Emotion regulation in trichotillomania (hair-pulling disorder): The role of stress and trauma

by

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DECLARATION

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ABSTRACT

Introduction: Trichotillomania (hair-pulling disorder, or TTM) is characterized by pathological hair-pulling, repeated unsuccessful attempts to stop the behaviour, and significant distress. Various affective states (e.g. tension, stress or pleasure) occur before, during or after hair-pulling, and difficulties in regulating these have been noted in TTM. When applied to TTM, the emotion regulation (ER) model is based on the argument that pulling serves to regulate emotions. However, this appears to be an arduous relationship. For example, stress may increase hair-pulling as a way to assuage feelings of extreme anxiety and depression, whereas hair-pulling and its sequelae may also increase stress levels. There is also evidence to suggest significantly greater severity of childhood trauma in individuals with TTM compared to controls. However, the relationship between stress, childhood trauma and ER in TTM is not yet known. This study aimed to address this gap in our knowledge, by firstly comparing the rates of these variables in TTM with matched healthy controls. A second aim was to investigate whether there was a relationship between hair-pulling severity and difficulties in ER. A third aim was to investigate whether there was a relationship between stress, childhood trauma, and ER difficulties in TTM, while controlling for the presence of mood and anxiety disorders.

Methods: The majority of the data included in the study formed part of a larger on-going study. Fifty-six adults with TTM and 31 sex- and age-matched controls were included. Participants in this study completed a battery of questionnaires, which included the Perceived Stress Scale (PSS), the Childhood Trauma Questionnaire (CTQ) and the Difficulties in Emotion Regulation Scale (DERS). The data were analysed using the Statistical Package for the Social Sciences (SPSS v. 22).

Findings: Stress (p = .03), childhood trauma (p = .03), and difficulties in ER (p < .01) were all significantly increased in TTM patients compared to the healthy controls. Second, there was no statistically significant relationship between hair-pulling severity and difficulties

in ER. Last, a combination of stress and childhood trauma explained 28.7% of the variance in ER difficulties in TTM [F (2.51) = 7.00, p < .01). However, stress was the only variable that significantly correlated with difficulties in ER in TTM (β = .47, p < 0.001).

Conclusion: As one of the first studies to explore ER in TTM in-depth, the study findings suggested significantly increased stress, childhood trauma, and difficulties in ER in individuals with TTM. While individuals with TTM had greater difficulty in regulating their emotions compared to healthy controls, the data showed no significant relationship between TTM severity and ER difficulties. In keeping with the ER model, one would expect that increased pulling could be used as an attempt to regulate emotions – however this data did not support this hypothesis. Rather, increased stress in TTM individuals significantly explained difficulties in ER. It may be argued that stress and difficulties in ER seem to be more closely related than hair-pulling and difficulties in ER. This suggests that the ER model may not be the best model to explain the phenomenon of pathological hair-pulling. Further research into the underlying mechanisms and dynamics of stress, trauma and ER in TTM may assist in finding a more appropriate explanatory model. In the clinic, emphasis should be placed on the assessment of difficulties in ER in patients with TTM and on addressing modifiable features (such as stress) associated with such difficulties, in addition to reducing hair-pulling.

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OPSOMMING

Inleiding: Trigotillomanie (haaruittreksteuring, of TTM) word gekenmerk deur patologiese uittrek van hare, herhaaldelike onsuksesvolle pogings om die gedrag te stop, en beduidende distres. Verskeie emosies (bv. spanning, stres of plesier) kom vooraf, gedurende of na afloop van haaruittrekkery voor, en probleme met die regulering van hierdie emosies is tipies in TTM. Die model van emosieregulering (ER) bied in die geval van toepassing op TTM die argument dat haaruittrekkery daarop gemik is om emosies te reguleer. Dit blyk egter ’n komplekse verhouding te wees: stres kan byvoorbeeld haaruittrekkery wat daarop gemik is om erge angs en depressie te verminder, vererger, terwyl haaruittrekkery en die gevolge daarvan stresvlakke kan verhoog. Daar is ook bewyse dat daar beduidend meer kindertydtrauma by individue met TTM voorkom vergeleke met kontrolegroepe. Die presiese verband tussen huidige stresvlakke, kindertydtrauma en ER in patologiese haaruittrekkery is egter nog onbekend. Hierdie studie het ten doel gehad om hierdie kennisgaping aan te spreek kindertydtrauma, die stres wat die individu ervaar en ER-probleme tussen pasiënte met TTM en gesonde kontrolepersone (GK) te vergelyk. ’n Tweede doelwit was om uit te vind of daar ’n verhouding tussen die graad van haaruittrekkery en ER-probleme is. ’n Finale doelwit was om die verband tussen die stres wat die persoon ervaar, kindertydtrauma en ER-probleme te meet terwyl daar statisties vir die teenwoordigheid van komorbiede gemoeds- en angssteurings oor die leeftyd beheer word. **Metode:** Die meerderheid van die data wat in die analise ingesluit is, het deel uitgemaak van ’n groter langertermyn- studie. 56 volwassenes met TTM en 31 kontrolepersone van dieselfde geslag en ouderdomsgroep is by die studie ingesluit. Die deelnemers aan hierdie studie het ’n battery vraelyste voltooi, insluitend die *Perceived Stress Scale (PSS)*, die *Childhood Trauma Questionnaire (CTQ)* en die *Difficulties in Emotion Regulation Scale (DERS)*. Die data is met behulp van die *Statistical Package for the Social Sciences* (SPSS weergawe 22) ontleed.

Bevindinge: Kindertydtrauma (p = .03), die ervaring van stres (p = .03) en ER-probleme (p < .01) was beduidend meer in TTM-pasiënte vergeleke met die GK's. Daar was geen beduidende verhouding tussen die graad van haaruittrekkery en die vlak van ER-probleme nie. Laastens het 'n kombinasie van kindertydtrauma en die ervaring van stres 28.7% van die variansie in ER-probleme in TTM [F (2.51) = 7.00, p < .01) verklaar. Die huidige stresvlakke was die enigste veranderlike wat beduidend met ER-probleme in TTM gekorreleer het (β = .47, p < 0.001).

Gevolgtrekkings: Hierdie is een van die eerste studies wat ER in TTM in diepte ondersoek. Die bevindinge toon verhoogde kindertydtrauma, huidige stres en ER-probleme by individue met TTM in vergelyking met GK's. Daar was nie 'n beduidende verband tussen die erns van haaruittrekkery en ER-probleme nie. Volgens die ER-model sou daar die verwagting wees dat verhoogde uittrekkery sou gebruik kon word as 'n poging om emosies te reguleer – hierdie data het egter nie hierdie hipotese bevestig nie. Gegewe hierdie bevinding en die meegaande bevinding wat daarop dui dat huidige stresvlakke die enigste veranderlike is wat beduidend met ER-probleme in TTM gekorreleer het, kan daar aangevoer word dat daar 'n sterker verband tussen huidige stres en ER-probleme is as tussen haaruittrekkery en ER-probleme. Dit suggereer dat die ER-model dalk nie die mees gepaste model is om die verskynsel van patologiese haaruittrekkey te verklaar nie. Verdere navorsing oor die onderliggende meganismes en dinamika van ER in TTM en oor die verband tussen haaruittrekkery, kindertydtrauma en huidige stres kan ons help om 'n meer gepaste model te vind. In praktyk behoort daar gefokus te word op die assessering van ER-probleme by pasiënte met TTM, die hantering van veranderbare korrelate van ER-probleme (soos huidige stresvlakke), en die vermindering van haaruittrekkery.

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List of Acronyms / Abbreviations

ACT	Acceptance and commitment therapy
ARS	Affective Regulation Scale
BDI	Beck Depression Inventory
BFRB	Body-focused repetitive behaviours
CDI	Clinical diagnostic interview
CTQ	Childhood Trauma Questionnaire
DBT	Dialectical behavioural therapy
DERS	Difficulties in Emotion Regulation Scale
DSM	Diagnostic and Statistical Manual of Mental Disorders
DTS	Distress Tolerance Scale
EA	Emotional abuse
EN	Emotional neglect
ER	Emotion regulation
GHQ	General Health Questionnaire
HREC	Health Research Ethics Committee
MDD	Major depressive disorder
MGHHPS	Massachusetts General Hospital-Hair Pulling Scale

NMR	Negative mood regulation
NRF	National Research Foundation
OCD	Obsessive-compulsive disorder
PA	Physical abuse
PSS	Perceived Stress Scale
PTSD	Post-traumatic stress disorder
SPD	Skin-picking disorder
SPSS	Statistical Package for the Social Sciences
STAI	State-Trait Anxiety Inventory
TTM	Trichotillomania
VIF	Variance inflation factor

Glossary of Terms

Acceptance and commitment therapy	A therapeutic approach that focuses on the acceptance of one's thoughts, feelings and urges, rather than reducing or aiming to stop the thoughts/feelings/urges.
Automatic hair-pulling	Hair-pulling that happens outside of the awareness of the individual. This is usually when the individual is busy with another task or is in deep thought.
Body-focused repetitive behaviours	The BFRBs are behaviours directed at the body. They are recurrent, problematic and destructive. There is usually a focus on excessive grooming or removing parts of the body such as nails, skin, or hair. These behaviours are usually difficult to suppress and may lead to impaired functioning. They usually include hair-pulling, skin-picking and nail-biting.
Childhood trauma	Childhood trauma refers to early adverse experiences, which may include emotional abuse, emotional neglect, physical abuse, physical neglect, and/or sexual abuse.

Dialectical behavioural therapy	A treatment approach that focuses on creating awareness of different affective states (for example anger) and maladaptive emotion regulation strategies, with the goal of replacing them with more adaptive emotion regulation strategies.
Emotion regulation (ER)	ER refers to the ability to identify and respond to emotional experiences such as stress. It is the process of identifying and regulating the presence, intensity, timing and expression of both positive and negative emotions.
Focused hair-pulling	Hair-pulling that happens when an individual is aware that they are pulling out their hair. It usually occurs with goal-directed behaviour, e.g. to relieve tension while stressed.
Perceived stress	Perceived stress is an individual's current subjective appraisal of stressful experiences.

Obsessive-compulsive and related disorders	A chapter in the current diagnostic nomenclature that includes obsessive-compulsive disorder, trichotillomania, skin-picking disorder, body dysmorphic disorder, and hoarding disorder.
Trichotillomania (TTM, hair-pulling disorder)	A disorder classified under the obsessive-compulsive and related disorders (OCRDs) category in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), characterized by repeated attempts to reduce/stop hair-pulling, and significant distress and/or functional impairment.

Chapter 1
Introduction

Trichotillomania (hair-pulling disorder, or TTM) is characterized by pathological hair-pulling and is classified as one of the obsessive-compulsive and related disorders (OCRD) in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association [APA], 2013). An individual with TTM repeatedly and unsuccessfully attempts to reduce or stop pulling out their hair, leading to significant distress and/or functional impairment (APA, 2013).

TTM has an estimated prevalence ranging from 0.5% to 3.9% in community samples (Chamberlain et al., 2010; Grant, Odlaug, & Kim, 2009; Grant, Odlaug, & Chamberlain, 2011; Mansueto, Thomas, & Brice, 2007; Roberts, O'Connor, Aardema, & Belanger, 2015; Shusterman, Feld, Baer, & Keuthen, 2009). However, these prevalence rates were established when TTM was still defined as an impulse control disorder in previous editions of the DSM (Snorrason, Berlin, & Lee, 2015). With the revised and less strict diagnostic criteria for TTM in the DSM-5/International Classification of Diseases eleventh edition (ICD-11), researchers report that its prevalence is likely to be higher (APA, 2013; Grant & Stein, 2014; Roberts et al., 2015).

While the prevalence of TTM is surprisingly high, there is still a paucity of research investigating TTM, and significant knowledge gaps remain (Curley, Tung, & Keuthen, 2016; Duke, Keeley, Geffken, & Storch, 2010; Meunier, Tolin, & Franklin, 2009). For example, there is uncertainty on what triggers and maintains hair-pulling (Curley et al., 2016; Duke et al., 2010). Various theoretical models have been established in an attempt to explain the dynamics of TTM (Arabatzoudis, Rehm, Nedeljkovic, & Moulding, 2017; Duke et al., 2010), but these are not comprehensive and do not explain the condition and its underpinnings fully. For example, the trauma model (Duke et al., 2010) follows the premise that individuals with TTM

pull their hair in response to stress and trauma (Duke et al., 2010; Gershuny et al., 2006). This model does not necessarily support a direct causal relationship between trauma and TTM, but rather an indirect relationship, where hair-pulling may act as a maladaptive mechanism to regulate the negative affect associated with the trauma (Houghton et al., 2016; Shusterman et al., 2009). Researchers and clinicians are also still attempting to understand why hair-pulling behaviours persist despite the repeated attempts to stop the negative sequelae (McDonald, 2012; Roberts, O'Connor, & Belanger, 2013; Shusterman et al., 2009).

Consistent with some aspects of the trauma model, the emotion regulation (ER) model (Arabatzoudis et al., 2017; Diefenbach, Tolin, Meunier, & Worhunsky, 2008; Roberts et al., 2013) posits that some individuals use hair-pulling to regulate negative emotional states (e.g. providing stimulation when feeling bored, or relieving tension when stressed or anxious) (Grant, Leppink, & Chamberlain, 2015; Roberts et al., 2015; Shusterman et al., 2009). Indeed, there is support for the proposition that hair-pulling reduces negative affective states such as boredom, stress and anxiety (Curley et al., 2016; Duke et al., 2010; Grant et al., 2015; Shusterman et al., 2009). The converse also applies: hair-pulling usually leads to negative emotions such as guilt and depression (Grant et al., 2015; Shusterman et al., 2009). The literature also supports the premise that individuals with TTM have more difficulty constructively regulating their emotions than healthy controls (Arabatzoudis et al., 2017; Shusterman et al., 2009).

In TTM, stress specifically is associated with the worsening of hair-pulling behaviours (Grant et al., 2015). In addition, trauma may also be associated with hair-pulling, with some authors arguing that hair-pulling is sometimes used as a mechanism to manage trauma-related symptoms (Gershuny et al., 2006; Houghton et al., 2016). This premise finds support in many studies suggesting that rates of past trauma are significantly higher in TTM participants compared to healthy controls (Gershuny et al., 2006; Lochner, Simeon, Niehaus, & Stein, 2002;

Özten et al., 2015). Childhood trauma refers to early adverse experiences, which may include emotional abuse and neglect, physical abuse and neglect, as well as sexual abuse (Lochner et al., 2002; Matthews, Kaur, & Stein, 2008). It has been argued that some *types* of trauma may be specifically associated with hair-pulling. For example, one study found that sexual abuse, neglect, and physical abuse were significantly higher in TTM and skin-picking disorder (SPD) cohorts compared to healthy controls (Özten et al., 2015). Moreover, individuals who have experienced high levels of childhood emotional and physical abuse have also been found to have high levels of ER difficulties (Choi et al., 2014). This is consistent with work suggesting that negative affective states such as depression experienced after trauma, may be associated with maladaptive ER strategies such as hair-pulling (Houghton et al., 2016).

In summary, hair-pulling may potentially be construed as a non-constructive or unhealthy way to regulate negative emotions, also those associated with childhood trauma. In addition, psychiatric comorbidity frequently co-occurs with TTM (Arabatzoudis et al., 2017; Grant et al., 2011; Johnson & El-Alfy, 2016), where mood and anxiety disorders have a very high co-occurrence. For example, mood disorders are found to have a comorbidity rate over 50%, and anxiety disorders with a 25% co-occurrence rate (Arabatzoudis et al., 2017). The high rate of mood and anxiety disorders with TTM may be because depression and anxiety could be understood as triggers, emotional consequences and emotional maintaining factors of hair-pulling (Mansueto et al., 2007). Therefore, it is possible that these variables may influence the relationship between stress, childhood trauma and ER difficulties in individuals with TTM.

To my knowledge there are currently no studies investigating the relationship between stress, childhood trauma, ER difficulties and psychiatric comorbidity in individuals with TTM. The relationships between these variables are not clear, and the ER model may provide a theoretical basis for an improved understanding. This study aimed to address these gaps in the literature.

Rationale

While it is well known that TTM may cause individuals significant distress and/or functional impairment, there is a paucity of knowledge on the maintenance of hair-pulling behaviours (Curley et al., 2016; Duke et al., 2010; Meunier et al., 2009). Hair-pulling has been considered a maladaptive coping mechanism to relieve tension, but it may in return have negative consequences for the individual, such as increased negative affect such as guilt, depressed mood or anxiety (Diefenbach et al., 2008; Houghton et al., 2016; Shusterman et al., 2009). The ER hypothesis of TTM has gained much support in the last decade (Arabatzoudis et al., 2017; Curley et al., 2016; Drysdale, Jahoda, & Campbell, 2009; Roberts et al., 2015; Shusterman et al., 2009). Additionally, treatment strategies that affect ER processes, such as dialectical behavioural therapy (DBT) and acceptance and commitment therapy (ACT), have been found to decrease TTM severity (Arabatzoudis et al., 2017; Keuthen et al., 2012; Woods, Wetterneck, & Flessner, 2006), supporting the importance of ER processes in the dynamics of TTM. For example, DBT focuses on creating awareness of affective states and maladaptive ER strategies, with the goal of replacing them with more adaptive ER strategies (Arabatzoudis et al., 2017; Snorrason et al., 2015). Therefore, investigating the association between stress and childhood trauma with ER difficulties is likely to give us a better understanding of the dynamics that lead to and maintain pathological hair-pulling. Second, the research could also contribute to a more appropriate selection of treatment targets and choice of strategies, for example substituting pathological "coping" strategies such as hair-pulling with other more constructive ones.

Research Question

The study aimed to address the following research questions:

1. *How do rates of stress, childhood trauma, and difficulty with ER in a TTM cohort compare to healthy controls?*
2. *Are difficulties in ER related to the severity of TTM?*
3. *What is the relationship between stress, childhood trauma, ER, and comorbid mood and anxiety disorders in individuals with a primary diagnosis of TTM?*

Study Aims

The aims of the study were threefold:

- Aim 1: To compare rates of stress, childhood trauma, and difficulties in ER between patients with TTM and healthy controls.
- Aim 2: To investigate the relationship between hair-pulling severity and difficulties in ER.
- Aim 3: To assess the relationship between stress, childhood trauma, and ER difficulties in TTM, while controlling for the presence of comorbid mood and anxiety disorders.

Research Hypotheses

1. Levels of stress, childhood trauma, and difficulties in ER will differ significantly between patients with TTM and healthy controls, with TTM patients reporting increased levels in all of these respects.
2. Hair-pulling severity and difficulties in ER will correlate significantly.
3. Stress, childhood trauma, and ER difficulties in TTM, while controlling for the presence of comorbid mood and anxiety disorders, will correlate significantly.

4. In linear combination, stress and childhood trauma, while controlling for the presence of comorbid mood and anxiety disorders, will significantly predict ER difficulties in TTM.

Overview of Chapters

This chapter included an introduction to TTM, its prevalence and association with stress, childhood trauma, and ER. It also covered the rationale for the study, the research question and study aims and objectives. The remainder of this thesis is divided into five chapters, organized as follows:

Chapter 2. This chapter presents a literature review of the current and relevant knowledge on TTM, including stress, trauma history, ER difficulties and psychiatric comorbidity in TTM. The chapter ends with a proposed theoretical framework, which is used as a lens to interpret the current study findings.

Chapter 3. The methodological procedures of the study, including the study design, data collection (sample, settings, questionnaires used), as well as the type of statistical analyses used, are described in this chapter.

Chapter 4. This chapter presents the study findings, including graphical representations (graphs and tables) of the results.

Chapter 5. This chapter consists of a discussion of the main findings. Second, it covers the limitations of the study, as well as implications and recommendations for the clinic and for future research.

Chapter 2
Literature Review

Pathological hair-pulling is at the core of TTM. It generally has a bimodal onset, either in early childhood or in adolescence, and is known to have a chronic course (Duke et al., 2010; McDonald, 2012). The affected individual may pull hair from one specific part of the body, or from multiple areas. Patients often pull hair mostly from the scalp, but they may also pull from the eyebrows, eyelashes, beard, arms, legs and the pubic area (Duke et al., 2010; Roberts et al., 2015). The individual can pull their hair either one strand at a time, which is said to be the most common, or in clumps with the use of fingers, tweezers, combs or brushes (McDonald, 2012). The triggers of hair-pulling may be sensory (for example, the physical sensations on the scalp, or the fact that the individual notices particular or apparently different hairs), emotional (for example, anxiety, tension, boredom, stress, anger), and cognitive (for example, thoughts about hair-pulling, such as "this hair is out of place"; rigid thinking, such as "wiry hairs are bad"; or cognitive errors such as catastrophizing, "I cannot feel better until this hair is gone") (Grant & Chamberlain, 2016; Snorrason et al., 2015; Walther, Ricketts, Conelea, & Woods, 2010). Although individuals may report various triggers of hair-pulling, emotional triggers seem to be the most common and the main focus in many TTM studies (Arabatzoudis et al., 2017; Roberts et al., 2013; Snorrason et al., 2015).

