B

HAIR PULLING QUESTIONNAIRE

Hair Pulling Questionnaire

Date: \_\_\_\_\_

Name: \_\_\_\_\_

Age: \_\_\_\_\_

Address: \_\_\_\_\_

Birthdate: \_\_/\_\_/\_\_

\_\_\_\_\_

Ethnicity: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

1. Do you engage in hair pulling? (please circle) Yes No

If yes, how old were you when you began pulling? \_\_\_\_\_

2. Has your pulling resulted in noticeable hair loss? Yes No

3. Do you feel tension right before you pull or when you are trying to resist pulling your hair? Yes No

4. Do you feel pleasure, comfort, or relief when pulling out the hair? Yes No

5. Has your hair pulling behavior been diagnosed by a doctor? Yes No

If yes, what is the diagnosis? \_\_\_\_\_

6. Have you ever been officially diagnosed with trichotillomania? Yes No

7. Does your hair pulling cause you significant distress or impairment in your





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