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A qualitative exploration of participant perceptions, opinions and experiences of Trichotillomania

Chané Anne Roodt

A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the degree of Doctor of Philosophy

University of Huddersfield

December 2020

Dedication

Noreen.
A dream of a mother and constant source of support. I'm so grateful for you. Love you more than words. Your strength, resilience and selflessness are an inspiration.

P.S.
Andrew.
Life is not always fair; I wish we had more time.

Abstract

Trichotillomania (TTM) is a poorly understood disorder with no consensus on aetiology or epidemiology. TTM is often overlooked due to high rates of comorbidity with other disorders and is difficult to treat, often with a poor prognosis. The primary aim of this study is to explore the opinions, perceptions and experiences of people with TTM. Study objectives include identifying participant treatment preferences to potentially inform an intervention and to consider implications for future development and delivery of support for people with TTM.

An internationally-inclusive and geographically diverse sample was utilised as TTM occurs across the world, and incorporating an international approach aimed to generate new insights. The study employed a generic qualitative approach, with thematic analysis being used to analyse data from 20 asynchronous email interviews and 10 blog posts. The asynchronous email interview sample comprised 7 male and 13 female participants from 15 different countries.

Findings revealed a cycle of TTM, key themes and sub-themes emerged relating to negative thoughts and emotions, secrecy, non-disclosure, embarrassment, avoidances, perceived stigma and fear of judgement. Coexisting physical and psychological health implications were reported, alongside persistent and extensive effects and impairments across all aspects of life, including academic life, work life, relationships, self-identity and lost opportunities. Participants described engaging in permission-giving behaviours to gain control over TTM and outlined concealment as a method of coping. Blog post data reinforced email interview themes relating to secrecy, shame and stigma. Blog post data also revealed new themes: acceptance and societal view of beauty. Participants experienced barriers to seeking treatment, a lack of training and lapse in duty of care from their primary healthcare providers was noted. Email interview participants clearly detailed their ideal TTM treatment which may be used to inform development of a future intervention, with highlights to the importance of therapeutic alliance.

Findings are discussed in relation to relevant theory and applied to relevant models. The severe and far-reaching impairments in all areas of life coupled with the coexisting health implications further signifies that TTM can be a life impacting disorder for which there is no cure or effective treatment protocol.

Acknowledgements

A sincere thank you to Professor Philip Keeley, who has supervised this project from the very beginning, I am so grateful for the invaluable support you have provided. Special thank you to Dr Mary Turner and Dr Amanda Edmondson who joined the team at a later stage and have provided comprehensive feedback at crucial times of the project. Thank you to Dr Sarah Kendal and Dr Tammy Walker who joined the supervision team at various stages in the project, who both provided feedback that helped shape the project. I appreciate all your efforts.

Thanks to the 20 email interview participants who took the time to participate in the study.

Thanks to the PGR research office staff for their assistance throughout the years.