A number of authors have suggested that TTM is a heterogeneous disorder and that there may be distinct hair-pulling subtypes or styles. For example, hair-pulling may be categorized as either focused or automatic (Flessner et al., 2008; Grant et al., 2015). Focused hair-pulling occurs when an individual is aware that they are pulling out their hair. During focused hair-pulling, the urge to pull hair is intense, with an increase in tension and an increase in thoughts about hair-pulling (Arabatzoudis et al., 2017; Duke et al., 2010; Flessner et al., 2008; Shusterman et al., 2009). This "type" of hair-pulling is known to increase in intensity

between the ages of 13 to 18 years, which may relate to the onset of puberty and the stressors associated with this age bracket (Duke et al., 2010). Automatic hair-pulling occurs when an individual is unaware that they are pulling hair. This type of hair-pulling usually happens when the individual is busy with something else, or is in deep thought (Flessner et al., 2008; McDonald, 2012), often during sedentary activities like watching television or reading (Flessner et al., 2008). With automatic hair-pulling, the individual may only realize that they have pulled out their hair after it has occurred. It is not uncommon for individuals to experience varying degrees of both automatic and focused hair-pulling (Duke et al., 2010; Flessner et al., 2008; Shusterman et al., 2009). Different combinations, including low-automatic, high-automatic, low-focused, and high-focused hair-pulling have also been described in the literature (Flessner et al., 2008).

The prevalence of TTM has mostly been measured by means of college student surveys (Duke et al., 2010; McDonald, 2012). Further research findings indicate that in adults, TTM is more common in females than in males with a 9:1 ratio; whereas in children the gender distribution is usually equal (Meunier et al., 2009; Woods & Houghton, 2014). Although the true prevalence of TTM in both adults and children is unknown, the estimated prevalence is thought to be higher than previously thought (Duke et al., 2010; Grant & Chamberlain, 2016). The increase in prevalence rate may be a result of changes in diagnostic criteria from DSM-IV TR criteria to DSM-5 (Duke et al., 2010). The previous DSM-IV TR criteria included the requirement of an urge to pull, and pleasure, gratification, or relief on pulling, but these symptoms are not found in every case (Duke et al., 2010; Meunier et al., 2009). Therefore, these criteria were excluded from the diagnostic set (Lochner et al., 2011). According to the review by Duke et al. (2010) there have been studies that support this claim, with 17 to 27 % of patients with hair-pulling who do not report tension before, during, or after hair-pulling. In addition to this, the criterion of noticeable hair-loss is too subjective as a requirement to

diagnose hair-pulling. This is because hair-pulling can be from different parts of the body, some of which are covered, or where the hair loss is hidden; thereby not noticeable (Duke et al., 2010). The exclusion of these problematic criteria may lead to increased numbers of individuals with pathological hair-pulling receiving a diagnosis of TTM.

The severity of TTM is known to fluctuate over time (Bloch, 2009). However, irrespective of its severity, TTM causes the individual great distress, and may impair functioning on a physical and/or psychosocial level (Grant et al., 2011). Physical impairments may include skin infections, hair follicle damage, bleeding and scalp irritation, as well as enamel erosion from manipulating their hair orally. Other physical impairments that may be associated with TTM include strain injuries such as carpal tunnel syndrome or trichobezoars (hairballs from ingestion) in the stomach and/or large intestine, which can cause gastrointestinal bleeding (Duke et al., 2010; McDonald, 2012; Roberts et al., 2013). Hair-pulling may thus necessitate medical attention, for example surgery to remove trichobezoars (Grant & Chamberlain, 2016). Psychosocial impairments associated with TTM may include poorer academic, occupational, social, and psychological functioning. Individuals with more severe hair-pulling report increased functional impairment on multiple levels (Duke et al., 2010). Impaired social functioning could include avoidance of social situations due to feelings of shame related to their hair-pulling behaviours and hair-loss (Arabatzoudis et al., 2017; Mansueto et al., 2007; Meunier et al., 2009). Social avoidance commonly includes the avoidance of sexual intimacy, social interaction, hairdressers, medical exams, swimming or even being in the wind (Duke et al., 2010; McDonald, 2012), and is usually related to worrying about hair loss being noticed. Avoidance may also lead to feelings of isolation (Duke et al., 2010). The embarrassment and secrecy about hair-pulling and its sequelae usually result in limited help-seeking behaviours, if any, which limits knowledge (Mansueto et al., 2007). There is also evidence of impaired occupational and/or academic functioning due to hair-pulling

(Flessner et al., 2008). This may be because individuals with hair-pulling often have concentration difficulties (McDonald, 2012). In conclusion, individuals with TTM have impairment in multiple life domains and a significantly reduced quality of life (Diefenbach, Tolin, Hannan, Crocetto, & Worhunsky, 2005; Ghosh, Mazunder, Bhattacharjee, & Battacharjee, 2016; Odlaug, Kim, & Grant, 2010).

Emotion Regulation

ER refers to the manner in which individuals identify and respond to the presence, intensity, timing and expression of both positive and negative emotions (Gratz & Roemer, 2004). Some researchers argue that individuals with body-focused repetitive behaviours (BRFBs, e.g. hair-pulling, skin-picking, and nail-biting), have deficits in ER (Shusterman et al., 2009), and that they use these BFRBs to cope with their negative emotions. The maladaptive coping mechanism, in this case hair-pulling, is said to develop through both negative and positive reinforcement. For example, through negative reinforcement the individual attempts to reduce negative emotions (e.g. anxiety), and through positive reinforcement the individual attempts to increase positive emotions (e.g. calmness) (Arabatzoudis et al., 2017). So, in summary, difficulties in ER may play a role in problem behaviours such as pathological hair-pulling (Sundermann & DePrince, 2015), which may manifest as a mechanism to regulate such emotional experiences (Diefenbach et al., 2008).

Measures of ER. There are a few measures of ER such as the Affective Regulation Scale (ARS), the Distress Tolerance Scale (DTS), the Negative Mood Regulation Scale (NMR), and the Difficulties in Emotion Regulation Scale (DERS) (Arabatzoudis et al., 2017). Each of these scales measure different but related aspects of ER and usually come in self-report format. For example, the ARS is a self-report scale that measures an individual's ability to control certain emotions, for example boredom, anger, and guilt (Roberts et al., 2015). The

DTS is another self-report scale that measures an individual's belief in their ability to tolerate distress. The NMR measures an individual's belief that a specific behaviour or cognition will reduce or alleviate a negative state so that it becomes a more positive state (Gratz & Roemer, 2004), and lastly, the DERS, which was used in this study, is a more comprehensive measure that assesses emotion dysregulation (Gratz & Roemer, 2004) (see Methods for more information on the DERS).

ER difficulties in TTM. Individuals with TTM demonstrate difficulty with regulating or managing emotions, especially negative emotions (Arabatzoudis et al., 2017; Curley et al., 2016; Roberts et al., 2015; Shusterman et al., 2009). For example, in an online survey, nine emotions (including boredom, shame, anxiety, anger, sadness, irritability, tension, indifference, and guilt) were investigated using the ARS. The findings indicate that individuals with TTM have greater difficulty regulating these types of emotions compared to healthy controls. In addition, TTM severity was positively correlated with difficulty with regulating emotions (Shusterman et al., 2009). Some researchers postulate that individuals with TTM use hair-pulling to regulate both high arousal (for example, anxiety and stress) and low arousal (for example, boredom) affective states (Arabatzoudis et al., 2017; Diefenbach et al., 2008). The relief or gratification often associated with pulling in the short term may then reinforce pulling behaviours over time.

Some studies have suggested that the difficulties in ER may occur in individuals living with TTM because they may experience difficulty tolerating discomfort/distress. They are known to have higher urges than healthy controls to engage in body-focused behaviours when feeling bored or impatient, for example (Arabatzoudis et al., 2017; Roberts et al., 2013; Roberts et al., 2015). In one study, all facets of emotion dysregulation significantly correlated with the severity of TTM. Total scores on the two DERS subscales named Goals and Strategies, respectively, had the highest (positive) correlations with TTM severity (Arabatzoudis et al.,

2017), with the Goals subscale referring to difficulty to engage in goal-directed behaviour, and the Strategies subscale to the individual's limited access to constructive ER strategies (Gratz & Roemer, 2004). Similarly, in a study by Roberts et al. (2015), the DERS and the ARS were used to measure ER in participants with BFRBs (which included TTM participants, among others) and healthy controls. The researchers found that participants with BFRBs experienced significantly greater behavioural urges (to pull hair, bite nails, or pick at skin) than healthy controls on mood induction tasks for stress, frustration, and even relaxation. However, the study had limited statistical power due to a small sample size. In a study by Keuthen et al. (2010), the researchers conducted a pilot trial of DBT-enhanced habit reversal in a female sample with TTM. Interestingly, the researchers also found that there was no significant correlation between hair-pulling severity and difficulties in ER at baseline. Keuthen et al. (2012) had similar findings where the researchers speculated that affective comorbidity might have *interfered* with this relationship.

Further, deficits in ER may be due to difficulty in identifying, defining and accepting some emotions, as well as problems with impulse control (Roberts et al., 2013; Rufer et al., 2014). The difficulty to differentiate between various emotions in TTM individuals may affect their ability to choose appropriate coping strategies, and they use hair-pulling instead (Weidt et al., 2016). For example, in a study by Rufer et al. (2014) the researchers found that in their TTM sample, difficulty with identifying feelings was a strong predictor of hair-pulling severity.

Therefore, the current study aimed to improve on the previous studies by including a larger sample and by narrowing down the ER/TTM investigation to stress and childhood trauma.

Treatment of ER difficulties. Various treatment studies have focused on ER difficulties in TTM (Arabatzoudis et al., 2017), including DBT and ACT (Arabatzoudis et al., 2017). DBT focuses on difficulties in ER, which have been assumed to maintain hair-pulling

behaviour (Snorrason et al., 2015). DBT aims to increase the individual's awareness of their emotions and to replace maladaptive ER strategies that may reinforce and maintain hair-pulling behaviours with more adaptive ER strategies (Snorrason et al., 2015). ACT focuses on assisting the individual to accept their thoughts, urges and emotions rather than reducing/eliminating their thoughts, feelings or urges to pull their hair (McDonald, 2012). Both forms of therapy focus on ER processes and have been found to decrease TTM severity, supporting arguments for an indirect association between TTM and ER (Arabatzoudis et al., 2017).

Stress in TTM

As noted earlier, pathological hair-pulling has often been considered a behavioural response to stress (Duke et al., 2010), or a mechanism to regulate emotions or stress (Grant & Chamberlain, 2016). Stress is the manner in which an individual perceives the environmental demands to exceed his or her ability to adapt (Cohen, Janicki-Deverts, & Miller, 2007). As a result, the individual may feel that he or she cannot cope (Austin et al., 2014). The current study focused on individuals with TTM's subjective appraisals of stressful experiences over the last month (Reis, Hino, & Rodriguez-Anez, 2010).

In a study investigating stress and BFRBs, which included 140 participants with TTM and SPD, 19.3 % of the sample reported severe stress and 15.7% reported mild stress as measured using the Perceived Stress Scale (PSS) (Grant et al., 2015). The findings suggested participants with severe hair-pulling had moderate to high levels of stress, and the higher the stress, the worse the hair-pulling symptoms were (for example, longer duration of hair-pulling per day). Although numerous studies indicate an association between stress and hair-pulling, the debate about the dynamics and causality continues, as there are inconsistencies. For example, not all studies support the hypothesis that stress triggers hair-pulling and other BRFBs, and that these behaviours are strategies to regulate unpleasant emotions. For example,

in the study by Roberts et al. (2015), the findings indicated that stress levels did not have a significant correlation with ER.

More work to address inconsistencies in the literature and to clarify the relationship between stress levels and ER in TTM is warranted.

Trauma in TTM

Trauma can be classified as an extreme variant of stress (Gershuny et al., 2006; Houghton et al., 2016). The various types of trauma may include sexual abuse, physical abuse, emotional abuse, emotional neglect, and physical neglect, to name a few. Exposure to trauma can increase the risk of a range of vulnerabilities, including mental illness. The earlier the onset of adverse experiences/maltreatment, the higher the risk of mental illness symptoms later in life (Houghton et al., 2016; Özten et al., 2015; Sundermann & DePrince, 2015).

There is an abundance of data on trauma and TTM. Researchers suggest that an increase in the number of traumatic experiences is associated with a longer duration of hair-pulling (Gershuny et al., 2006). In addition, researchers have found that the onset and the increase in hair-pulling symptoms are often precipitated by traumatic life events (Houghton et al., 2016). In support of this finding, Boughn and Holdom (2003) found that in their sample of 44 women with TTM, 86% reported an experience of violence (a type of trauma) prior to the onset of TTM. In a recent study, it was found that traumatic experiences in childhood were significantly higher in TTM participants and in SPD participants than in healthy controls (Özten et al., 2015). In the same study, it was found that childhood events such as sexual harassment, intercourse, neglect, abuse, and extreme violence were significantly higher for the TTM cohort compared to the SPD and healthy control cohorts. In another study, the researchers found that three quarters of the TTM total sample (n = 42) had experienced at least one type of trauma (Gershuny et al., 2006). Additionally, two or more types of trauma had an association with

more frequent pulling from the scalp, as well as a longer duration of TTM (Gershuny et al., 2006). Houghton et al. (2016) found that more than half (52.9%) of their participants had experienced at least one traumatic event in their lifetime. Furthermore, they found an increase in TTM severity following the trauma. Notably, these findings of an association between childhood adversity and hair-pulling do not imply that trauma is evident in all individuals with TTM or that there is a causal relationship between trauma and TTM. Indeed, there is evidence to suggest that trauma is also significantly higher in individuals with other psychiatric disorders (such as post-traumatic stress disorder [PTSD], or obsessive-compulsive disorder [OCD], for example), and not only in those with TTM (Houghton et al., 2016; Özten et al., 2015).

Research has shown that although there may be an association, other variables may mediate or play a role in the association between childhood trauma and TTM (Houghton et al., 2016; Lochner et al., 2002). Hair-pulling may function as a regulator for the symptoms associated with childhood trauma, such as depression or anxiety. The study by Houghton et al. (2016) concluded that hair-pulling acted as an emotion regulator for depressive symptomatology related to traumatic events; and is indirectly related to anxiety symptoms such as stress, tension, guilt, and perfectionism. These findings suggest that childhood trauma is in some way associated with TTM, but also that both childhood trauma and TTM may be related to an individual's affective state and their ability (or inability) to regulate their emotions.

Psychiatric Comorbidity in TTM

While it is important to investigate the relationship between stress and childhood trauma and ER, the potential influence of other relevant variables in this relationship, such as psychiatric comorbidity, should also be considered.

TTM often occurs concurrently with other psychiatric disorders (Arabatzoudis et al., 2017; Bohne, Savage, Deckersbach, Keuthen, & Wilhelm, 2008; Corso & McGeary, 2008;

Grant et al., 2011; Johnson & El-Alfy, 2016;). Other disorders that often co-occur with TTM include tic disorder (4.5%), OCD (13-16%), eating disorders (3.8%), disruptive behaviour disorder (3%), and body dysmorphic disorder, Asperger's syndrome, borderline personality disorder, and PTSD (0.8%) (Franklin et al., 2008). Specifically, mood and anxiety disorders have the most frequent co-occurrence with TTM (Grant, Redden, Leppink, & Chamberlain, 2017; McDonald, 2012; Woods & Houghton, 2014). In clinical and treatment-seeking samples, the comorbidity percentage rates exceed 50% for mood disorders and 25% for anxiety disorders (Arabatzoudis et al., 2017). Symptoms of depression and anxiety are often considered triggers of hair-pulling, as well as emotional consequences of hair-pulling (Mansueto et al., 2007). Therefore, the current study focused on comorbidity with mood and anxiety disorders in particular.

Mood disorders. Depression, a mood disorder, is strongly associated with hair-pulling (Stein et al., 2008). For example, the study by Grant et al. (2015) found that along with TTM, stress increased depressive symptoms. Additionally, negative affective states, such as depression, may mediate the relationship between trauma and TTM severity (Houghton et al., 2016). Researchers have also shown that symptoms of depression are significantly higher in TTM participants than in control participants (Diefenbach et al., 2005; Duke, Bodzin, Tavares, Geffken, & Storch, 2009; Özten et al., 2015), and are significantly associated with hair-pulling severity (Weidt et al., 2016). In a small TTM sample, one study found during the six-month follow-up that depression had an influence on the participants' ability to regulate guilt and aggression (Weidt et al., 2016), suggesting that affective disorders may influence ER in TTM in the longer run.

Anxiety disorders. Hair-pulling can also be understood as a behavioural response to anxiety (Grant et al., 2017). Some researchers consider it a mechanism to cope with the anxiety associated with a trauma history (Gershuny et al., 2006; McDonald, 2012). However, there are

research findings that suggest a cyclical relationship, with anxiety prior to hair-pulling and as a consequence of hair-pulling (Mansueto et al., 2007). Researchers have also found positive correlations between anxiety levels and TTM severity (Neal-Barnett, Statom, & Stadulis, 2011). In addition, there are research findings that indicate a significant association between TTM, stress, and symptoms of anxiety, where stress increases both hair-pulling behaviour, and symptoms of anxiety (Grant et al., 2015; Stein et al., 2008).

Therefore, this study controlled for mood and anxiety disorders when investigating the relationship between stress, childhood trauma, and ER in TTM.

Theoretical Framework

There are a few models that attempt to explain the mechanisms behind hair-pulling, for example early models of BFRBs, the biopsychosocial model, and the ER model. Early models of BFRBs propose that BFRBs such as hair-pulling first occur as a normal behavioural response to stress. The behaviour is then either negatively reinforced (for example, with the reduction of negative emotions such as anxiety), or positively reinforced (for example, with the increase in positive emotions such as relief or calmness) (Arabatzoudis et al., 2017).

The biopsychosocial model proposes that individuals with TTM have a biological predisposition towards grooming behaviours and difficulty tolerating discomfort, which results in the likelihood of using hair-pulling to regulate negative emotions (Arabatzoudis et al., 2017).

Similar to the biopsychosocial model, the ER model, as mentioned earlier, follows the premise that hair-pulling functions as a mechanism to regulate negative affect (e.g. stress, anxiety and depression) (Shusterman et al., 2009). Hair-pulling may be regarded as a problematic strategy to regulate emotions – the crux of the ER model as applied to TTM (Curley et al., 2016; Roberts et al., 2015; Shusterman et al., 2009).

Several research studies have supported the ER model to explain TTM dynamics (Arabatzoudis et al., 2017; Roberts et al., 2015; Shusterman et al., 2009). With reference to trauma history, Gershuny et al. (2006) speculate that following a traumatic experience an individual's capacity to cope emotionally is impaired, often giving rise to maladaptive coping strategies as a means of self-soothing. Hair-pulling has been considered one such a maladaptive coping mechanism to regulate the negative affect associated with trauma (Gershuny et al., 2006; Houghton et al., 2016). This is consistent with work on stress and pulling, with survey findings indicating that 56% of individuals with TTM have reported that they pull out their hair as a way of coping with stress (Grant et al., 2015). Therefore, with reference to the ER model, the individual may use hair-pulling as a maladaptive coping mechanism to regulate negative affect – which may be directly or indirectly associated with traumatic experiences or stress (Houghton et al., 2016). Figure 2.1, provides a theoretical illustration of the ER model which may be appropriate to explain the relationship between stress, childhood trauma, and anxiety and depression in TTM. As already mentioned, researchers have suggested that after experiencing trauma an individual may struggle to cope with the negative affect associated with trauma, in this case anxiety, depression and stress, and then use maladaptive coping mechanisms, such as hair-pulling (Gershuny et al., 2006; Grant et al., 2017; McDonald, 2012). Trauma is known to increase the risk of developing mental disorders, for example anxiety disorders (Houghton et al., 2016; Özten et al., 2015; Sundermann & DePrince, 2015). Second, the presence of psychiatric conditions such as anxiety disorders and depression is also suggested to influence ER difficulties in TTM (Shusterman et al., 2009). Third, although pulling out hair may be used to regulate emotions, it can also lead to excessive concern or worry over hair and hair loss, as well as exacerbate other symptoms such as anxiety (Shusterman et al., 2009). The same could apply to depression where hair-pulling may be a mechanism to distract the individual from the depressed mood, but also that hair-pulling can

result in depression (Rufer, 2014). Depressive symptoms often occur in individuals with TTM, and have been found to mediate the relationship between emotion regulation and TTM severity (Weidt et al., 2016). It is evident that there is an association between these variables (stress, trauma, anxiety disorders and depression), which could be understood through the ER model.