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Contents

Abstract……..……. 3

Acknowledgements……..…..…..4

Copyright……..…….. 5

Contents…….…6

List of Tables…….…...10

List of Figures…….……..10

Glossary……..……11

Chapter One: Introduction and Background…….12

1.1 History of Trichotillomania 12

1.2 Overview of Trichotillomania 13

Onset and Sub-Types of TTM 13

Three subsets of TTM; Automatic, Focused and Early Onset 14

Histology, Presentation of TTM and Confusion with Alopecia 14

1.3 Aetiology and Epidemiology of TTM 15

Prevalence 15

Gender 16

Ethnicity 16

Physiological Aspects 16

Trauma 17

1.4 Affective, Cognitive and Environmental Factors 17

Health and Wellbeing Impact 18

Social Impact 19

1.5 Psychological Models of Trichotillomania 21

1.6 Early Research on Neurobiologic, Pharmacologic, Behavioural and Dual-phase Approaches 22

1.7 Structure of the Thesis 26

Chapter Two: Literature Review……...28

2.1 Systematic Approach to the Literature Review 29

Search Terms 30

Inclusion and Exclusion Criteria 30

2.2. Literature Review Findings 31

Behaviour-based Treatment Approaches 35

Cognitions and Beliefs in TTM 38

Trauma and TTM 42

Review Summary 43

2.3 The need for Qualitative Research and Rationale for the study 45

2.4 Aims and Objectives 46
Chapter Three: Methodology..... 48
3.1. Ontology 48
3.2. Epistemology 49
3.3 Choosing a Methodology 49
Ethnography 51
Case Study 51
Grounded Theory 51
Narrative Approach 52
Phenomenology 52
Phenomenology vs. The Generic Qualitative Approach 53
3.4 Adopting and Using a Generic Approach 54
3.5 Establishing Rigour - Trustworthiness in Qualitative Research 57
3.6 Introducing Asynchronous Email Interview and Blogs 60
Researchers and the Internet; Introducing Email Interviews 60
Introducing Blogs and the 'Blogosphere' 60
3.7 Chapter Summary 62
Chapter Four: Methods..... 63
Reflexive Pause – Early Development of the Project 63
Engagement with Service Users to Inform Study Design 63
4.1 Ethical Considerations 64
Ethical Approval 64
Ethical Considerations Phase One – Email Interview 64
Information Sheet and Informed Consent 64
Consent Form 65
Confidentiality and Anonymity 66
Debriefing and Safety Protocols 66
Ethical Considerations for Phase Two – Blog Posts 66
Anonymity and Privacy 67
Informed Consent 69
4.2 Asynchronous Email Interviews 70
Recruiting Participants 70
Sampling Hard to Reach Populations 71
Sampling – Inclusion and Exclusion Criteria 71
The Email Interview Schedule 72
Data Collection, Timescales and Transcription 73
Advantages and Disadvantages of Email-Interviews 74
Netiquette and Rapport 75
Sensitivity and Reflexivity 75

4.3 Using Blog Posts in Qualitative Research 76
Access and Recruitment 76
Data Collection and Sample 76
Analysis 77
Advantages and Disadvantages of Blogs 77
4.4 Data Analysis 78
Inductive and Deductive Identification of Themes 79
Semantic and Latent Level Themes 80
Reflexive Pause – Being Reflexive during Data Analysis 82
4.5 Saturation vs. Information Power in Qualitative Research 82
4.6 Chapter Summary 84
Chapter Five: Presentation of Findings 85
5.1 The Cycle of TTM 86
5.2 Themes and Subthemes from the Email Interview: Experiences, Opinions and Perceptions of Trichotillomania 89
A Journey of Uphill Battles 89
Demonization and Hate of TTM 89
Shame and Distress 90
The Implications of Fearing Judgement 91
Coping by Concealment 91
Perceived Stigma, Secrecy and Non-Disclosure 92
Embarrassment and Avoidances 94
Persistent and Extensive Effects 94
Academic 95
Work 95
Relationships 96
Self-Identity and Lost Opportunities 96
Coexisting Health Implications 98
Physical implications 98
Psychological 98
Impulse Control and Permission Giving Behaviours 99
5.3 Themes and Subthemes from the Email Interviews: Experiences of Previous Treatments alongside perceptions and opinions of participants' ideal treatment strategy 100
Successful Treatments 100
Behavioural Treatments 100
Pharmacological Treatments 101
A Combined Approach 102
Unsuccessful Treatments 102
Behavioural Treatments 102
Pharmacological Treatments 103

Lapse in Duty of Care 104
Inadequate Training of Healthcare Professionals 105
Ideal Treatment Intervention 106
Dual-Phase Combined Treatment Approach 106
Working with Mental Health Professionals 108
Face to Face Support 108
Frequency and Duration 109
5.4 Acceptability and Feasibility of the Email Interview Method 110
5.5 Themes and Subthemes from the Blog Posts: Experiences, Opinions and Perceptions of Trichotillomania. 113
Acceptance 113
Societal View of Beauty 114
Secrecy and Shame 114
Stigma 115
An Endless Cycle that causes Distress 115
5.6 Summary of Findings 116
Chapter Six: Discussion 120
6.1 Critique of Project in relation to Aim and Objectives 120
6.2 Critical Discussion of Themes and Sub-Themes 123
Cycle of TTM 123
Shame and Distress 124
Coping by Concealment 126
Persistent and Extensive Effects 126
Self-Identity and Lost Opportunities 127
Impulse Control and Permission Giving Behaviours 128
Perceived Stigma, Secrecy and Non-Disclosure 129
Embarrassment and Avoidances 131
Acceptance 131
6.3 Discussion around the DSM-5 criteria in relation to the current findings 131
6.4 Professional Relevance and Implications 133
Medically Unexplained Conditions and the need for Individualised Treatment Plans 136
Trichotillomania applied to Briddon's ABC-E model of Emotion 137
6.5 Discussion around Acceptability and Feasibility of the Email Interview Method 139
6.6 Reflexive Account of the Research Process 140
Reflections on the Methodology and Methods 140
Reflections on the Sample and Recruitment 141
The 'Insider Perspective' 141
An Online Connection for people with Shared Conditions 142
6.7 Strengths 142