In conclusion, the present study used the ER model to guide the understanding between stress, childhood trauma, and ER difficulties in a large sample of adult individuals with TTM, while controlling for the influence of comorbid anxiety disorders and depression.

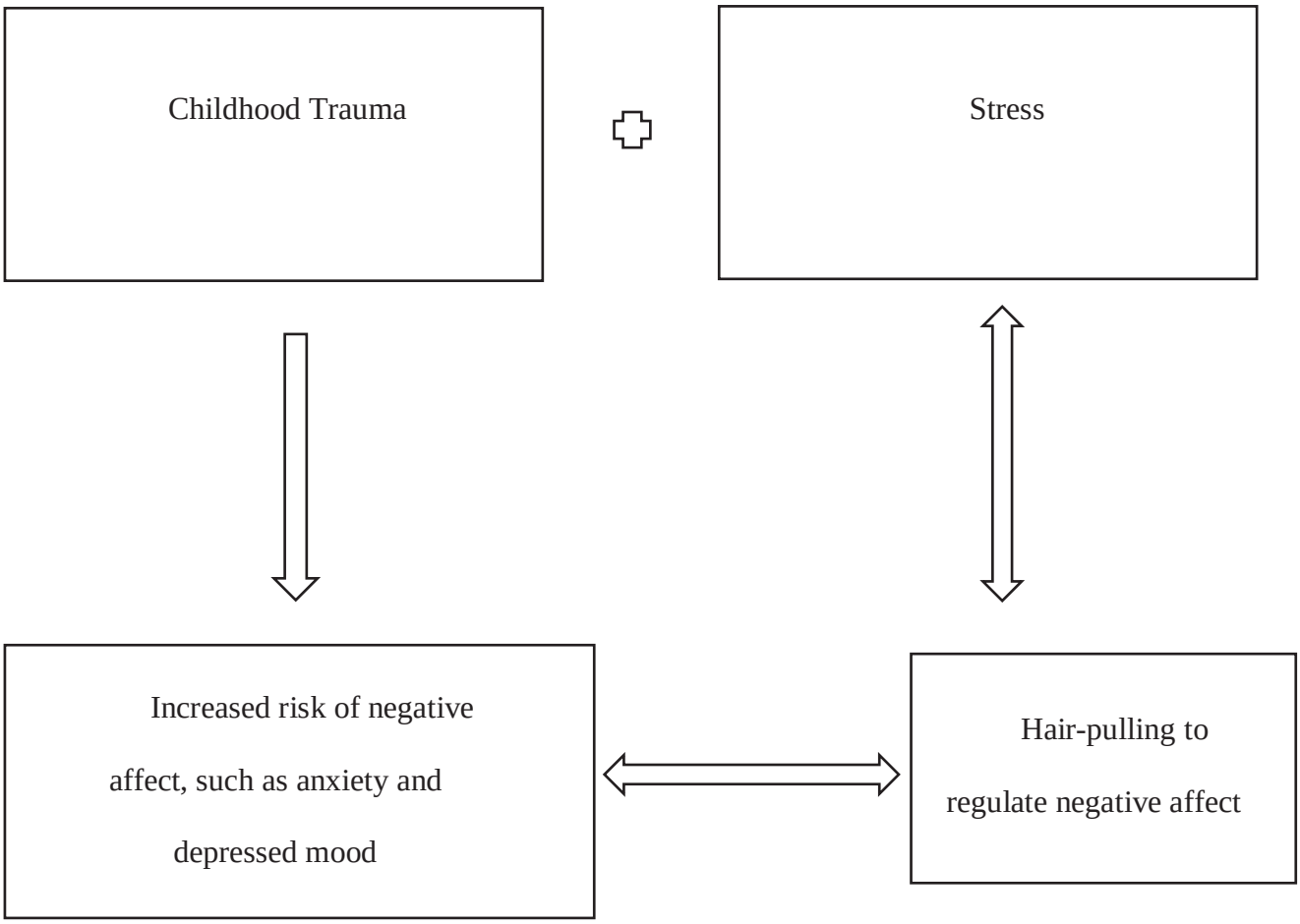

Figure 2.1: Diagram to show the relationship between childhood trauma, difficulties in ER, anxiety disorders and depression in TTM

Chapter Summary

This chapter reviewed the current and relevant literature on TTM, with reference to key concepts such stress, trauma history, ER, and psychiatric comorbidity. The ER model may be appropriate to explain the dynamics of TTM within this context. However, the tenuous relationship between these different variables is still unexplored, warranting further investigation.

CHAPTER 3
METHODOLOGY

Design and Setting

The study had a correlational research design. The research questions addressed by this study were:

1. *How do rates of stress, childhood trauma, and difficulties in ER in a TTM cohort compare to healthy controls?*
2. *Are difficulties in ER related to the severity of TTM?*
3. *What is the relationship between stress, childhood adversity, ER, and comorbid mood and anxiety disorders in individuals with a primary diagnosis of TTM?*

The data used in this study included:

- Secondary data from two larger on-going studies conducted at the MRC Unit on Risk and Resilience in Mental Disorders, at Stellenbosch University.
- Primary data collected from a subset of participants from the two larger studies.

The Secondary Data

The data from the two larger on-going studies were collected at the MRC Unit on Risk and Resilience in Mental Disorders at Stellenbosch University. The unit is under the directorship of Prof Dan J. Stein and the co-directorship of Prof Christine Lochner. The unit conducts a wide range of research studies, including clinical trials, laboratory work, animal models, genetics and brain imaging studies.

The first study from which data were obtained, the so-called "Genetics of Anxiety Disorders Study", commenced in 1999 and is still on-going (HREC SU reference no: 99/01; see Appendix C). This study primarily focuses on investigating the genetic variations in anxiety

disorders, a category which used to include OCD (DSM-IV). TTM is considered an OCD-related condition and is one of the many disorders investigated within this project.

The second study is titled "Delineating Endophenotypes of Obsessive-Compulsive Disorder (OCD) and Hair Pulling Disorder (Trichotillomania [TTM]): An Integrated Pharmacological, Neurocognitive, Genetic and Imaging Study" (UCT HREC reference no: 261/2007 and SU HREC reference no: M07/05/019; see Appendix D). This study first commenced in 2007 and is also on-going. This study is a case-control cross-sectional study in which participants are required to complete several rating scales and brain imaging scans [e.g. functional magnetic resonance imaging (fMRI)].

In combination, these two studies provided data on 91 individuals with TTM and 83 healthy controls (n = 174). They were all contacted with an invitation to take part in the present study. Data from 66 participants out of the 174 (51 TTM, and 15 healthy controls) were included as 47 participants were no longer contactable and 61 did not respond to follow-up.

From the existing datasets, I extracted data on:

- Demographics
- Current stress, using the PSS
- Childhood adversity, using the Childhood Trauma Questionnaire (CTQ)
- Hair-pulling severity, using the Massachusetts General Hospital Hair-pulling Scale (MGHHP) (TTM participants only)

The Primary Data

Following a careful screening of the secondary data, there were missing data on the measures of perceived stress (PSS), and childhood trauma (CTQ), for seven TTM participants. There were data on hair-pulling severity (MGHHP) for all the respective participants. CTQ and

PSS data were also collected from healthy controls. Therefore, as part of this study, the missing data were collected from the respective participants.

Data on difficulties in ER were not collected as part of the two larger studies. As such, primary data on the DERS were collected from all participants. The primary investigator applied for permission to collect these additional data from the Health Research Ethics Committee (HREC) at Stellenbosch University as an amendment to the original protocol of the "Genetics of Anxiety Disorders" study (26th April 2017, Ref no: 99/013; See Appendix E and F).

Procedure for the Collection of the Primary Data

In an effort to recruit participants, I put up posters and flyers containing information on the study and eligibility which were distributed on Stellenbosch University's main campus and the medical campus at Tygerberg. These flyers were also posted on social media (see Appendix G and H). The flyers and posters contained the contact details of the researchers.

Participants with TTM were deemed eligible for the study if they had pathological hair-pulling, irrespective of meeting Criteria B (urge before pulling) and Criteria C (pleasure, relief or gratification with pulling) of DSM-IV criteria for TTM (See Appendix B). The healthy controls were deemed eligible if they had no psychiatric disorder or diagnosis. Healthy controls were matched to TTMs in terms of sex and age. All participants provided informed consent before being included in the study.

I then followed up with the participants who responded to the flyers and posters myself. During the follow-up communication, participants were further informed about the details of the study. As such, participants were informed that their participation would entail:

- A once-off face-to-face structured interview with a clinical psychologist/research psychiatrist.

- The completion of the four self-report measures.

Participants who were willing to participate were informed about a time and place for the interviews. They were also given the informed consent form to complete before the interview (see Appendices I & J).

The participant's area of residence was considered to select an interview location that would be convenient, either at the Tygerberg campus or at Stellenbosch campus. The interviews were conducted by the primary investigator, Prof Christine Lochner, or by her colleague, Dr Karen Mare, a research psychiatrist. The participants were not reimbursed or incentivized for taking part in the study. Participation was completely voluntary.

The Interview

On the day of participation, participants took part in a semi-structured interview with either Prof Lochner or Dr Mare. The interview lasted about two hours and the following data were collected during the interview:

- Demographic information on current age, age of onset of primary disorder and/if any secondary comorbid psychiatric disorders, ethnicity, level of education, and employment status.
- Psychiatric and medical assessments were conducted using the Structured Clinical Interview, including family psychiatric history, as well as the treatment history of the participants.
- Participants were requested to complete the following self-report measures (when applicable): the DERS, PSS, CTQ, and the MGHHPs.

Data collection took place from the 7th of July 2017 until the 30th of April 2018. Twenty-one (21) additional participants were recruited (five TTM, and 16 sex-age matched healthy

controls). I included the additional participants in the final dataset, which finally comprised of data from 87 participants (56 TTM and 31 healthy controls).

Measures

Demographics

Demographics questionnaire. This questionnaire included information on current age, age of the onset of the primary disorder and/if any secondary psychiatric disorders, ethnicity, level of education, and employment status.

Psychiatric and medical assessments

Structured Clinical Interview for DSM-IV-TR Axis-I Disorders (SCID-I) and the Structured Clinical Interview for Obsessive Compulsive Spectrum Disorders (SCID-OCSD). The SCID is generally a semi-structured interview that assesses psychiatric disorders (Curley et al., 2016). It has been widely used in psychiatric research (Gorman et al., 2004). The SCID tests for DSM-IV Axis-I disorders and is known as the gold standard when measuring for psychiatric disorders (Lobbestael, Leurgans, & Arntz, 2011).

The SCID-I has demonstrated sound psychometric properties in several studies, with samples from hospital settings in Japan (Tomita et al., 2016), from a clinic in the Netherlands (Lobbestael et al., 2011), and at research centres in France, the UK, and the USA, to name a few (Gorman et al., 2004; Lobbestael et al., 2011; Spitzer, Williams, Gibbon, & First, 2005). Reliability refers to how consistent a scale measures a specific construct (Foxcroft & Roodt, 2013). Inter-rater reliability is usually assessed when investigating the psychometric properties of the SCID and it is often reported as a Kappa coefficient (Viera & Garrett, 2005). Reliability Kappa coefficients (*k*) between .41 and .60 are considered moderate, between .61 and .80 are

considered strong, and between .81 and .99 are considered almost perfect (Du Toit, Van Kradenburg, Niehaus, & Stein, 2001; Viera & Garrett, 2005). The SCID-I has demonstrated good inter-rater reliability (k = .72) between raters of videotaped interviews for outpatients from eight countries (France, Ireland, the USA, the UK, Portugal, Austria, Brazil, and Switzerland). The participants were recruited from antenatal clinics or childbirth preparation classes, where the researchers used the SCID-I to assess postnatal depression (Gorman et al., 2004). Good inter-rater reliability has also been found by Lobbestael et al. (2011) with Kappa values of .71 for inter-rater reliability. Additionally, in studies measuring major depression and generalized anxiety, the reliability Kappa coefficients have ranged between .93 and .95 (Gorman et al., 2004).

Validity refers to how well a measure assesses what it ought to measure (Foxcroft & Roodt, 2013). Kranzler, Kadden, Babor, Tennen, and Rounsaville (1996) investigated the validity of the SCID in patients with substance abuse (n = 100). The researchers found good to excellent validity for substance abuse disorders, moderate validity for major depression, and poor validity for anxiety (Kranzler et al., 1996). In addition, Shear et al. (2000) investigated the concordance of the SCID with a clinical diagnosis for participants from both urban (n = 50) and rural (n = 114) communities from Western Pennsylvania. The participants were nonpsychotic patients (n = 164) with primary Axis-I disorders, such as mood disorders (59%), anxiety disorders (14%), adjustment disorders (12%), and other Axis-I disorders (16%). Most of the patients met the DSM-V criteria using the SCID-I. In addition, the primary diagnosis and concurrent disorders were similar for rural groups and urban groups (Shear et al., 2000). A more recent study investigated the validity of the SCID-I and the SCID-II in a sample of veterans seeking treatment for substance use disorders (DeMarce, Lash, Parker, Burke, & Grambow, 2013). The researchers found strong concurrent, discriminant, and predictive validity of the SCID-I for substance use disorders. Another study (Drill, Nakash, DeFife, &

Westen, 2015) investigated the validity of the SCID and the Clinical Diagnostic Interview (CDI) in a sample of patients from the United States (n = 245), and found no significant differences between the two scales. Thereby, the assessments made using the CDI are valid against the SCID, and vice versa. However, there is currently limited research on the validity of the SCID. According to Spitzer et al. (2005), this is because the validity of SCID cannot easily be determined because the scale has been deemed the gold standard. Other scales of a similar nature are measured against or compared with the SCID to assess whether they match up with the scale (Tomita et al., 2016). Therefore, it is implied that the scale measures what it ought to measure as it is deemed the gold standard. Secondly, psychiatric disorders are not easily defined; which means assessing the validity of the SCID would be difficult (Spitzer et al., 2005).

In South Africa the SCID has been used in various studies (Campbell et al., 2017; Madigoe, Burns, Zhang, & Subramaney, 2017; Rochat, Tomlinson, Bärnighausen, Newell, & Stein, 2011). It was for example used to assess depression in perinatal women in rural South Africa (Rochat et al., 2011). Another example is a study that assessed schizophrenia and cultural beliefs in a Xhosa sample (Campbell et al., 2017). In South Africa specifically, the PTSD section of the SCID was used to assist with the design of a culturally sensitive scale for trauma in a Zulu sample based in Northeastern KwaZulu-Natal. The SCID had a Cronbach alpha of .88 for this specific sample (Madigoe et al., 2017). In another study the SCID-research version (SCID-RV) was used to investigate major depressive disorder (MDD) in a South African sample (n = 500). The researchers also conducted a pilot study where they found that the SCID was suitable for individuals living with HIV in South Africa (Saal, Kagee, & Bantjes, 2018). However, to my knowledge there are limited studies that assessed the psychometric properties of the SCID-I in South Africa. Despite the limitation of assessing the scale's validity,

the scale has sufficient support with regard to its psychometric properties, making it adequate for this study.

The SCID-OCSD is based on the SCID-I, and includes nine subscales that measure related obsessive-compulsive disorders that are not included in the SCID-I. The nine subscales are (1) Tourette's syndrome, (2) compulsive self-injury, (3) kleptomania, (4) pyromania, (5) pathological gambling, (6) compulsive buying, (7) hypersexual disorder, (8) intermittent explosive disorder, (9) and trichotillomania (Du Toit et al., 2001). The SCID-OCSD has also demonstrated strong Kappa coefficients ranging from .45 to .82 among 18 patients (Du Toit et al., 2001). However, there is not a lot of evidence on the psychometric properties of the SCID-OCSD specifically, as it is a new scale (Du Toit et al., 2001).

Self-report measures

Massachusetts General Hospital-Hair Pulling Scale (MGHHPS; see Appendix K). The MGHHPS is a self-report scale that measures the severity of hair-pulling with eight items. These items include: (1) frequency of urges, (2) intensity of urges, (3) ability to control the urges, (4) frequency of hair-pulling, (5) attempts to resist hair-pulling, (6) control over hair-pulling, (7) associated distress, (8) and consequences of hair-pulling. The items are ranked from a scale of zero (no symptoms) to four (severe symptoms) (Johnson & El-Alfy, 2016).

This instrument has illustrated good internal consistency, with a Cronbach alpha of .83 (Flessner et al., 2008). Internal consistency, a type of reliability, refers to how consistently the items on a scale correlate with one another when measuring a specific construct (Foxcroft & Roodt, 2013). In addition to this, in the study by Arabatzoudis et al. (2017), the researchers found a strong internal consistency with a Cronbach alpha of .91 for TTM participants (n = 20). It is important to note that the sample was predominantly female (90%), with males only making up 10%, which may skew the results. Subsequently, the majority of the participants

were from Australia (65%), with other nationalities being the UK (20%), Ireland (5%), South Africa (5%), Europe (5%), and Southeast Asia (5%) (Arabatzoudis et al., 2017).

Researchers have also found strong convergent validity and good divergent validity in a sample of predominantly Caucasian participants (87.4%) where the MGHHPS illustrated great test-retest reliability (Keuthen et al., 2007). Convergent validity means that the MGHHPS correlates highly with other measures or variables associated with hair-pulling; and good divergent validity means that it does not correlate with other measures or variables that are not associated with hair-pulling (Foxcroft & Roodt, 2013).

Diefenbach et al. (2005) also report that the MGHHPs has demonstrated strong convergent validity with other clinical hair-pulling scales, as well as strong divergent validity with depression and anxiety. However, for their study sample the MGHHPs did not significantly correlate with hair-pulling severity. With the inconsistency in findings, it is important to consider that the sample group determines the psychometric properties of the scale, and not the scale itself (Foxcroft & Roodt, 2013). Furthermore, despite the limited research on the psychometric properties of the MGHHPs in South Africa, the aforementioned findings indicate the validity and reliability of this scale to be adequate for research use.

For this study, items referring to urges to pull (items 1, 2, 3) were excluded when measuring severity of TTM, as not all of the participants reported that they experienced urges to pull. There are approximately a quarter of adults who report that they do not experience urges before hair-pulling or relief after hair-pulling (Bloch, 2009). Additionally, urges to pull do not indicate the actual severity of hair-pulling (which this study aimed to measure). This made it unnecessary to include urges to pull if some participants obtained scores of zero for this subsection. Therefore, items, 4, 5, 6, and 7 were used to measure TTM severity.

Perceived Stress Scale-10 Items (PSS-10; See Appendix M). The PSS is a self-report scale that measures an individual's appraisal of stressful events (Lee, 2012). The scale consists

of 10 items that are scored on a five-point Likert scale, with 0 = never, to 4 = very often (Reis et al., 2010). Four of the items are reversed scored (4, 5, 7, 8); therefore a score of 0 = 4 points (very often), and a score of 4 = 0 points (never), for example (Reis et al., 2010). The total score can range from 0 to 40, with a higher score indicating greater perceived stress (Reis et al., 2010).

The PSS is widely used in research and has been translated into approximately 25 languages (Lee, 2012). In a systematic review the psychometric properties of the scale across 19 studies, representative of the USA, Greece, Brazil, the UK, Canada, Japan, Spain, Mexico, China, Turkey, Thailand, and France, were explored. The PSS demonstrated excellent reliability in two studies from the UK (n = 285), and the USA (n = 60), Spain (n = 440), Turkey (n = 508), Brazil (n = 793), in two studies from China (n = 1 800; n = 240), in a study from Thailand (adults: n = 479, medical students: n = 368, patients: n = 111), Greece (n = 941), and a study from France (n = 501) ($\alpha > .80$) (Lee, 2012).

Additionally, the test-retest reliability coefficients for the PSS-10 were all above .70 (Lee, 2012). The criterion validity was also measured. The PSS either strongly or moderately correlated with items from the Beck Depression Inventory (BDI), State-Trait Anxiety Inventory (STAI), or the General Health Questionnaire (GHQ), to name a few. Validity in general was also assessed. However, there was an inconsistency in findings as scores were higher in females than in males in some studies, but not in others (Lee, 2012).

Furthermore, scores were lower in young, white, married, employed, high-income individuals, or in parents with fewer children (Lee, 2012). Although the PSS has not been widely used in the African context, Hamad, Fernald, and Zinman (2008) investigated the correlation between depressive symptoms and stress in a South African population group. Their sample consisted of low-income adults form Cape Town, Durban, and Port Elizabeth (n = 257).

The researchers found that the scale demonstrated a Cronbach alpha of .72 for the PSS within their sample group.

Despite some inconsistencies between studies, the psychometric properties of this scale justify the use of this scale for the sample in this study. Although the psychometric properties of the scale have not been investigated in South Africa, it can be assumed that the scale would have sound psychometric properties similar to the abovementioned countries. However, this will be determined by the sample for which the scale is used.

The Childhood Trauma Questionnaire-28 Items (CTQ-28; See Appendix L). The CTQ, created by Bernstein and colleagues (2003), is one of the most widely used scales internationally. It has been used in both clinical and non-clinical samples to investigate early childhood trauma, with over 1 000 citations (Bernstein et al., 2003; MacDonald et al., 2016; Matthews et al., 2008; Viola et al., 2016). The scale consists of five subscales, which include (1) emotional, (2) sexual, and (3) physical abuse, as well as (4) emotional and (5) physical neglect. The scale originally consisted of 70 items, but has been shortened to 28 self-report items, with a five-point Likert scale ranging from 1 = never true to 5 = very often true (MacDonald et al., 2016; Viola et al., 2016). The total score of each subscale can be classified as either none to minimal, low to moderate, moderate to severe, or severe to extreme (MacDonald et al., 2016). For example, for the emotional abuse subscale, a score of 8 or below is considered none to minimal, a score between 8 and 12 is considered low to moderate, a score between 12 and 15 is moderate to severe, and above 16 is severe to extreme (MacDonald et al., 2016). Furthermore, a total score of the subscales combined can range from 25 to 125 to determine severity (Viola et al., 2016).

In a study by Paivio and Cramer (2004), the researchers investigated the psychometric properties of the CTQ-SF with students (n = 87) from the Psychology Department at the University of Winsdor. The reliability coefficients ranged between Cronbach alphas of .70 to

.93, with physical neglect having the lowest score of .75. However, despite this, emotional abuse was .86, emotional neglect .97, physical abuse .84, and sexual abuse .92, with a total reliability coefficient of .96. The researchers also found strong internal validity for the scale with a Cronbach alpha of .96 (Paivio & Cramer, 2004; Ritacco & Suffla, 2012).

The scale also demonstrated good criterion-related validity in psychiatric patients, with a good internal consistency of .83 to .80 for physical abuse, .84 to .89 for emotional abuse, .92 to .95 for sexual abuse, .91 to .78 for physical neglect, and .85 to .91 for emotional neglect (Bernstein et al., 2003; Thombs, Bernstein, Lobbestael, & Arntz, 2009). In addition, according to Ritacco and Suffla (2012), the CTQ has demonstrated sound psychometric properties when used in different groups in cross-cultural settings. However, in South Africa, the CTQ has not been used in research for child maltreatment, but rather on HIV risk behaviours and violence against women (Ritacco & Suffla, 2012). Despite this, the scale has demonstrated sound psychometric properties within various sample groups. For example, in a Dutch sample (n = 488), the Cronbach alphas ranged between .63 and .95 where the participants were either recruited from prisons, psychiatric hospitals, mental health clinics, and forensic clinics, or were non-patients (Paivio & Cramer, 2004; Ritacco & Suffla, 2012; Thombs et al., 2009). Another example could include the study by Paivio and Cramer (2004), where the CTQ had Cronbach alphas ranging between .70 and .93 in a sample of 470 Canadian university students. These examples show that it is applicable for use in South Africa, where there are various cultures. Based on the scale's wide use, its multidimensional assessment of childhood trauma, and its sound psychometric properties, the CTQ is an appropriate instrument for this study.

Difficulties in Emotion Regulation Scale-36 items (DERS-36, See Appendix N). The DERS is a commonly used self-report scale, introduced by Gratz and Roemer in 2004 (Bardeen, Fergus, & Orcutt, 2012). The scale consists of 36 items, which are categorized into

six dimensions (Roberts et al., 2015). These include (1) non-acceptance of emotional responses, (2) difficulties engaging in goal-directed behaviour, (3) impulse control difficulties, (4) lack of emotional awareness, (5) limited access to effective ER strategies, (6) and lack of emotional clarity (Roberts et al., 2015). According to Bardeen et al. (2012), most researchers will assess the level of emotional regulation by using the total score of the DERS.

The scale has evidence supporting a strong internal consistency with Cronbach alphas ranging between .80 and .93 in a sample of 45 female undergraduates from Midwestern University (Bardeen et al., 2012; Roberts et al., 2015). Although this study only included females, in another study (Gratz & Roemer, 2004), no significant difference was found in age, gender, and race in a sample of 357 undergraduate students from the University of Massachusetts, Boston. Furthermore, the construct validity as well as predictive validity were clinically significant for the DERS within the sample group. Good internal consistency for the subscales has also been reported with a Cronbach alpha of more or less .80 (Roberts et al., 2015). Additionally, the scale has a good test-retest reliability of .88 between four to eight weeks (Roberts et al., 2015). The DERS has also shared a significant correlation with a history of childhood emotional abuse (except for one subscale: Awareness). However, it is important to consider the sample from which the psychometric properties have been obtained. Therefore, based on the aforementioned findings, this scale will be used as a result of its wide use, and consistently sound psychometric properties.

Data Analysis

The data were analysed using the 22nd version of the Statistical Package for the Social Sciences (SPSS v. 22).

Descriptive Analysis. The available data were checked for missing values, as well as for normality by assessing skewness with histograms, as well with the use of the Shapiro-Wilks

test for normality. Thereafter, measures of central tendency (i.e. mean), as well as measures of dispersion (i.e. range, and standard deviation) were calculated for each group based on the demographic data obtained. The reliability for the questionnaires and their subscales were also measured using Cronbach's alpha.

Aim One. To compare stress, childhood trauma, and difficulties in ER between patients with TTM and healthy controls.

Null hypothesis: There are no significant differences in the rates of difficulties with emotion regulation, stress, and childhood trauma between TTM patients and healthy controls.

The data were not normally distributed for the DERS total score and DERS subscale scores, as well as for the CTQ total scores and the CTQ subscale scores. Therefore, the Mann-Whitey U test was used to compare the mean ranks between two independent groups (Field, 2009). The mean rank of the DERS total score and DERS subscale scores were compared between TTM participants and the healthy controls. The mean ranks of the CTQ total scores and the CTQ subscale scores were compared between TTM participants and the healthy controls. The data for the PSS total score were normally distributed and therefore a one-way ANOVA was used to compare the mean differences of the PSS total scores between the TTM participants and the healthy control cohort.

Aim Two. To investigate the relationship between hair-pulling severity and difficulties in ER.

Null hypothesis: There is no significant relationship between hair-pulling severity and difficulties with emotion regulation.

The data for both the MGHHP total score and the DERS total score were not normally distributed. Therefore, a Spearman rank correlation was used to investigate whether there was a correlation between the MGHHP total score (of items 4, 5, 6, & 7) with the DERS total score.

This analysis was used to assess whether there was a correlation between hair-pulling severity and difficulties in ER.

Aim Three. To assess the relationship between stress, childhood trauma, and ER difficulties in TTM while controlling for the presence of comorbid mood and anxiety disorders.

Null hypotheses:

1. *Stress, Childhood trauma, and ER difficulties in TTM, while controlling for the presence of comorbid mood and anxiety disorders, will not correlate significantly.*
2. *In linear combination, stress and childhood trauma, while controlling for the presence of comorbid mood and anxiety disorders, will not significantly predict ER difficulties in TTM.*

A hierarchical regression was used to assess the relationship between several independent variables and a dependent variable (Richardson, Hamra, MacLehose, Cole, & Chu, 2015). The independent variables were the CTQ total score, the PSS total score, and psychiatric comorbidity. Last, the outcome variable used in the respective analyses was the DERS total score, which was on an interval scale. The CTQ total score and the PSS total score were on an interval scale and psychiatric comorbidity was on a categorical scale. Psychiatric comorbidity were grouped into lifetime anxiety disorders, which included social anxiety disorder, panic disorder, panic attacks without agoraphobia, general anxiety disorder, PTSD, and specific phobias. The second group was lifetime mood disorders including MDD and bipolar disorder. Although categorical variables are not usually used in regression, in the social sciences these variables frequently occur. Therefore, the use of this data was enabled by creating *dummy* variables during the regression analyses for the present study. Here, dummy coding was done by assigning a numerical value to categorical variables (Holgersson, Nordström, & Öner, 2014). Data were coded as no = 0 and yes = 1 to indicate whether the participant did not have (variable = 1) or had (variable = 2) lifetime mood and/or anxiety disorders, allowing for

regression analyses between the relevant variables. A regression analysis was used to estimate the relationship between PSS and CTQ (independent variables) and DERS (dependent variable), while controlling for lifetime mood and anxiety disorders.

Chapter Summary

This chapter discussed the study design and research procedures used. The procedures included the participants and eligibility criteria, the recruitment and data collection, the measures, and the data analyses used.

CHAPTER 4
RESULTS

Sample Characteristics

The study included 56 participants with a primary diagnosis of TTM and 31 sex- and age-matched healthy controls. The majority of the sample was female (92%). The age distribution in the two groups were comparable: in the TTM group 91.1% were female and 8.9% male and in the healthy control group, 93.5 % were female and 6.5% male. The mean age of the sample was 33.72 years (TTM mean age = 36.04 *SD* = 14.55; healthy control mean age = 29.61, *SD* = 9.78) (see Table 4.1 below). The population of the sample group consisted of 85.6 % Caucasians and 14.3% non-Caucasians. In addition, the onset of TTM was at a mean age of 13.98 years (*SD* = 5.72).

Table 4.1:

Demographic Characteristics of the TTM Patients and the Healthy Controls

	TTM		HC		
	Frequency (n = 56)	Percentage (%)	Frequency (*n* = 30)	Percentage (%)	*p*
Age (*M*)	36.04 (*SD*: 14.55)		29.61 (*SD*: 9.78)		.03
Gender					.69
Male	5	8.9	2	6.5	
Female	51	91.1	29	93.5	
Population group					.54
Caucasian	48	85.6	26	83.9	
Non-Caucasian	8	14.3	4	12.9	
Level of education					.82
Grade 12 or less	12	21.4	8	26.7	
College/Technicon	8	14.3	4	13.3	
University	35	62.5	18	60	
Lifetime mood disorders	29	51.8			
Lifetime anxiety disorders	27	48.2			

Note. M is the mean, SD is the standard deviation and HC is healthy controls

Reliability of Measures

Cronbach's alpha was used to measure internal consistency. This measure is a widely used measure of reliability (Taber, 2017). Cronbach alphas above .70 are deemed acceptable coefficients for internal consistency (Taber, 2017). As can be seen from Table 4.2, the internal consistency of the DERS was high for this sample group, (α = .95). However, the internal consistency of one DERS subscale (clarity) was low (α = .18). The internal consistency of the MGHHPS (α = .71) and the CTQ (α = .79) was satisfactory. One of the CTQ subscales (i.e. physical neglect) had a low alpha coefficient (α = .12). The PSS had a high Cronbach alpha of .89 for this study sample.

Table 4.2:

Reliability Coefficients of the Scales and Subscales Used in this Study

	α
CTQ Emotional Neglect	.87
CTQ Emotional Abuse	.83
CTQ Physical Neglect	.12
CTQ Physical Abuse	.84
CTQ Sexual Abuse	.87
CTQ Total	.79
DERS Non-acceptance	.94
DERS Goals	.52
DERS Impulse	.58
DERS Awareness	.83
DERS Strategies	.65
DERS Clarity	.18
DERS Total	.95
PSS Total	.89

Note. CTQ is the Childhood Trauma Questionnaire; DERS is the Difficulties with Emotion Regulation Scale; and PSS is the Perceived Stress Scale.

Inferential Statistics

Aim One. To compare rates of stress, childhood trauma, and difficulties in ER between patients with TTM and healthy controls.

Hypothesis 1 (Ho): There are no significant differences in the levels of stress, childhood trauma, and difficulties in ER between participants with TTM and healthy controls

In order to address this hypothesis, the Mann-Whitney U Test was used to assess the difference in mean ranks of the CTQ total score, the CTQ subscale scores, the DERS total scores, and the DERS subscale scores between individuals with TTM and the healthy control cohort.

As can be seen in Table 4.3, the DERS total scores were significantly higher for the TTM cohort (mean rank = 50.34) compared to the healthy control cohort (mean rank = 32.55); $U = 513.00$, $p = .002$.

The mean rank of the CTQ total score was significantly higher in the TTM cohort (mean rank = 48.46) compared to the healthy control cohort (mean rank = 35.94*) (U = 618.00, p =* .03). The CTQ EA subscale was significantly higher in participants with TTM (mean rank = 48.57) compared to the healthy controls (mean rank = 35.74) ($U = 612.00$, $p = .02$). The CTQ EN subscale was also significantly higher in the TTM participants (mean rank = 50.38) compared to the healthy controls (mean rank = 32.48); $U = 511.00$, $p = .001$.

Lastly, a one-way ANOVA was used to investigate the differences in stress between TTM and healthy control participants. There was a statistically significant difference between TTM ($M = 18.38$, $SD = 7.37$) and the healthy controls ($M = 14.47$, $SD = 8.01$) ($F(1, 84) = 5.12$, $p =$. 03), with the TTM patients reporting higher stress levels than the healthy controls (See Table 4.3 & 4.4).

Table 4.3:

The Mean Rank Differences in the DERS Total, DERS Subscales, the CTQ Total and CTQ Subscales in TTM Participants Compared to the Healthy Controls

	TTM (*n* = 56)		**HC (*n* = 31)**			
	Mean Ranks	Sum of Ranks	Mean Ranks	Sum of Ranks	*U*	*p*
DERS (Total)	50.34	2819.00	32.55	1009	513.00	.00**
Non-Acceptance	48.42	2711.50	36.02	1116.50	620.50	.03
Goals	49.96	2797.50	33.24	1030.50	534.50	.00*
Impulse	49.45	2769.00	34.16	1059.00	563.00	.01*
Awareness	46.29	2592.00	39.87	1236.00	740.00	.26
Strategies	50.27	2815.00	32.68	1013.00	517.00	.00*
Clarity	46.19	2586.50	40.05	1241.50	745.00	.28
CTQ (Total)	48.46	2714.00	35.94	1114.00	618.00	.03*
Emotional Abuse	48.57	2720.00	35.74	1108.00	612.00	.02*
Emotional Neglect	50.38	2821.00	32.48	1007.00	511.00	.00***
Physical Abuse	45.93	2572.00	40.52	1256.00	760.00	.28
Physical Neglect	44.98	2586.50	40.05	1241.50	813.00	.58
Sexual Abuse	44. 63	2499.00	42.87	1329.00	833.00	.68

Note. * represents statistical significance, where p <0.05, ** represents p < 0.01, and *** is p < 0.001. DERS is the Difficulties with Emotion Regulation, and CTQ is Childhood Trauma Questionnaire. HC is healthy controls.

Table 4.4:

Comparison of PSS Total Score between TTM Participants and the Healthy Controls

	TTM (*n* = 56)		**HC (*n* =31)**		
	M	*SD*	*M*	*SD*	*P*
Perceived stress (Total)	18.38	7.37	14.47	8.01	.026*

Note. * represents statistical significance, where $p < 0.05$, *M* is the mean, *SD* is the standard deviation, and HC is healthy controls.

Aim two. To investigate the relationship between hair-pulling severity and difficulties in ER.

Hypothesis 2 (Ho): There is no significant relationship between hair-pulling severity and difficulties in ER

The data were checked for normality and were not normally distributed; therefore the Spearman rank correlation was used to investigate the relationship between MGHHPs total score with the DERS total score. As can be seen in Figure 4.1, there was no statistically significant relationship between difficulties in ER and hair-pulling severity in this cohort (r = -.0.03, p = 0.85).

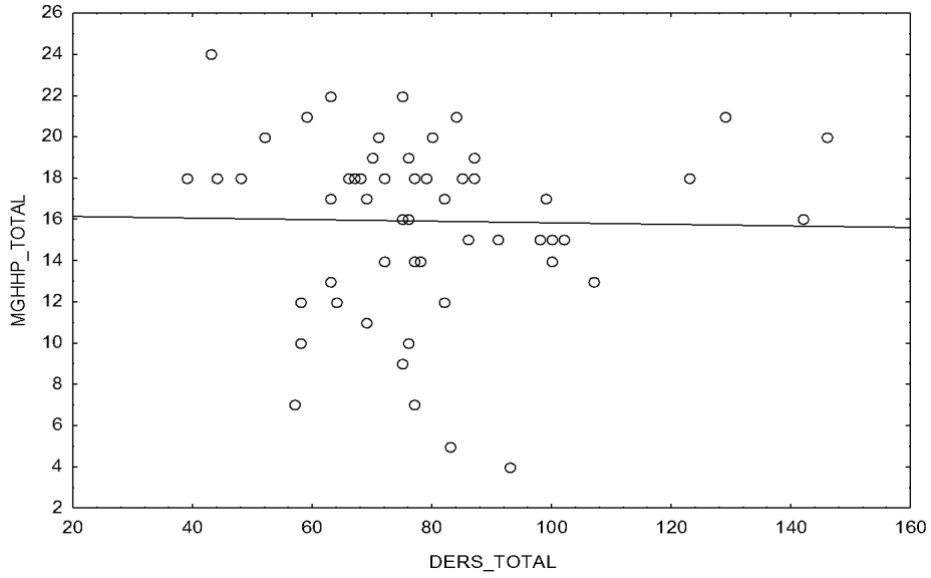

Figure 4.1: Scatter plot of the correlation between the DERS total scores and the MGHHP total scores

Note. DERS total score is the total score of the Difficulties in Emotion Regulation Scale, and the MGHHP total score is the total score of the Massachusetts General Hospital Hair-pulling Scale, where $p > .05$

Aim Three. To assess the relationship between stress, childhood trauma and ER difficulties in TTM, while controlling for the presence of comorbid mood and anxiety disorders.

Hypothesis 3 (Ho): Stress, childhood trauma, and ER difficulties in TTM, while controlling for the presence of comorbid mood and anxiety disorders, will not correlate significantly.

Hypothesis 4 (Ho): In linear combination, stress and childhood trauma, while controlling for the presence of comorbid mood and anxiety disorders, will not significantly predict ER difficulties in TTM.

Assumptions of a hierarchical regression. Before a hierarchical regression could be conducted, a few assumptions had to be met. The first assumption was the assumption of normality, which means that the residuals are normally distributed or form a bell shape. P-Plots were used to assess normality (Jeong & Jung, 2016). When looking at the P-Plot below (Figure 4.2), although there is some diversion from the diagonal line, the residuals are relatively close to the diagonal line.

The second assumption was the assumption of linearity where the relationship between the independent variable and dependent variable are expected to be linear. This occurs when there is a random pattern between the standardized residuals and standardized estimates of the dependent variable (Jeong & Jung, 2016). See figure 4.3, which illustrates that the assumption has been met.

The third assumption of no multicollinearity was also met. Multicollinearity occurs when there is a strong correlation between two or more predictor variables (Field, 2009). For a hierarchical regression, the predictors should not correlate greatly, as it would be difficult to assess the influence of a specific predictor on the outcome variable. To assess for this, the variance inflation factor (VIF) was used. VIF indicates whether there is a strong linear relationship between a predictor variable with other predictor variables. The VIF should not be higher than 10 (Field, 2009; Jeong & Jung, 2016). For this study, the VIFs were all below 10, which indicates that the assumption of multicollinearity was met.

The last assumption that was met was the assumption of homoscedasticity, which is when the variances of the residuals are equal or constant. This can be seen by means of a graphical representation where the residuals are scattered around the zero point (Field, 2009). Figure 4.3 illustrates that the assumption of homoscedasticity was met.

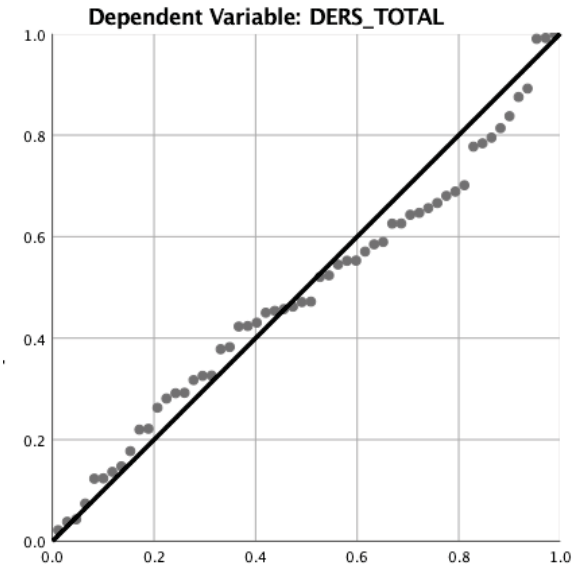

Figure 4.2: Normality P-Plot demonstrating the normal distribution of the residuals from the DERS total score

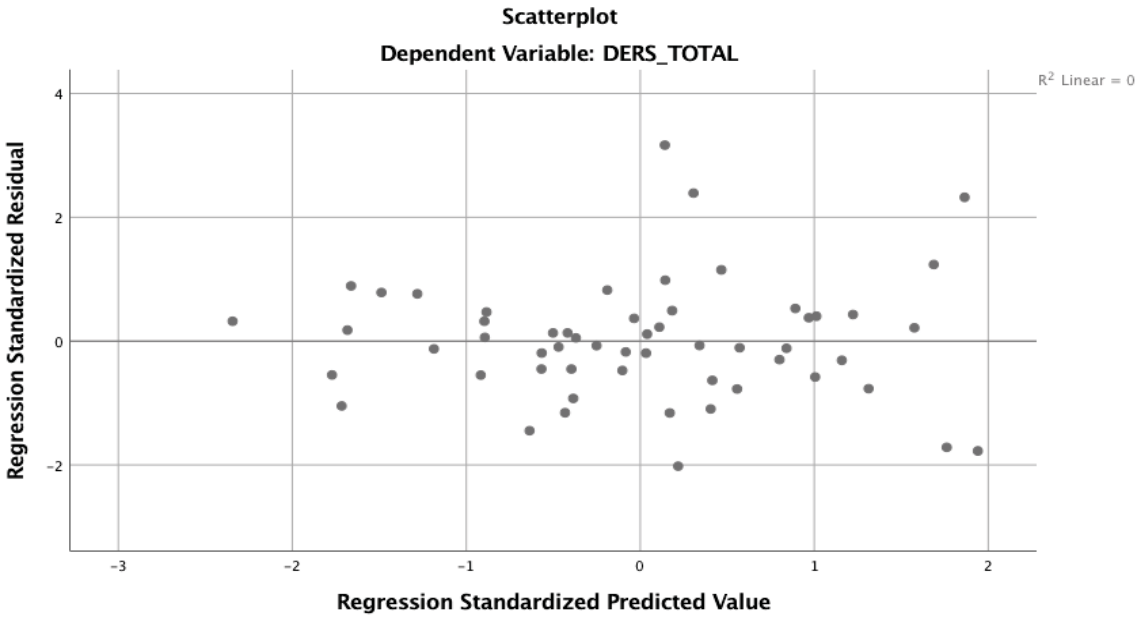

Figure 4.3: Scatterplot to illustrate homoscedasticity amongst residual variances of the final regression model

Correlations between stress, childhood trauma, and difficulties in ER. The highest correlation was between the PSS total score and the DERS total score, $r = .50$, $p < 0.05$. Second, there was also a significant correlation between the total CTQ score and the PSS total score ($r = .29$). (See table 4.5 below).

Table 4.5:
Correlations between Childhood Trauma, Perceived Stress, and Difficulties in ER in the TTM Cohort

	Difficulties with Emotion Regulation Scale	**Perceived Stress Scale**	**Childhood Trauma Questionnaire**
Difficulties with Emotion Regulation Scale	1	.504**	.152
Perceived Stress Scale	.504***	1	.294*
Childhood Trauma Questionnaire	.152	.294*	1

Note. *r* represents correlation coefficient; * represents statistical significance where $p < 0.05$, ** represents $p < 0.01$, and *** represent $p < 0.001$

The relationship between stress and childhood trauma, and difficulties in ER in TTM. A hierarchical regression was used to investigate whether stress and childhood trauma play a role in ER difficulties (the outcome variable, as measured using the DERS) while controlling for the potential influence of lifetime anxiety and mood disorders. The independent variables were the CTQ and the PSS total scores.

In the first step of the hierarchical regression, the variables that are controlled for are usually inserted first. The variables that were controlled for were lifetime anxiety disorders and lifetime mood disorders. The linear combination of these variables did not significantly explain the outcome of the DERS total score.

In the second step, the two main variables of interest, i.e. the PSS and the CTQ total scores, were entered. The linear combination of these two predictors explained 28.7% of the variance of the DERS total (F (2. 51) = 7.00, $p < 0.01$). In the final adjusted model only one of the predictor variables (PSS total score) was statistically significant, i.e. the PSS total score had the highest Beta value ($\beta = .47$, $p < 0.001$) (see Table 4.6 and Table 4.7). Therefore, out of all the variables combined, stress was the only variable that significantly influenced the variance of difficulties in ER (see Table 4.7).

Table 4.6:

Model Summary with Difficulties in Emotion Regulation as a Criterion Variable

	Model	***R***	***R²***	***Adjusted R²***	***F Change***	***Sig.Δ F***
DERS	1	.301[a]	.091	.056	2.640	.081
	2	.535[b]	.287	.231	7.002	.002*

Note. * represents statistical significance, where $p < 0.05$; R^2 is the amount of variance between predictor variables; ΔR^2 is the additional (change) variance in the dependent variables.

Model 1 included: lifetime mood disorders and lifetime anxiety disorders, with the DERS total score as the outcome variable

Model 2 included: the CTQ total score and the PSS total score, with the DERS total score as the outcome variable

Table 4.7:

Model 1: The Relationship between Childhood Trauma, Stress, Lifetime Anxiety and Mood Disorders, and Difficulties with Emotion Regulation

	Unstandardized coefficients		**Standardized coefficients**		
Model	β	Standard Error	β	*T*	*p*
Step 1					
Constant	54.99	11. 57		4.75	.00***
Lifetime anxiety disorders	11.44	5.80	.26	1.97	.54
Lifetime mood disorders	4.67	5.79	.107	.806	.424
Step 2					
Constant	43.62	13.07		3.34	.00**
Lifetime anxiety disorders	7.55	5.52	.17	1.37	.18
Lifetime mood disorders	3.28	5.51	.08	.60	.55
Perceived Stress Scale	1.40	.375	.47	3.73	.00***
Childhood Trauma Questionnaire	-.13	.257	-.07	-.50	.62

Note. * represents statistical significance, where $p < 0.05$; ** represents $p < 0.01$, and *** represents $p < 0.001$.

Chapter Summary

The study findings suggested that total scores on the PSS, CTQ, and the DERS were significantly higher in the TTM cohort compared to the healthy controls. In terms of the childhood trauma subtypes, EN and EA were significantly higher in the TTM cohort compared to the healthy controls. There was no significant relationship between emotion regulation difficulties and hair-pulling severity. Lastly, stress and childhood trauma significantly explained 28.7% of the variance in ER difficulties. However, stress was the only variable investigated here that significantly positively correlated with emotion regulation difficulties in the TTM cohort. The study findings will be discussed in the following chapter, with reference to the ER model.

CHAPTER 5
DISCUSSION

The aims of this study were threefold. First, I wanted to investigate whether adults with TTM had increased levels of stress, childhood trauma, and ER difficulties compared to healthy individuals. Second, I aimed to determine whether hair-pulling severity in this TTM cohort correlated with difficulties in ER. Finally, I aimed to assess whether stress levels and the presence of childhood trauma had an impact on patients' ability to regulate their emotions while controlling for the influence of lifetime mood and anxiety disorders. The study findings suggested that, compared to sex- and age-matched healthy controls, adults with TTM presented with increased levels of stress, significantly more trauma in their childhood, and increased difficulties in ER. Hair-pulling severity had no significant relationship with ER difficulties. Controlling for the influence of lifetime anxiety disorders and depression, I found that a combination of stress and childhood trauma partially accounts for ER difficulties in TTM, with stress being the only variable that significantly influenced the variation in ER difficulties.

Difficulties with Emotion Regulation

Difficulties in ER was the primary outcome variable investigated in this study. Previous research on ER in TTM participants has indicated that individuals with TTM have greater difficulty regulating their emotions compared to healthy controls (Arabatzoudis et al., 2017; Weidt et al., 2016). This finding is consistent with my results that suggest that difficulties in ER are significantly higher in TTM participants compared to the healthy controls.

Arguably, individuals with TTM experience emotions more intensely than the healthy controls (Diefenbach et al., 2008; Shusterman et al., 2009). So in keeping with the ER model, one would expect that if pulling is used as an attempt to regulate emotions, increased pulling severity would be associated with improved emotional states (e.g. feeling more calm). This

hypothesis stands in contrast to previous studies that have found that the more severe the hair-pulling, the more difficulty the individuals actually had in regulating their emotions (Curley et al., 2016; Shusterman et al., 2009). My findings also did not support the ER hypothesis, where TTM severity did not correlate with the level of ER difficulties in my TTM cohort. These inconsistencies suggest that there may be a more complex interaction between these variables or that another model may be more suitable to explain the dynamics of pathological hair-pulling. Considering the other variables investigated here – i.e. stress, childhood trauma, and comorbidity – further exploring the extent to which the ER model fits the TTM framework could be helpful.

Childhood Trauma and Stress

Childhood trauma levels were also significantly higher in the TTM participants compared to the healthy control cohort. This finding is consistent with other studies pointing to an increased level of adversity history in patients with TTM (e.g. Lochner et al., 2002; Matthews et al., 2008; Özten et al., 2015). More specifically, the levels of emotional neglect (EN) and emotional abuse (EA) were significantly higher in the TTM cohort compared to the healthy control cohort. This finding is partly consistent with the study by Lochner et al. (2002), where EN was significantly higher in both the TTM and OCD participants compared to the healthy controls. In the study by Özten et al. (2015), the researchers also found significant differences in childhood trauma in the TTM cohort compared to the healthy controls. However, these differences were neglect, abuse, and sexual abuse; the researchers did not specify the type of neglect or abuse. The researchers also measured trauma differently to this study, using a list of traumatic experiences. Indeed, evidence for the role of trauma, and childhood trauma in particular, in TTM is not conclusive. Some have even argued that this relationship is a tenuous one (Houghton et al., 2016; Shusterman et al., 2009). Notably, the relationship between

childhood trauma and pathological hair-pulling is not causal and is rather an indirect one (Houghton et al., 2016; Özten et al., 2015). Also, increased childhood trauma is not particular to TTM, but rather to TTM and many other psychiatric disorders, such as OCD and PTSD.

In terms of studies that investigated the relationship between childhood trauma and ER difficulties, there was one (Choi et al., 2014) that found that EA along with physical abuse (PA) were significantly related to difficulties in ER. Another study found that EA explained significantly more of the variance in difficulties in ER compared to other instances of trauma such as sexual abuse and PA (Burns, Jackson, & Harding, 2010). However, childhood trauma in general and trauma subtypes were not predictive of difficulties in ER in my TTM cohort.

In the present study, stress levels were significantly higher in TTM patients compared to the healthy controls. This finding may tie in with claims that individuals with TTM find it more difficult to tolerate discomfort or distress and are thus more stressed in general compared to healthy controls (Arabatzoudis et al., 2017). Notably, causality cannot be inferred from this particular finding. However, it may be postulated that a cyclical relationship exists: individuals pull hair more often when stressed, and pulling and its sequalae (thinning hair, baldness, embarrassment and shame, for example) may in turn create even more stress, to some extent in keeping with the ER model in TTM.

The Association between Stress, Childhood Trauma, and Emotion Regulation in TTM

In the present study it was shown that the linear combination of stress and childhood trauma significantly explained 28.7 % of the variance in difficulties in ER in participants with TTM. In addition, I also found that stress was the only variable that had a significant positive influence on the variance in ER difficulties in the TTM participants ($\beta = .47$, $p < 0.001$). These findings suggest that stress, and not childhood trauma, is the primary contributor to difficulties in ER in this cohort of TTM patients. In the present study, childhood trauma severity was also

not specifically correlated with ER difficulties. Increased levels of stress on the other hand seem to play a stronger predictive role in the higher levels of difficulties in ER experienced by my TTM cohort. It would be important to investigate whether this relationship between stress and emotion dysregulation is particular to TTM or whether the association would be found in other conditions such as other anxiety related disorders (and even healthy controls) as well.

However, an association between stress and childhood trauma was found. My findings suggest that childhood trauma was significantly and positively correlated with stress in TTM patients. This correlation was moderate in strength and may partly support the premise that hair-pulling may be one way of coping with stress and/or emotional consequences of childhood trauma. The relationship or dynamics between stress, childhood trauma and difficulties in ER are not fully delineated, however, and the role that hair-pulling plays in this triangle, remains unclear.

As illustrated in fig. 2.1, I hypothesised that a combination of stress and trauma (while controlling for the presence of anxiety disorders and depression) would explain difficulties in ER in individuals with TTM. While the combination of stress and trauma explained some of the variance in ER difficulties, stress alone was the only significant predictor of ER difficulties.

Comorbid Anxiety and Mood Disorders

Psychiatric comorbidity is common in TTM. More than half of my TTM sample had a lifetime history of mood and/or anxiety disorders. Consideration of such comorbidity may assist in disentangling the complex association between stress, childhood trauma, and ER in TTM. Indeed, the potential influence mood disorders (depression, for example), and anxiety disorders (panic disorder, for example) may have on the relationship between stress, trauma, and hair-pulling severity has been questioned (Grant et al., 2015; Houghton et al., 2016). As a result, there is a study that suggests that depression plays a mediating role in the relationship

between trauma and hair-pulling severity (Houghton et al., 2016). In the study by Houghton et al. (2016), the researchers found that the relationship between trauma and hair-pulling severity was mediated by depression. Anxiety was not measured as a mediator variable as the researchers found that it was not significantly associated with trauma. To assess mediation, the researchers used Baron and Kenny's mediation test.

In another study by Arabatzoudis et al. (2017) depression did not significantly mediate the relationship between emotion regulation and hair-pulling severity. In the study by Sundermann and DePrince (2015) anxiety significantly influenced the variance in ER difficulties in TTM. Evidently, there is a discrepancy in the literature regarding the extent to which mood and anxiety disorders influence ER difficulties in TTM. Rather than controlling for the presence of mood and anxiety disorders, as done in this study, future studies may benefit from mediation analysis.

Limitations

There were a few limitations to this study. Firstly, rather than control for the presence of mood and anxiety disorders a mediation analysis was needed to determine the extent to which these disorders mediated the relationship between stress, childhood trauma, and ER in TTM. However, this study did not conduct a mediation analysis, as the primary aim was to assess ER difficulties in TTM, independent of other psychiatric conditions. Secondly, the data used in this study were collected at different time points. This could limit the validity of the findings due to environmental and physical factors (e.g. age) that may contribute to different responses previously in 2007, compared with the current responses. The collection of data at different time points was a result of missing data from the participants already included in previous studies, as well as the recent administration of another scale, the DERS, to a subset of participants. The DERS enabled the present analysis and thus benefited the current

investigation. Thirdly, majority of the scales used were all self-report measures, which may increase the risk of response bias, for example to increase social desirability (Foxcroft & Roodt, 2013; van de Mortel, 2008). Nevertheless, these questionnaires are well-established measures with good statistical properties. Fourthly, there was a relatively small number of healthy controls in comparison to the TTM participants; which could potentially limit the validity of the findings. Time constraints affected my ability to recruit additional healthy controls. Finally, the majority of the sample was made up of females. However, the high percentage of females is consistent with current knowledge, suggesting a 9:1 female to male ratio in TTM (Grant & Chamberlain, 2016; Meunier et al., 2009).

Conclusions and Recommendations

In conclusion, this was one of the first studies to explore the association of difficulties in ER, stress and childhood trauma in TTM. The findings suggested significantly increased stress, childhood trauma, and difficulties in ER in individuals with TTM compared to the healthy controls. My findings did not show a significant association between hair-pulling severity and difficulties in ER, to some extent contradicting the theory that hair-pulling may function as an emotion regulating strategy. However, it may be postulated that a cyclical relationship exists: individuals pull hair more often when stressed and pulling and its sequelae may in turn create even more stress, in keeping with the ER model in TTM. Notably, however, the finding of no correlation between hair-pulling severity and difficulties in ER, in combination with the finding that suggests that stress significantly explains some of the variation in ER, suggests that stress and difficulties in ER are more closely related with one another than hair-pulling and difficulties in ER. Further research into the underlying mechanisms and dynamics of ER in TTM, and also of the association of pulling with stress and trauma history, is warranted. In the clinic, emphasis should be placed on the assessment of

difficulties in ER in patients with TTM, and on addressing modifiable features associated with such difficulties (such as stress), in addition to reducing hair-pulling, respectively.

Chapter Summary

This study investigated the role of stress and childhood trauma in ER difficulties in TTM. The ER model was also used to understand the study findings with reference to current literature. The study findings indicate that despite significantly higher levels of ER difficulties in the TTM cohort compared to the healthy controls, stress was the only variable that significantly influenced ER difficulties in individuals with TTM. Therefore, using the ER model a discussion on stress and ER in TTM was explored. It was concluded that ER difficulties are more closely related to stress, than to TTM, with the ER model not being such an appropriate framework for TTM. This chapter also addressed the limitations of and implications for future research and clinical practice for ER in TTM.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Washington, DC: American Psychiatric Association.

Arabatzoudis, T., Rehm, I. C., Nedeljkovic, M., & Moulding, R. (2017). Emotion regulation in individuals with and without trichotillomania. *Journal of Obsessive-Compulsive and Related Disorders, 12*, 87-94. doi:10.1016/j.jocrd.2017.01.003

Austin, T., Bezuidenhout, C., Botha, K., Du Plessis, E., Du Plessis, L., Jordaan, E., . . . Vorster, A. (2014). Anxiety, Obsessive-Compulsive and Trauma Related Disorders. In M. Lake (Ed.), *Abnormal Psychology: A South African perspective* (pp. 106). South Africa: Oxford University Press.

Bardeen, J. R., Fergus, T. A., & Orcutt, H. K. (2012). An examination of the latent structure of the Difficulties in Emotion Regulation Scale. *Journal of Psychopathology and Behavioural Assessment, 34*, 382-392. doi:10.1007/s10862-12-9280-y

Bernstein, D. P., Stein, J. A., Newcomb, M. D., Walker, E., Pogge, D., Ahluvalia, T., . . . Zule, W. (2003). Development and validation of a brief screening version of the Childhood Trauma Questionnaire. *Child Abuse & Neglect, 27*, 169-190. doi:10.1016/S0145-2134(02)00541-0

Bloch, M. H. (2009). Trichotillomania across the life span. *Journal of the American Academy of Child & Adolescent Psychiatry, 48*(9), 879-883. doi: 10.1097/CHI.0b013e3181ae09f3

Bohne, A., Savage, C. R., Deckersbach, T., Keuthen, N. J., & Wilhelm, S. (2008). Motor inhibition in trichotillomania and obsessive-compulsive disorder. *Journal of Psychiatric Research, 42*, 141-150. doi:10.1016/j.jpsychires.2006.11.008

Boughn, S., & Holdom, J. J. (2003). The relationship of violence and trichotillomania. *Journal of Nursing Scholarship, 35*(2), 165-170. doi: 10.1111/j.1547-5069.2003.00165.x

Burns, E. E., Jackson, J. L., & Harding, H. G. (2010). Child maltreatment, emotion regulation, and posttraumatic stress: The impact of emotional abuse. *Journal of Aggression, Maltreatment & Trauma, 19*(8), 801-819. doi: 10.1080/10926771.2010.522947

Campbell, M. M., Sibeko, G., Mall, S., Baldinger, A., Nagdee, M., Susser, E., & Stein, D. J. (2017). The content of delusions in a sample of South African Xhosa people with schizophrenia. *BMC Psychiatry, 17*(41), 1-9. doi: 10.1186/s12888-017-1196-3

Chamberlain, S. R., Hampshire, A., Menzies, L. A., Garyfallidis, E., Grant, J. E., Odlaug, B. L., . . . Sahakian, B. J. (2010). Reduced brain white matter integrity in trichotillomania: A diffusion tenor imaging study. *Archives of General Psychiatry, 67*(9), 965-971. doi:10.1001/archgenpsychiatry.2010.109

Choi, J. Y., Choi, Y. M., Gim, M. S., Park, J. H., & Park, S. H. (2014). The effects of childhood abuse on symptom complexity in a clinical sample: Mediating effects of emotion regulation. *Child Abuse & Neglect, 38*, 1313-1319. doi:10.1016/j.chiabu.2014.04.016

Cohen, S., Janicki-Deverts, D., & Miller, G. E. (2007). Psychological stress and disease. *JAMA, 298*(14), 1685-1687. doi: 10.1001/jama.298.14.1685

Corso, K. A., & McGeary, D. D. (2008). Trichotillomania and post-traumatic stress disorder: A case study. *Military Medicine, 173*, 1136-1141. doi:10.7205/MILMED.173.11.1136

Curley, E. E., Tung, E. S., & Keuthen, N. J. (2016). Trait anger, anger expression, and anger control in trichotillomania: Evidence for the emotion regulation model. *Journal of Obsessive-Compulsive and Related Disorders, 9,* 77-81. doi:10.1016/j.jocrd.2016.04.005

DeMarce, J. M., Lash, S. J., Parker, J. D., Burke, R. S., & Grambow, S. C. (2013). Validity of the Structured Clinical Interview for DSM-IV among veterans seeking treatment for substance use disorders. *International Journal of Mental Health and Addiction, 11*, 546-556. doi:10.1007/s11469-013-9435-4

Diefenbach, G. J., Tolin, D. F., Hannan, S., Crocetto, J., & Worhunsky, P. (2005). Trichotillomania: Impact on psychosocial functioning and quality of life. *Behaviour Research and Therapy, 43*, 869-884. doi:10.1016/j.brat.2004.06.010

Diefenbach, G. J., Tolin, D. F., Meunier, S., & Worhunsky, P. (2008). Emotion regulation and trichotillomania: A comparison of clinical and nonclinical hair pulling. *Journal of Behavior Therapy and Experimental Psychiatry, 39*, 32-41. doi:10.1016/j.jbtep.2006.09.002

Drill, R., Nakash, O., DeFife J. A., & Westen, D. (2015). Assessment of clinical information: Comparison of the validity of a Structural Clinical Interview (SCID) and the Clinical Diagnostic Interview. *The Journal of Nervous and Mental Disease, 203*(6), 459-462. doi:10.1097/NMD.0000000000000300

Drysdale, E., Jahoda, A., & Campbell, E. (2009). The manipulation of arousal on the intensity of urges to pull hair in a 16 year old female with trichotillomania: A single case study. *Behavioural and Cognitive Psychotherapy, 37*, 115-120. doi:10.1017/S1352465808004712

Duke, D. C., Bodzin, D. K., Tavares, P., Geffken, G. R., & Storch, E. A. (2009). The phenomenology of hairpulling in a community sample. *Journal of Anxiety Disorders, 23*, 1119-1125. doi:10.1016/j.janxdis.2009.07.015

Duke, D. C., Keeley, M. L., Geffken, G. R., & Storch, E. A. (2010). Trichotillomania: A current review. *Clinical Psychology Review, 30*, 181-193. doi:10.1016/j.cpr.2009.10.008

Du Toit, P. L., Van Kradenburg, J., Niehaus, D., & Stein, D. J. (2001). Comparison of obsessive-compulsive disorder patients with and without comorbid putative obsessive-compulsive spectrum disorders using a Structured Clinical Interview. *Comprehensive Psychiatry, 42*(4), 291-300. doi:10.1053/comp.2001.24586

Field, A. (2009). *Discovering statistics using SPSS (3rd ed.).* London, United Kingdom: SAGE Publications Limited.

Flessner, C. A., Conelea, C. A., Woods, D. W., Franklin, M. E., Keuthen, N. J., & Cashin, S. E. (2008). Styles of pulling in trichotillomania: Exploring differences in symptom severity, phenomenology, and functional impact. *Behaviour Research and Therapy, 46*, 345-357. doi:10.1016/j.brat.2007.12.009

Franklin, M. E., Flessner, C. A., Woods, D. W., Keuthen, N. J., Piacentini, J. C., Moore, P., . . . Wilson, M. A. (2008). The child and adolescent trichotillomania impact project: Descriptive psychopathology, comorbidity, functional impairment, and treatment utilization. *Journal of Developmental & Behavioral Pediatrics, 29*(6), 493-500. doi:10.1097/DBP.0b013e31818d4328

Foxcroft, C., & Roodt, G. (2013). *Introduction to psychological assessment: In the South African context (4th ed.).* Cape Town, South Africa: Oxford University Press Southern Africa (Pty) Limited.

Gershuny, B. S., Keuthen, N. J., Gentes, E. L., Russo, A. R., Emmott, E. C., Jameson, M., . . . Jenike, M. A. (2006). Current posttraumatic stress disorder and history of trauma in trichotillomania. *Journal of Clinical Psychology, 62*(12), 1521-1529. doi:10.1002/jclp.20303

Ghosh, S., Mazumder, G., Bhattacharjee, S., & Bhattacharjee, A. (2016). Correlation of perceived stress with symptom severity and quality of life in trichotillomania patients. *Journal of Evolution of Medical and Dental Sciences, 5*(30), 1518-1521. doi:10.14260/jemds/2016/358

Gorman, L. L., O'Hara, M. W., Figueredo, B., Hayes, S., Jacquemain, F., Kammerer, M. H., . . . Sutter-Dallay, A. -L. (2004). Adaptation of the Structured Clinical Interview for DSM-IV Disorders for assessing depression in women during pregnancy and post-partum across countries and cultures. *British Journal of Psychiatry, 184*(46), 17-23. doi:10.1192/bjp.184.46.s17

Grant, J. E., Odlaug, B. L., & Kim, S. W. (2009). N-Acetylcysteine, a glutamate modulator, in the treatment of trichotillomania: A double-blind, placebo-controlled study. *Archives of General Psychiatry, 66*(7), 756-763. doi:10.1001/archgenpsychiatry.2009.60

Grant, J. E., Odlaug, B. L., Chamberlain, S. R., & Kim, S. W. (2011). Dronabinol, a cannabinoid agonist, reduces hair pulling in trichotillomania: A pilot study. *Psychopharmacology, 218*(3), 493-502 doi:10.1007/s00213-011-2347-8

Grant, J. E. & Stein, D. J. (2014). Body-focused repetitive behavior disorder in ICD-11. *Revista Brasileira de Psiquiatria, 36*(1) , 59-64. doi:10.1590/1516-4446-2013-1228

Grant, J. E., Leppink, E., & Chamberlain, S. (2015). Body focused repetitive behaviour disorders and perceived stress: Clinical and cognitive associations. *Journal of Obsessive-Compulsive and Related Disorders, 5,* 82-86. doi:10.1016/j.jocrd.2015.02.001

Grant, J. E., & Chamberlain, S. R. (2016). Trichotillomania. *American Journal of Psychiatry, 173*(9), 868-874. doi: 10.1176/appi.ajp.2016.15111432

Grant, J. E., Redden, S.A., Leppink, E. W., & Chamberlain, S. R. (2017). Trichotillomania and co-occurring anxiety. *Comprehensive Psychiatry, 72*, 1-5. doi: 10.1016/ju.comppsych.2016.09.005

Gratz, K. L., & Roemer, L. (2004). Multidimensional assessment of emotion regulation and dysregulation: Development, factor structure, and initial validation of the Difficulties in Emotion Regulation Scale. *Journal of Psychopathology and Behavioral Assessment, 26*(1), 41-54. doi:10.1007/s1082-008-9102-4

Hamad, R., Fernald, L. C. H., & Zinman, J. (2008). Social and economic correlates of depressive symptoms and perceived stress in South African adults. *Journal of Epidemiology and Community Health, 62*, 538-544. doi:10.1136/jech.2007.066191

Holgersson, H. E. T., Nordström, L., & Öner, Ö. (2014). Dummy variables vs. category-wise models. *Journal of Applied Statistics, 41*(2), 233-241. doi: 10.1080/02664763.2013.838665

Houghton, D. C., Matthew, A. S., Twohig, M. P., Saunders, S. M., Franklin, M. E., Compton, S. N., . . . Woods, D. W. (2016). Trauma and trichotillomania: A tenuous relationship. *Journal of Obsessive-Compulsive and Related Disorders, 11*, 91-95. doi:10.1016/j.jocrd.2016.09.003

Jeong, Y., & Jung, M. J. (2016). Application and interpretation of hierarchical multiple regression. *Orthopaedic Nursing, 35*(5), 338-341. doi:10.1097/NOR.0000000000000279

Johnson, J., & El-Alfy, A. T. (2016). Review of available studies of the neurobiology and pharmacotherapeutic management of trichotillomania. *Journal of Advanced Research, 7*, 169-184. doi:10.1016/j.jare.2015.05.001

Keuthen, N. J., Flessner, C. A., Woods, D. W., Franklin, M. E., Stein, D. J., & Cashin, S. E. (2007). Factor analysis of the Massachusetts General Hospital Hairpulling Scale. *Journal of Psychosomatic Research, 62*, 707-709. doi:10.1016/j.jpsychores.2006.12.003

Keuthen, N. J., Rothbaum, B. O., Welch, S. S., Taylor, C., Falkenstein, M., Heekin, M., . . . Jenike, M. A. (2010). Pilot trial of dialectical behavior therapy-enhanced habit reversal for trichotillomania. *Depression and Anxiety, 27*(10), 1-7. doi: 10.1002/da.20732

Keuthen, N. J., Rothbaum, B. O., Fama, J., Altenburger, E., Falkenstein, M. J., Sprich, S. E., . . . Welch, S. S. (2012). DBT-enhanced cognitive-behavioral treatment for trichotillomania: A randomized controlled trial. *Journal of Behavioral Addictions, 1*(3), 106-114. doi:10.1556/JBA.1.2012.003

Kranzler, H.R., Kadden, R.M., Babor, T.F., Tennen, H., & Rounsaville, B.J. (1996). Validity of the SCID in substance abuse patients. *Addition, 91*(6), 859-868. doi: 10.1080/09652149640068

Lee, E.-H. (2012). Review of the psychometric evidence of the Perceived Stress Scale. *Asian Nursing Research, 6*, 1271-127. doi:10.1016/j.anr.2012.08.004

Lobbestael, J., Leurgans, M., & Arntz, A. (2011). Inter-rater reliability of the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I) and Axis II Disorders (SCID II). *Clinical Psychology and Psychotherapy, 18*, 75-79. doi:10.1002/cpp.693

Lochner, C., Simeon, D., Niehaus, D., & Stein, D. J. (2002). Trichotillomania and skin-picking: A phenomenological comparison. *Depression and Anxiety, 15*, 83-86. doi:10.1002/da.10034

Lochner, C., Stein, D. J., Woods, D., Pauls, D. L., Franklin, M. E., Loerke, E. H., & Keuthen, N. J. (2011). The validity of DSM-IV-TR criteria B and C of hair-pulling disorder (trichotillomania): Evidence from a clinical study. *Psychiatry Research, 189*, 276-280. doi: 10.1016/j.psychres.2011.07.022

MacDonald, K., Thomas, M. L., Sciolla, A. F., Schneider, B., Pappas, K., Bleijenberg, G., . . . Wingenfeld, K. (2016). Minimization of childhood maltreatment is common and consequential: Results from a large, multinational sample using the Childhood Trauma Questionnaire. *PLOS ONE, 11*(1), 1-16. doi:10.1371/journal.pone.0146058

Madigoe, T., Burns, J., Zhang, M., & Subramaney, U. (2017). Towards a culturally appropriate trauma assessment in a South African Zulu community. *Psychological Trauma: Theory, Research, Practice, and Policy, 9*(3), 274-281. doi:10.1037/tra0000231

Mansueto, C. S., Thomas, A. M., & Brice, A. L. (2007). Hair pulling and its affective correlates in an African-American university sample. *Journal of Anxiety Disorders, 21*, 590-599. doi:10.1016/j.janxdis.2006.08.004

Matthews, C. A., Kaur, N., & Stein, M. B. (2008). Childhood trauma and obsessive-compulsive symptoms. *Depression and Anxiety, 25*, 742-751.doi:10.1002/da.20316

McDonald, K. E. (2012). Trichotillomania: Identification and treatment. *Journal of Counseling and Development, 90*, 421-426. doi:10.1002/j.1556-6676.2012.0053.x

Meunier, S. A., Tolin, D. F., & Franklin, M. (2009). Affective and sensory correlates of hair pulling in pediatric trichotillomania. *Behavior Modification, 3*(33), 396-407. doi:10.1177/0145445508326260

Neal-Barnett, A., Statom, D., Stadulis, R. (2011). Trichotillomania symptoms in African American women: Are they related to anxiety and culture. C*NS Neuroscience & Therapeutics, 17*, 207-213. doi:10.1111/j.1755-5949.2010.00138.x

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

Özten, E., Sayar, G. H., Eryilmaz, G., Kagan, G., Isik, S., & Karamustafalioglu, O. (2015). The relationship of psychological trauma with trichotillomania and skin picking. *Neuropsychiatric Disease and Treatment, 11*, 1203-1210. doi:10.2147/NDT.S79554

Paivio, S. C., & Cramer, K. M. (2004). Factor structure and reliability of the Childhood Trauma Questionnaire in a Canadian undergraduate student sample. *Child Abuse & Neglect, 28*, 889-904. doi:10.1016/j.lchiabu.2004.01.011

Reis, R. S., Hino, A. A. F., & Rodrigues-Anez, C. R. (2010). Perceived Stress Scale: Reliability and validity study in Brazil. *Journal of Healthy Psychology, 15*(1), 107-114. doi:10.1177/1359105309346343

Richardson, D. B., Hamra, G. B., MacLehose, R. F., Cole, S. R., & Chu, H. (2015). Hierarchical regression for analyses of multiple outcomes. *American Journal of Epidemiology, 182*(5), 459-467. doi:10.1093/aje/kwv047

Ritacco, G., & Suffla, S. (2012). A critical review of child maltreatment indices: Psychometric properties and application in the South African context. *African Safety Promotion Journal, 10*(2), 3-17. Retrieved from: http://hdl.handle.net/10500/8913

Roberts, S., O'Connor, K., & Belanger, C. (2013). Emotion regulation and other psychological models for body-focused repetitive behaviors. *Clinical Psychology Review, 33*, 745-762: doi:10.1016/j.cpr.2013.05.004

Roberts, S., O'Connor, K., Aardema, F., & Belanger, C. (2015). The impact of emotions on body-focused repetitive behaviors: Evidence from a non-treatment-seeking sample. *Journal of Behavior Therapy and Experimental Psychiatry, 46*, 189-197. doi:10.1016/j.jbtep.2014.10.007

Rochat, T. J., Tomlinson, M., Bärnighausen, T., Newell, M. -L., & Stein, A. (2011). The prevalence and clinical presentation of antenatal depression in rural South Africa. *Journal of Affective Disorders, 135*, 362-373. doi: 10.1016/j.jad.2011.08.011

Rufer, M., Bamert, T., Klaghofer, R., Moritz, S., Schilling, L., & Weidt, S. (2014). Trichotillomania and emotion regulation: Is symptom severity related to alexithymia. *Psychiatry Research, 218*, 161-165. doi:10.1016/j.psychres.2014.03.029

Saal, W., Kagee, A., & Bantjes, J. (2018). Utility of the Beck Depression Inventory in measuring major depression among individuals seeking HIV testing in the Western Cape, South Africa. *AIDS CARE, 30*(1), 29-36. doi:10.1080/09540121.2018.1499856

Shear, M. K., Greeno, C., Kang, J., Ludewig, D., Frank, E., Swartz, H. A., & Hanekamp, M. (2000). Diagnosis of nonpsychotic patients in community clinics. *American Journal of Psychiatry, 157*(4), 581-587. doi:10.1176/appi.ajp.157.4.581

Shusterman, A., Feld, L., Baer, L., & Keuthen, N. (2009). Affective regulation in trichotillomania: Evidence from a large-scale internet survey. *Behaviour Research and Therapy, 47*, 637-644. doi:10.1016/j.brat.2009.04.004

Snorrason, I., Berlin, G. S., & Lee, H. -J. (2015). Optimizing psychological interventions for trichotillomania (hair-pulling disorder): An update on current empirical status. *Psychology Research and Behavior Management, 8,* 105-113. doi:10.2147/PRBM.S53977

Spitzer, R. L., Williams, J. B. W., Gibbon, M., & First, M. B. (2005). *User's guide for the Structured Clinical Interview for DSM-III-R (SCID).* Washington, DC: American Psychiatric Press, Inc.

Stein, D. J., Flessner, C. A., Franklin, M., Keuthen, N. J., Lochner, & Woods, D. W. (2008). Trichotillomania a stereotypic movement disorder? An analysis of body-focused repetitive behaviors in people with hair-pulling. *Annals of Clinical Psychiatry, 20*(4), 194-198. doi:10.1080/10401230802435625

Sundermann, J. M., & DePrince, A. P. (2015). Maltreatment characteristics and emotion regulation difficulties as predictors of mental health symptoms: Results from a community-recruited sample of female adolescents. *Journal of Family Violence, 30,* 329-338. doi:10.1007/s10896-014-9656-8

Taber, K. S. (2017). The use of Cronbach's Alpha when developing and reporting research instruments in science education. *Research in Science Education*, 1-24. doi: 10.1007/s11165-016-9602-2

Thombs, B. D., Bernstein, D. P., Lobbestael, J., & Arntz, A. (2009). A validation study of the Dutch Childhood Trauma Questionnaire-Short Form: Factor structure, reliability, and known-groups validity. *Child Abuse & Neglect, 33,* 518-523. doi:10.1016/j.chiabu.2009.03.001

Tomita, T., Yasui-Furukori, N., Sugawara, N., Ogasawara, K., Katagai, K., Saito, H., . . . Nakamura, K. (2016). Prevalence of major depressive disorder among haemodialysis patients compared with healthy people in Japan using the Structured Clinical Interview for DSM-IV. *Neuropsychiatric Disease and Treatment, 12*, 2503-2508. doi:10.2147/NDT.S106817

Van de Mortel, T. F. (2008). Faking it: Social desirability response bias in self-report research. *Australian Journal of Advanced Nursing, 25*(4), 40-48. Retrieved from http://www.ajan.com.au/ajan_25.4.html

Viera, A. J., & Garrett, J. M. (2005). Understanding inter observer agreement: The kappa statistic. *Family Medicine, 37*(5), 360-363. Retreived from http://www.stfm.org/fmhub/fm2005/May/Anthony360.pdf

Viola, W. T., Salum, G. A., Kluwe-Schiavon, B., Sanvicente-Vieira, B., Levandowski, M. L., & Grassi-Oliveira, R. (2016). The influence of geographical and economic factors in estimates of childhood abuse and neglect using the Childhood Trauma Questionnaire: A worldwide meta-regression analysis. *Child Abuse & Neglect, 51*, 1-11. doi:10.1016/j.chiabu.2015.11.019

Walther, M. B., Ricketts, E. J., Conelea, C. A., & Woods, D. W. (2010). Recent advances in the understanding and treatment of trichotillomania. *Journal of Cognitive Psychotherapy, 24*(1), 46-64. doi: 10.189/0889-8391.24.1.46

Weidt, S., Zai, G., Drabe, N., Delsignore, A., Bruehl, A.B., Klaghofer, R., & Rufer, M. (2016). Affective regulation in trichotillomania before and after self-help interventions. *Journal of Psychiatric Research, 75*, 7-13. doi: 10.1016/j.psychires.2015.12.020

Woods, D. W., Wetterneck, C. T., & Flessner, C. A. (2006). A controlled evaluation of acceptance and commitment therapy plus habit reversal for trichotillomania. *Behaviour Research and Therapy, 44*, 639-656. doi:10.1016/j.brat.2005.05.006

Woods, D. W. & Houghton, D. C. (2014). Diagnosis, evaluation, and management of trichotillomania. *Psychiatric Clinics of North America, 37*, 301-317. doi: 10.1016/j.psc.2014.05.005

Appendices

Appendix A

DSM-5 Criteria for Trichotillomania

Criteria A: Hairpulling is removed with intention on any site of the body, hairpulling can occur on multiple sites and pulling patterns differ amongst individuals (concentrated or large areas). Hairpulling can result in bald spots or thinning of the hair.

Criteria B and C: There is several attempts to decrease or stop hair pulling. The hair pulling causes significant distress or impairment in social, occupational, or other important areas of functioning

Criteria D: The hair pulling or hair loss is not attributable to another medical condition or mental disorder where hairpulling and alopecia exists.

(American Psychiatric Association [APA], 2013)

Appendix B

DSM-IV Criteria for Trichotillomania

Criteria A. The recurrent pulling out of one's hair, which may result noticeable hair loss.

B.The presence of an increasing sense of tension immediately before hair-pulling, or when the individual attempts to resist hair-pulling behaviour

C. The presence of pleasure, gratification, or sense of relief during hair-pulling

D. The hair-pulling, or loss of hair, is not attributable to another mental disorder, and general medical condition (e.g., a dermatological condition).

E. Hair-pulling causes the individual clinically significant distress or impairment in social, occupational, or other important areas of functioning.

(Stein et al., 2010)

Appendix C

Ethics Letter for Larger On-going Study

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

Ethics Letter

14-July-2017

Ethics Reference #: 99/013

Title: Genetics of Anxiety Disorders

Dear Prof Christine Lochner,

Your request for extension/annual renewal of ethics approval dated 21 June 2017 refers.

The Health Research Ethics Committee reviewed and approved the annual progress report you submitted through an expedited review process.

The approval of the research project is extended for a further year.

Approval Date: 14 July 2017

Expiry Date: 13 July 2018

Kindly be reminded to submit progress reports two (2) months before expiry date.

Where to submit any documentation

Kindly submit **ONE HARD COPY** to Elvira Rohland, RDSD, Room 5007, Teaching Building, and **ONE ELECTRONIC COPY** to ethics@sun.ac.za .

Please remember to use your **protocol number (99/013)** on any documents or correspondence with the HREC concerning your research protocol.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005240 for HREC1
Institutional Review Board (IRB) Number: IRB0005239 for HREC2

The Health Research Ethics Committee complies with the SA National Health Act No. 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the South African

Fakulteit Geneeskunde en Gesondheidswetenskappe
Faculty of Medicine and Health Sciences

Afdeling Navorsingsontwikkeling en -Steun • Research Development and Support Division

Posbus/PO Box 241 • Cape Town 8000 • Suid-Afrika/South Africa
Tel: +27 (0) 21 938 9677

Appendix D

Ethics Letter for Larger On-going Study

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Ethics Letter

03-Feb-2017
Lochner, Christine C

Ethics Reference #: M07/05/019
Clinical Trial Reference #:
Title: "Delineating endophenotypes of obsessive-compulsive disorder: An integrated pharmacological, neurocognitive, genetic and imaging study."

Dear Prof Christine Lochner

At a meeting of HREC 1 on 01 February 2017 the following progress report was approved:

Progress Report dated: 11 November 2016

The approval of this project is extended for a further year.

Approval date: 01 February 2017

Expiry date: 31 January 2018

Where to submit any documentation
Kindly submit **ONE HARD COPY** to Elvira Rohland, RDSD, Room 5007, Teaching Building, and **ONE ELECTRONIC COPY** to ethics@sun.ac.za

Please remember to use your **protocol number** **(M07/05/019)** on any documents or correspondence with the HREC concerning your research protocol.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005240 for HREC1
Institutional Review Board (IRB) Number: IRB0005239 for HREC2

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Good Clinical Pracices Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Sincerely,
Franklin Weber
REC Coordinator
Health Research Ethics Committee 1

Appendix E

Ethics Amendment

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Ethics Letter

26-Apr-2017
Lochner, Christine C

Ethics Reference #: 99/013
Title: "Genetics of Anxiety Disorders"

Dear Prof Christine Lochner

Your amendment request dated 26 April 2017 refers.

The Health Research Ethics Committee approved the amended documentation through an expedited review process.

The following amendments were approved:

1. Difficulties in Emotion Regulation Scale (DERS)
2. Addition of Ms Salome Demetriou as a student and sub-investigator to the study.

Where to submit any documentation
Kindly submit **ONE HARD COPY** to Elvira Rohland, RDSD, Room 5007, Teaching Building, and **ONE ELECTRONIC COPY** to ethics@sun.ac.za

Please remember to use your **protocol number (99/013)** on any documents or correspondence with the HREC concerning your research protocol.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005240 for HREC1
Institutional Review Board (IRB) Number: IRB0005239 for HREC2

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Good Clinical Pracices Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Sincerely,
Francis Masiye
REC Coordinator
Health Research Ethics Committee 2

Appendix F

Ethics Amendment

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

Approval Letter

23 January 2018

Ethics Reference #: 99/013

Title: "Genetics of Anxiety Disorders"

Dear Prof Christine Lochner

Your letter dated 15 January 2018 refers.

The Health Research Ethics Committee (HREC) approved the amendment pertaining to the abovementioned study.

- The Difficulties in Emotion Regulation Scale (DERS; Gratz and Roemer, 2004)
- Ms Sally Demetriou as a postgraduate student and sub-investigator

Where to submit any documentation:

Kindly submit **ONE HARD COPY** to Elvira Rohland, RDSD, Room 5007, Teaching Building, and **ONE ELECTRONIC COPY** to ethics@sun.ac.za

Please remember to use your **protocol number (99/013)** on any documents or correspondence with the HREC concerning your research protocol.

Federal Wide Assurance Number: 00001372

Institutiuonal Review Board (IRB) Number: IRB0005240 for HREC1

Institutiuonal Review Board (IRB) Number: IRB0005239 for HREC2

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulation Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Good Clinical Practices Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Sincerely,

Elvira Rohland

REC Coordinator

Health Research Ethics Committee 2

Appendix G

Poster Advert

RESEARCH PARTICIPANTS NEEDED!

We are looking for individuals to participate in our research study on emotions and trichotillomania (hair-pulling disorder)

Trichotillomania (hair-pulling disorder, or TTM) is a psychiatric disorder characterized by pulling hair from one or more body areas, resulting in hair loss, distress and even functional impairment. Hair-pulling may serve an **emotion regulation function** (i.e. stimulating when under-stimulated or bored, and soothing when over-stimulated or upset). **This project aims to investigate the phenomenon of emotional regulation and its link with stress and trauma in people with TTM.**

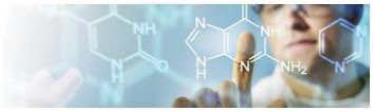
We are inviting people with TTM as well as healthy individuals, 18 years or older, to take part in our research study. To be included as a healthy participant, the individual must have no history of mental illness (e.g. depression).

If you are interested, your participation will include an interview with a clinical psychologist or psychiatrist and referral for treatment, if indicated. Participation is voluntary and confidential, and you can withdraw at any time. The interviews will take place at the MRC Unit on Risk and Resilience in Mental Disorders, Department of Psychiatry at the Tygerberg campus of Stellenbosch University.

Please contact Miss Salome Demetriou (email: 17506549@sun.ac.za; phone: 0764042055) or the principal investigator, Prof Christine Lochner (email: cl2@sun.ac.za; phone: 021 9389179).

Alternatively, you can also visit the following website: http://www.mrc.ac.za/anxiety/anxiety.htm

UNIVERSITEIT STELLENBOSCH UNIVERSITY



Appendix H

Electronic Noticeboard Advert

Appendix I

Informed Consent Form

PARTICIPANT INFORMATION AND INFORMED CONSENT FORM

TITLE OF RESEARCH PROJECT: Genetics of Anxiety Disorder

REFERENCE NUMBER: SU HREC: 99/013

PRINCIPAL INVESTIGATOR: Prof Dan Stein

ADDRESS: MRC Unit on Anxiety & Stress Disorders, Department of Psychiatry, Faculty of Medicine and Health Sciences, Stellenbosch University

CONTACT NUMBER: 021 – 938 9179

We would like to invite you to participate in a research study that involves genetic analysis and possible long-term storage of blood or tissue specimens. Please take some time to read the information presented here which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This research study has been approved by the **Health Research Ethics Committee of Stellenbosch University,** and it will be conducted according to international and locally accepted ethical guidelines for research, namely the Declaration of Helsinki, and the SA Department of Health's 2004 Guidelines: *Ethics in Health Research: Principles, Structures and Processes.*

What is Genetic research?

Genetic material, also called DNA, is usually obtained from a small blood sample. Occasionally genetic material is obtained from other sources such as saliva. Genes are found in every cell in the human body. Our genes determine what we look like and sometimes our susceptibility to

certain kinds of diseases. Worldwide, researchers in the field of genetics are continuously discovering new information. This information may be of great benefit to both future generations and people today, who suffer from particular diseases or conditions.

What does this particular research study involve?

This study is part of a research project we are conducting to learn more about the genetic causes and symptoms of anxiety disorders (including obsessive-compulsive and spectrum disorders such as hair-pulling disorder or trichotillomania (TTM), panic or social anxiety disorder). We would like to discuss your life experiences and those of your other family members with you. Doctors and scientists at the MRC Unit on Anxiety and Stress Disorders and the University of Stellenbosch, in collaboration with qualified researchers from other research institutions worldwide, hope to identify the genes that may increase susceptibility to these disorders.

This is not a treatment study. Information is being collected for research purposes only.

Why have you been invited to participate?

You have been invited to participate because you are interested in becoming involved as a healthy control participant or you have been diagnosed with an anxiety disorder (such as panic or social anxiety disorder, or obsessive-compulsive and related disorders such as TTM before, or you suspect that you may have any of these disorders.

What procedures will be involved in this research?

If you decide to participate, we shall ask you to attend an interview (which may be videotaped) with a researcher. This interview will include neuropsychological tasks and a number of questions related to your current illness, comorbid conditions like depression, family functioning, quality of life, your prior history of treatment for psychiatric conditions, and particular symptoms you may have experienced as part of your illness. In addition, we may ask to take photographs of your face and hands. This whole procedure will last about 3-4 hours (two 2-hour sessions with a break in-between).

You will also be asked to have your blood drawn. Approximately 48 ml (3 tablespoons) of blood will be drawn from your arm. We may need to contact you again to get another blood sample

should we fail to get a DNA sample from your blood. The blood sample you give may be used to create a cell line. This is done by changing some of your blood cells so that they can grow forever. The cell line is living tissue and it can be used to make more of your DNA at any time in the future. This process will take place at the MRC Centre for Molecular and Cellular Biology and the Division of Medical Biochemistry, Faculty of Medicine and Health Sciences, at the University of Stellenbosch. The DNA will then be taken from the cell line and saved for scientific analyses which will be performed now, and possibly in the future.

We may contact you later for further information, or request you to complete another interview at a later date, in order to obtain follow-up information that may be of use in our genetic analyses. This may involve an assessment similar to the current assessment, including a series of interviews and/or another blood sample. Your current participation is in no way binding to your future participation.

We would like your permission to contact your relatives in order to get more information about any family history of mental illness, if need be.

If you have been diagnosed with OCD, we hope to also interview one of your close (first-degree) relatives. You can still participate in the study even if your relatives do not. If you are a relative (e.g. a parent) of a person diagnosed with OCD who have participated in this project, we will ask you to complete a number of self-report scales. These scales will ask questions about your current psychiatric symptoms if any, depression, anxiety, family functioning and quality of life. These scales will also ask you whether your child has tics, OCD and other problems. They will also ask about your child's psychiatric condition and how you respond to it. It can take up to 4 hours to complete these self-report scales – either at home or at our Unit.

Are there any risks involved in participation?

There are no more than minimal medical or psychological risks associated with this study. If you feel fatigued, uncomfortable, or in any way upset during any part of the session(s), you may ask to stop for a rest break or have the interview or scanning discontinued. The research interview does not take the place of a full psychiatric evaluation. You may experience some emotional discomfort when answering some questions. If any particular question makes you feel uncomfortable, you may discuss its importance with the specially trained interviewer. You may choose not to answer any question should you feel uncomfortable.

You may feel some pain associated with having blood drawn from a vein. You may experience discomfort, bruising and/or other bleeding at the site where the needle is inserted. Occasionally, some people experience fleeting dizziness or feel faint when their blood is drawn. Some insurance companies may mistakenly assume that your participation in this study is an indication that you are at higher risk of a genetic disease, and this could hurt your access to health or other insurance. We will not share any information about you, or your family, with an insurance company. It is the opinion of the investigators that participation in this study does not constitute genetic testing. Therefore, participation in this study should not be reported as genetic testing.

Are there any benefits to your taking part in this study? Will the results of your participation be discussed with you?

There are no direct benefits to you. However, individuals who might develop one of these conditions in the future, their family members, and future generations may benefit if we can locate the genes and brain structures or functions that may have lead to these symptoms. That knowledge could then lead to the development of methods for prevention and new treatments for curing this disease.

An annual newsletter containing a summary of research findings will be made available on www.mentalhealthsa.org.za and/or may be sent to participants, if requested.

The study provides a cost-free psychiatric evaluation service to participants. If any person request treatment or referral for treatment, he/she will be referred to suitable clinical services. One possibility would be to refer to the Anxiety Disorders Clinic at Groote Schuur Hospital Outpatients (lead by Dr Don Wilson) to receive basic pharmacotherapeutic treatment.

How long will your blood/DNA sample be stored and where will it be stored?

Samples will be safely stored at the MRC Centre for Molecular and Cellular Biology and the Division of Medical Biochemistry, Faculty of Medicine and Health Sciences, at the University of Stellenbosch, and identified by a code number, and access will be limited to authorised scientific investigators. We also collaborate with researchers abroad; this means we may share DNA samples and anonymous information with these sites to study your condition.

Your cell line and DNA will be maintained permanently, unless you request to have it removed. If at any time in the future you wish to have your DNA, cell lines or clinical data removed from the storage site, you may do so by contacting the researchers conducting this study.

Will the information obtained from your DNA be used for other research?

You can also choose to share your DNA with other scientists through a central database. Other researchers would be able to learn from your sample and would be able to conduct studies that include DNA from many countries. This can lead to larger and better studies related to obsessive-compulsive disorder and other health conditions. An "online database" is a database that is created from the central database. Researchers all over the world will have access to this database (this is called "data sharing"). The DNA stored in this online database will be used for research into general medical conditions OR psychiatric illnesses.

If South African researchers wish to use your stored blood/DNA for **additional research** they will be required to apply for permission to do so from the Health Research Ethics Committee of Stellenbosch University. If researchers from abroad wish to use your DNA information that has been stored on the online database, they will be required to apply for permission to do so from the National Institute of Health in the United States of America. If you wish to withdraw your data or your sample in the future, this is possible. However, please note that by the time we withdraw your data or your sample, it may already have been shared with other researchers. The United States National Institute for Mental Health (NIMH) Repository would, however, then instruct researchers to destroy your data and your sample if requested.

How will your confidentiality be protected?

If you consent to participate in this study, your identity will be kept confidential. Your answers will not be shared with other family members or anyone else except for staff members involved in this study. All research information and laboratory samples obtained from you will be safely stored and identified by code number. This means that no identifying information will be shared. Access will be limited to authorised scientific investigators. Any publications resulting from this study will not identify you by name. Because some of your DNA/cells are going to be stored in the United States, there is a very small chance the United States government might forcibly gain access to it using one of their laws called "The Patriot Act". This Act is used when the United States government judges that access to DNA is important for security purposes.

Will you or the researchers benefit financially from this research?

You will not be paid to take part in this study although your travel expenses will be reimbursed.

Important information: In the unlikely event that this research leads to the development of a commercial application or patent, you or your family will not receive any profits or royalties.

Is there anything else that you should know or do?

Your participation in this study is voluntary and you may refuse to participate or withdraw from the study at any time without any loss of benefits to which you are otherwise entitled. Some members of the team of investigators conducting this study may be responsible for your clinical care. Refusal to participate in this study will not change your clinical care.

You can contact the principal investigator, Christine Lochner, on 021 – 938 9179 or cl2@sun.ac.za if you have any further queries or encounter any problems. You can contact the Health Research Ethics Committee of Stellenbosch University at 021 - 938 9207 or the UCT Faculty of Health Sciences Human Research Ethics Committee at 021 – 406 6346 if you have any concerns or complaints that have not been adequately addressed by study staff.

Declaration by participant

By signing below, I ..... agree to take part in a genetic research study entitled **Genetics of Anxiety Disorders**.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.

- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I have received a signed duplicate copy of this consent form for my records.

Tick the option you choose:

☐ I agree to take part in the study and consent to my blood being drawn. My blood sample will be stored and used for the current research project. Please destroy my DNA sample as soon as the current research project has been completed.

OR

☐ I agree that my blood or DNA sample can be stored, but I can choose to request at any time that my stored sample be destroyed. I have the right to receive confirmation that my request has been carried out.

OR

☐ I agree that my blood or DNA sample can be made available on an online database for use by other researchers, but I can choose to request that my stored sample be destroyed by the NIMH Repository. I have the right to receive confirmation that my request has been carried out.

Signed at (*place*) ..... on (*date*) .....

....

Signature of participant Signature of witness

Declaration by investigator

I *(name)* ..... declare that:

- I explained the information in this document to .....

- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ..... on (*date*) ..... .

....

Signature of investigator Signature of witness

Declaration by interpreter

I *(name)* ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) ..... .

....

Signature of interpreter Signature of witness

Appendix J

Informed Consent Form

PARTICIPANT INFORMATION AND INFORMED CONSENT FORM
(PATIENTS)

TITLE OF RESEARCH PROJECT: Obsessive-compulsive disorder and hair-pulling disorder (trichotillomania): An integrated pharmacological, neurocognitive, genetic and imaging study

REFERENCE NUMBER: SU HREC: M07/05/019
UCT HREC: 261/2007

PRINCIPAL INVESTIGATOR: Prof Christine Lochner

ADDRESS: MRC Unit on Anxiety & Stress Disorders, Department of Psychiatry, Faculty of Medicine and Health Sciences, Stellenbosch University

CONTACT NUMBER: 021 – 938 9179

We would like to invite you to participate in a research study that involves genetic analysis and possible long-term storage of blood or tissue specimens. Please take some time to read the information presented here which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This research study has been approved by the **Health Research Ethics Committees of Stellenbosch University and the Human Research Ethics Committee of the University of Cape Town,** and it will be conducted according to international and locally accepted ethical guidelines for research, namely the Declaration of Helsinki, and the SA Department of Health's 2004 Guidelines: *Ethics in Health Research: Principles, Structures and Processes*.

What is Genetic research?

Genetic material, also called DNA, is usually obtained from a small blood sample. Occasionally genetic material is obtained from other sources such as saliva. Genes are found in every cell in the human body. Our genes determine what we look like and sometimes our susceptibility to certain kinds of diseases. Worldwide, researchers in the field of genetics are continuously

discovering new information. This information may be of great benefit to both future generations and people today, who suffer from particular diseases or conditions.

What does this particular research study involve?

This study is part of a research project we are conducting to learn more about obsessive-compulsive disorder (OCD) and OCD-related conditions such as hair-pulling disorder (trichotillomania, or TTM).

Doctors and scientists at the MRC Unit on Anxiety and Stress Disorders, University of Stellenbosch, and the Department of Psychiatry, University of Cape Town, are collaborating with researchers from other research institutions worldwide, to investigate, the structure and functioning of selected brain areas in patients with OCD or TTM. This study also aims to identify the genes that may increase the risk for the development of these disorders. Information from patients will be compared with that of first-degree relatives of patients with OCD and healthy controls.

This is not a treatment study. Information is being collected for research purposes only.

Why have you been invited to participate?

You have been invited to participate because you have been diagnosed with OCD or TTM before, or you suspect that you may have any of these disorders.

What procedures will be involved in this research?

If you decide to participate, we will ask you to attend 2 sessions, each with a different study focus.

The first session will comprise an interview with a researcher and the drawing of bloods. These procedures will last approximately 3-4 hours (with a break in-between, if need be). The clinical interview will, amongst other things, include a number of questions related to OCD/TTM symptoms and your prior psychiatric history. Approximately 48 ml (3 tablespoons) of blood will be drawn from your arm. We may need to contact you again to get another blood sample should we fail to get a DNA sample (the genetic material) from your blood. The blood sample you give may be used to create a cell line. A cell line is living tissue that can be used to make more of your DNA at any time in the future. Genetic material previously found to be associated with OCD/TTM. Which may also play a role in brain activity, will also be investigated. This process will take place at the MRC Centre for Molecular and Cellular Biology and the Division of Medical Biochemistry, Faculty of Health Sciences, at the University of Stellenbosch.

The second session will involve 1.5 hours of brain scanning followed by neuropsychological testing (i.e. computer based tasks to test abilities such as decision making) of approximately 1.5 hours'

duration. The brain imaging and computer-based tasks will proceed at the Faculty of Medicine and Health Sciences at the Tygerberg Campus of Stellenbosch University or at the recently established scanning centre at Groote Schuur Hospital (UCT).

We may contact you later for further information, or request you to complete another interview at a later date, in order to obtain follow-up information that may be of use in our genetic analyses. This may involve an assessment similar to the current assessment, including a series of interviews and/or another blood sample. Your current participation is in no way binding to your future participation.

If you have been diagnosed with OCD, we would like your permission to contact one of your 1st degree (close) relatives (e.g. parent or sib) in order to invite them to participate as well. You can still participate in the study even if your relatives do not.

Are there any risks involved in participation?

There are no more than minimal medical or psychological risks associated with this study. If you feel fatigued, uncomfortable, or in any way upset during any part of the session(s), you may ask to stop for a rest break or have the interview or scanning discontinued. The research interview does not take the place of a full psychiatric evaluation. You may experience some emotional discomfort when answering some questions. If any particular question makes you feel uncomfortable, you may discuss its importance with the specially trained interviewer. You may choose not to answer any question should you feel uncomfortable.

You may feel some pain associated with having blood drawn from a vein. You may experience discomfort, bruising and/or other bleeding at the site where the needle is inserted. Occasionally, some people experience fleeting dizziness or feel faint when their blood is drawn. Some insurance companies may mistakenly assume that your participation in this study is an indication that you are at higher risk of a genetic disease, and this could hurt your access to health or other insurance. We will not share any information about you, or your family, with an insurance company. It is the opinion of the investigators that participation in this study does not constitute genetic testing. Therefore, participation in this study should not be reported as genetic testing.

You may feel some discomfort or fatigue associated with being in the brain scanner or while undergoing neuropsychological testing.

Are there any benefits to your taking part in this study? Will the results of your participation be discussed with you?

There are no direct benefits to you. However, individuals who might develop one of these conditions in the future, their family members, and future generations may benefit if we can locate the genes and brain structures or functions that may have lead to these symptoms. That knowledge could then lead to the development of methods for prevention and new treatments for curing this disease.

An annual newsletter containing a summary of research findings will be made available on www.mentalhealthsa.org.za and/or may be sent to participants, if requested..

The study provides a cost-free psychiatric evaluation service to participants. If any person request treatment or referral for treatment, he/she will be referred to suitable clinical services. One possibility would be to refer to the Anxiety Disorders Clinic at Groote Schuur Hospital Outpatients (lead by Dr Don Wilson) to receive basic pharmacotherapeutic treatment.

How long will your blood/DNA sample be stored and where will it be stored?

Samples will be safely stored at the MRC Centre for Molecular and Cellular Biology and the Division of Molecular Biology and Human Genetics, Faculty of Medicine and Health Sciences, at the University of Stellenbosch, and identified by a code number, and access will be limited to authorised scientific investigators. We also collaborate with researchers abroad; this means we may share DNA samples and anonymous information with these sites to study your condition.

Your cell line and DNA will be maintained permanently, unless you request to have it removed. If at any time in the future you wish to have your DNA, cell lines or clinical data removed from the storage site, you may do so by contacting the researchers conducting this study.

Will the information obtained from your DNA be used for other research?

You can also choose to share your DNA with other scientists through a central database. Other researchers would be able to learn from your sample and would be able to conduct studies that include DNA from many countries. This can lead to larger and better studies related to obsessive-compulsive disorder and other health conditions. An “online database” is a database that is created from the central database. Researchers all over the world will have access to this database (this is called “data sharing”). The DNA stored in this online database will be used for research into general medical conditions OR psychiatric illnesses.

If South African researchers wish to use your stored blood/DNA for **additional research** they will be required to apply for permission to do so from the Health Research Ethics Committee of Stellenbosch University and the Human Research Ethics Committee of the University of Cape Town. If researchers from abroad wish to use your DNA information that has been stored on the

online database, they will be required to apply for permission to do so from the National Institute of Health in the United States of America. If you wish to withdraw your data or your sample in the future, this is possible. However, please note that by the time we withdraw your data or your sample, it may already have been shared with other researchers. The United States National Institute for Mental Health (NIMH) Repository would, however, then instruct researchers to destroy your data and your sample if requested.

How will your confidentiality be protected?

If you consent to participate in this study, your identity will be kept confidential. Your answers will not be shared with other family members or anyone else except for staff members involved in this study. All research information and laboratory samples obtained from you will be safely stored and identified by code number. This means that no identifying information will be shared. Access will be limited to authorised scientific investigators. Any publications resulting from this study will not identify you by name. Because some of your DNA/cells are going to be stored in the United States, there is a very small chance the United States government might forcibly gain access to it using one of their laws called "The Patriot Act". This Act is used when the United States government judges that access to DNA is important for security purposes.

Will you or the researchers benefit financially from this research?

You will not be paid to take part in this study although your travel expenses will be reimbursed.

Important information: In the unlikely event that this research leads to the development of a commercial application or patent, you or your family will not receive any profits or royalties.

Is there anything else that you should know or do?

You can contact the principal investigator, Christine Lochner, on 021 – 938 9179 or cl2@sun.ac.za if you have any further queries or encounter any problems. You can contact the Health Research Ethics Committee of Stellenbosch University at 021 - 938 9207 or the UCT Faculty of Health Sciences Human Research Ethics Committee at 021 – 406 6346 if you have any concerns or complaints that have not been adequately addressed by study staff.

Declaration by participant

By signing below, I ..... agree to take part in a genetic research study entitled **Obsessive-compulsive disorder and hair-pulling disorder (trichotillomania): An integrated pharmacological, neurocognitive, genetic and imaging study**.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I have received a signed duplicate copy of this consent form for my records.

Tick the option you choose:

☐ I agree to take part in the study and consent to my blood being drawn. My blood sample will be stored and used for the current research project. Please destroy my DNA sample as soon as the current research project has been completed.

OR

☐ I agree that my blood or DNA sample can be stored, but I can choose to request at any time that my stored sample be destroyed. I have the right to receive confirmation that my request has been carried out.

OR

☐ I agree that my blood or DNA sample can be made available on an online database for use by other researchers, but I can choose to request that my stored sample be destroyed by the NIMH Repository. I have the right to receive confirmation that my request has been carried out.

Signed at (*place*) ..... on (*date*) .....

....

Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ..... declare that:

- I explained the information in this document to ……..……...
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ……..…….. on (*date*) ……...…….. .

…… ……

Signature of investigator **Signature of witness**

Declaration by interpreter

I *(name)* …… declare that:

- I assisted the investigator (*name*) …… to explain the information in this document to (*name of participant*) …….. using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ……..…….. on (*date*) ……...…….. .

…… ……

Signature of interpreter **Signature of witness**

Appendix K

The Massachusetts General Hospital (MGH) Hair-Pulling Scale

Name:_____ Date:_____

Instructions: For each question, pick the one statement in that group which best describes your behaviors and/or feelings over the past week. If you have been having ups and downs, try to estimate an average for the past week. Be sure to read all the statements in each group before making your choice.

For each question, pick the one statement in that group which best describes your behaviors and/or feelings over the past week. If you have been having ups and downs, try to estimate an average for the past week. Be sure to read all the statements in each group before making your choice.

For the next three questions, rate only the urges to pull your hair.

1. **Frequency of urges.** On an average day, how often did you feel the urge to pull your hair?

   0 This week I felt no urges to pull my hair.

   1 This week I felt an **occasional** urge to pull my hair.

   2 This week I felt an urge to pull my hair **often**.

   3 This week I felt an urge to pull my hair **very often.**

   4 This week I felt **near constant** urges to pull my hair.

2. **Intensity of urges.** On an average day, how intense or "strong" were the urges to pull your hair?

0 This week I did not feel any urges to pull my hair.

1 This week I felt **mild** urges to pull my hair.

2 This week I felt **moderate** urges to pull my hair.

3 This week I felt **severe** urges to pull my hair.

4 This week I felt **extreme** urges to pull my hair.

3. **Ability to control the urges.** On an average day, how much control do you have over the urges to pull your hair?

0 This week I could **always** control the urges, or I did not feel any urges to pull my hair.

1 This week I was able to distract myself from the urges to pull my hair **most of the time.**

2 This week I was able to distract myself from the urges to pull my hair **some of the time.**

3 This week I was able to distract myself from the urges to pull my hair **rarely.**

4 This week I was **never** able to distract myself from the urges to pull my hair.

For the next three questions, rate only the actual hair-pulling.

4. **Frequency of hair-pulling.** On an average day, how often did you actually pull your hair?

0 This week I did not pull my hair.

1 This week I pulled my hair **occasionally.**

2 This week I pulled my hair **often.**

3 This week I pulled my hair **very often.**

4 This week I pulled my hair so often it felt like I was **always** doing it.

5. **Attempts to resist hair-pulling.** On an average day, how often did you make an attempt to stop yourself from actually pulling your hair?

0 This week I felt no urges to pull my hair.

1 This week I tried to resist the urge to pull my hair **almost all of the time.**

2 This week I tried to resist the urge to pull my hair **some of the time.**

3 This week I tried to resist the urge to pull my hair **rarely**.

4 This week I **never** tried to resist the urge to pull my hair.

6. **Control over hair-pulling.** On an average day, how often were you successful at actually stopping yourself from pulling your hair?

0 This week I did not pull my hair.

1 This week I was able to resist pulling my hair **almost all of the time.**

2 This week I was able to resist pulling my hair **most of the time.**

3 This week I was able to resist pulling my hair **some of the time.**

4 This week I was **rarely** able to resist pulling my hair.

For the last question, rate the consequences of your hair-pulling.

7. **Associated distress.** Hair-pulling can make some people feel moody, "on edge," or sad. During the past week, how uncomfortable did your hair-pulling make you feel?

0 This week I did not feel uncomfortable about my hair-pulling.

1 This week I felt **vaguely uncomfortable** about my hair-pulling.

2 This week I felt **noticeably uncomfortable** about my hair-pulling.

3 This week I felt **significantly uncomfortable** about my hair-pulling.

4 This week I felt **intensely uncomfortable** about my hair-pulling.

Scoring the Massachusetts General Hospital (MGH) Hairpulling Scale

In scoring the MGH Hairpulling Scale, each item is scored on a 5-point scale from 0 = no symptoms to 4 = severe symptoms. The item scores are summed to produce a total score (range 0 to 28).

Appendix L

Childhood Trauma

Patient Name		Date	DD	MMM	YYYY

Childhood Trauma Questionnaire – Short Form (CTQ-SF)

Instructions: These questions ask about some of your experiences growing up **as a child and a teenager**. For each question, circle the number that best describes how you feel. Although some of these questions are of a personal nature, please try to answer as honestly as you can. Your answers will be kept confidential.

When I was growing up, …	Never True	Rarely True	Sometimes True	Often True	Very Often True
1. I didn't have enough to eat.	**1**	**2**	**3**	**4**	**5**
2. I knew there was someone to take care of me and protect me	**1**	**2**	**3**	**4**	**5**
3. People in my family called me things like "stupid", "lazy", or "ugly".	**1**	**2**	**3**	**4**	**5**
4. My parents were too drunk or high to take care of me.	**1**	**2**	**3**	**4**	**5**

When I was growing up, …	Never True	Rarely True	Sometimes True	Often True	Very Often True
5. There was someone in my family who helped me feel important or special.	1	2	3	4	5
6. I had to wear dirty clothes.	1	2	3	4	5
7. I felt loved.	1	2	3	4	5
8. I thought that my parents wished I had never been born.	1	2	3	4	5
9. I got hit so hard by someone in my family that I had to see a doctor or go to the hospital.	1	2	3	4	5
10. There was nothing I wanted to change about my family.	1	2	3	4	5
11. People in my family hit me so hard that it left bruises or marks.	1	2	3	4	5
12. I was punished with a belt, a board, a cord, or some hard object.	1	2	3	4	5
13. People in my family looked out for each other.	1	2	3	4	5
14. People in my family said hurtful or insulting things to me.	1	2	3	4	5
15. I believe that I was physically abused.	1	2	3	4	5
16. I had the perfect childhood.	1	2	3	4	5
17. I got hit or beaten so badly that it was noticed by someone like a teacher, neighbour, or doctor.	1	2	3	4	5
18. I felt that someone in my family hated me.	1	2	3	4	5
19. People in my family felt close to each other.	1	2	3	4	5
20. Someone tried to touch me in a sexual way, or tried to make me touch them.	1	2	3	4	5
21. Someone threatened to hurt me or tell lies about me unless I did something sexual with them.	1	2	3	4	5

When I was growing up, …	**Never True**	**Rarely True**	**Sometimes True**	**Often True**	**Very Often True**
22. I had the best family in the world.	**1**	**2**	**3**	**4**	**5**
23. Someone tried to make me do sexual things or make me watch sexual things.	**1**	**2**	**3**	**4**	**5**
24. Someone molested me.	**1**	**2**	**3**	**4**	**5**
25. I believe that I was emotionally abused.	**1**	**2**	**3**	**4**	**5**
26. There was someone to take me to the doctor if I needed it.	**1**	**2**	**3**	**4**	**5**
27. I believe that I was sexually abused	**1**	**2**	**3**	**4**	**5**
28. My family was a source of strength and support.	**1**	**2**	**3**	**4**	**5**

Appendix M

Perceived Stress Scale

PERCEIVED STRESS SCALE

Sheldon Cohen

The *Perceived Stress Scale* (PSS) is the most widely used psychological instrument for measuring the perception of stress. It is a measure of the degree to which situations in one's life are appraised as stressful. Items were designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. The scale also includes a number of direct queries about current levels of experienced stress. The PSS was designed for use in community samples with at least a junior high school education. The items are easy to understand, and the response alternatives are simple to grasp. Moreover, the questions are of a general nature and hence are relatively free of content specific to any subpopulation group. The questions in the PSS ask about feelings and thoughts during the last month. In each case, respondents are asked how often they felt a certain way.

Evidence for Validity: Higher PSS scores were associated with (for example):

- failure to quit smoking
- failure among diabetics to control blood sugar levels
- greater vulnerability to stressful life-event-elicited depressive symptoms
- more colds

Health status relationship to PSS: Cohen et al. (1988) show correlations with PSS and: Stress Measures, Self-Reported Health and Health Services Measures, Health Behavior Measures, Smoking Status, Help Seeking Behavior.

Temporal Nature: Because levels of appraised stress should be influenced by daily hassles, major events, and changes in coping resources, predictive validity of the PSS is expected to fall off rapidly after four to eight weeks.

Scoring: PSS scores are obtained by reversing responses (e.g., 0 = 4, 1 = 3, 2 = 2, 3 = 1 & 4 = 0) to the four positively stated items (items 4, 5, 7, & 8) and then summing across all scale items. A short 4 item scale can be made from questions 2, 4, 5 and 10 of the PSS 10 item scale.

Norm Groups: L. Harris Poll gathered information on 2,387 respondents in the U.S.

Norm Table for the PSS 10 item inventory

Category	N	Mean	S.D.
Gender			
Male	926	12.1	5.9
Female	1406	13.7	6.6
Age			
18-29	645	14.2	6.2
30-44	750	13.0	6.2
45-54	285	12.6	6.1
55-64	282	11.9	6.9
65 & older	296	12.0	6.3
Race			
white	1924	12.8	6.2
Hispanic	98	14.0	6.9
black	176	14.7	7.2
other minority	50	14.1	5.0

Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

Name _____ Date _____

Age _____ Gender (*Circle*): **M F** Other _____

	0 = Never	1 = Almost Never	2 = Sometimes	3 = Fairly Often	4 = Very Often
1. In the last month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2. In the last month, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
3. In the last month, how often have you felt nervous and "stressed"?	0	1	2	3	4
4. In the last month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
5. In the last month, how often have you felt that things were going your way?	0	1	2	3	4
6. In the last month, how often have you found that you could not cope with all the things that you had to do?	0	1	2	3	4
7. In the last month, how often have you been able to control irritations in your life?	0	1	2	3	4
8. In the last month, how often have you felt that you were on top of things?	0	1	2	3	4
9. In the last month, how often have you been angered because of things that were outside of your control?	0	1	2	3	4
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

Please feel free to use the *Perceived Stress Scale* for your research.

Mind Garden, Inc.
info@mindgarden.com
www.mindgarden.com

References

The PSS Scale is reprinted with permission of the American Sociological Association, from Cohen, S., Kamarck, T., and Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24,* 386-396.

Cohen, S. and Williamson, G. Perceived Stress in a Probability Sample of the United States. Spacapan, S. and Oskamp, S. (Eds.) *The Social Psychology of Health.* Newbury Park, CA: Sage, 1988.

Appendix N

Difficulties in Emotion Regulation Scale (DERS)

Difficulties in Emotion Regulation Scale (DERS)

Please indicate how often the following statements apply to you by writing the appropriate number from the scale below on the line beside each item.

1----------2----------3----------4----------5

almost never	sometimes	about half the time	most of the time	almost always
(0-10%)	(11-35%)	(36-65%)	(66-90%)	(91-100%)

_____ 1) I am clear about my feelings.
_____ 2) I pay attention to how I feel.
_____ 3) I experience my emotions as overwhelming and out of control.
_____ 4) I have no idea how I am feeling.
_____ 5) I have difficulty making sense out of my feelings.
_____ 6) I am attentive to my feelings.
_____ 7) I know exactly how I am feeling.
_____ 8) I care about what I am feeling.
_____ 9) I am confused about how I feel.
_____ 10) When I'm upset, I acknowledge my emotions.
_____ 11) When I'm upset, I become angry with myself for feeling that way.
_____ 12) When I'm upset, I become embarrassed for feeling that way.
_____ 13) When I'm upset, I have difficulty getting work done.
_____ 14) When I'm upset, I become out of control.
_____ 15) When I'm upset, I believe that I will remain that way for a long time.
_____ 16) When I'm upset, I believe that I will end up feeling very depressed.
_____ 17) When I'm upset, I believe that my feelings are valid and important.
_____ 18) When I'm upset, I have difficulty focusing on other things.
_____ 19) When I'm upset, I feel out of control.
_____ 20) When I'm upset, I can still get things done.
_____ 21) When I'm upset, I feel ashamed at myself for feeling that way.
_____ 22) When I'm upset, I know that I can find a way to eventually feel better.
_____ 23) When I'm upset, I feel like I am weak.
_____ 24) When I'm upset, I feel like I can remain in control of my behaviors.
_____ 25) When I'm upset, I feel guilty for feeling that way.
_____ 26) When I'm upset, I have difficulty concentrating.
_____ 27) When I'm upset, I have difficulty controlling my behaviors.
_____ 28) When I'm upset, I believe there is nothing I can do to make myself feel better.
_____ 29) When I'm upset, I become irritated at myself for feeling that way.
_____ 30) When I'm upset, I start to feel very bad about myself.
_____ 31) When I'm upset, I believe that wallowing in it is all I can do.
_____ 32) When I'm upset, I lose control over my behavior.
_____ 33) When I'm upset, I have difficulty thinking about anything else.
_____ 34) When I'm upset I take time to figure out what I'm really feeling.
_____ 35) When I'm upset, it takes me a long time to feel better.
_____ 36) When I'm upset, my emotions feel overwhelming.

Reverse-scored items (place a subtraction sign in front of them) are numbered 1, 2, 6, 7, 8, 10, 17, 20, 22, 24 and 34.

Calculate total score by adding everything up. Higher scores suggest greater problems with emotion regulation.

SUBSCALE SCORING:** The measure yields a total score (SUM) as well as scores on six sub-scales:

1. Nonacceptance of emotional responses (NONACCEPT): 11, 12, 21, 23, 25, 29
2. Difficulty engaging in Goal-directed behavior (GOALS): 13, 18, 20R, 26, 33
3. Impulse control difficulties (IMPULSE): 3, 14, 19, 24R, 27, 32
4. Lack of emotional awareness (AWARENESS): 2R, 6R, 8R, 10R, 17R, 34R
5. Limited access to emotion regulation strategies (STRATEGIES): 15, 16, 22R, 28, 30, 31, 35, 36
6. Lack of emotional clarity (CLARITY): 1R, 4, 5, 7R, 9

Total score: sum of all subscales

**"R" indicates reverse scored item

REFERENCE:

Gratz, K. L. & Roemer, L. (2004). Multidimensional assessment of emotion regulation and dysregulation: Development, factor structure, and initial validation of the Difficulties in Emotion Regulation Scale. *Journal of Psychopathology and Behavioral Assessment, 26,* 41-54.

Appendix O

Declaration of Language Editing

cumlaude
language practitioners

Director: CME Terblanche - BA (Pol Sc), BA Hons (Eng), MA (Eng), TEFL

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DECLARATION OF LANGUAGE EDITING

I, Christina Maria Etrecia Terblanche, hereby declare that I edited the research study titled:

Emotion regulation in trichotillomania (hair-pulling disorder): The role of stress and trauma

for **Salome Demetriou** for the purpose of submission as a postgraduate study for examination. Changes were indicated in track changes and implementation was left to the author.

Regards,

CME Terblanche

Cum Laude Language Practitioners (CC)

SATI accreditation no: 1001066 (South African Translators Institute)

Full member of PEG (Professional Editor's Guild)