6.8 Limitations..... 143
6.9 Recommendations for Policy and Practice 143
6.10 Recommendations for Future Research..... 146
6.11 Contribution to Knowledge 147
Chapter Seven: Conclusion……..……..150
References……...153
Appendices……..172

Appendix One Successful Ethical Approval Application ……..……....172
Appendix Two Resubmitted Ethical Approval Application with Photo Consent……..…….....175
Appendix Three Participant Information Sheet and Consent Form……...178
Appendix Four Photo Consent Form……....181
Appendix Five Participant Debrief Sheet …….....…182
Appendix Six Email Interview Schedule……..…….....184
Appendix Seven Example of Coded Data Set (Email Interview) ……..….187
Appendix Eight Visual Representation of Hair Loss…….....198
Appendix Nine Summary of Themes and Subthemes discussed in Chapter Five…….……..199
Appendix Ten Example of Theme and Subtheme Development……..……..200

List of Tables

Table 2.1 Key and Descriptive Characteristics of the Nine Review studies……..31
Table 4.1 Table indicating Advantages and Disadvantages of the Email Interview Method……..75
Table 4.2 Braun and Clarke (2006) Six Phase Description of the Thematic Analysis Process…..80
Table 5.1 Demographic Information of the 20 Asynchronous Email Interview Participants……...85
Table 6.1 Summary of ICD-10-CM and DSM-5 Definitions of Trichotillomania……..132

List of Figures

Figure 5.1 The Cycle of TTM……....88
Figure 5.2 Diagram Illustrating the Themes and Sub-Themes from the Email Interview illustrating participant experiences, opinions and perceptions of TTM…….....89
Figure 5.3 Diagram Illustrating the Themes and Sub-Themes of the Email Interview illustrating previous successful and unsuccessful treatments, alongside an outline of participants' ideal treatment plan…….....100
Figure 5.4 Diagram Illustrating the Themes and Sub-Themes of from Blog Posts, illustrating blog user's experiences, opinions and perceptions of TTM…….....116
Figure 5.5 Conceptual Map highlighting relationships between TTM themes and sub-themes….119
Figure 6.1 Summary of Themes and Sub-themes from the Email Interview relating to primary aim…….121
Figure 6.2 Summary of Themes and Sub-themes from the Blog Data relating to a study objective……..…122
Figure 6.3 Four Types of Stigma Model (based on Pryor and Reeder, 2011) applied to TTM…..131
Figure 6.4 Outline of potential TTM treatment strategy, based on email interview responses…..136
Figure 6.5 Trichotillomania applied to the ABC-E model……....…139

Glossary

ACT	Acceptance and Commitment Therapy
BPS	British Psychological Society
BFRB	Body Focussed Repetitive Behaviour
CTD	Chronic Tic Disorders
CBT	Cognitive Behavioural Therapy
ComB	Comprehensive Model for Behavioural Treatment
CMC	Computer-Mediated Communication
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision
DOCS	Dimensional Obsessive-Compulsive Scale
ESS	Experience of Shame Scale
fMRI	Functional Magnetic Resonance Imaging
GP	General Practitioner
HRT	Habit Reversal Therapy
ICD	International Statistical Classification of Diseases and Related Health Problems
IPA	Interpretative Phenomenological Analysis
MRI	Magnetic Resonance Imaging
MGH-HPS	Massachusetts General Hospital Hair Pulling Scale
MUS	Medically Unexplained Symptoms
NAC	N-acetyl cysteine
NICE	National Institute for Health and Care Excellence
OCD	Obsessive Compulsive Disorder
ORM	Online Research Methods
PTSD	Post-Traumatic Stress Disorder
PITS	Psychiatric Institute for Trichotillomania
QOLS	Quality of Life Scale
SSRI	Selective Serotonin Reuptake Inhibitor
SPS	Skin Picking Scale
SPSS	Statistics Package for Social Sciences
SR	Stimulus Regulation
TTM	Trichotillomania
TDI	Trichotillomania Diagnostic Interviews
TCA	Tricyclic Anti-Depressants
WHOQOL-BREF	World Health Organization Quality of Life Scale
WAI-SR	Working Alliance Inventory-Short Revised
VHA	National Veterans Health Administration

Chapter One: Introduction and Background

This chapter will introduce and define trichotillomania (TTM), offering an outline of the history of TTM and an overview of TTM, including sub-types, prevalence, onset, histology and presentation of TTM. Aetiology and epidemiology will be presented, followed by a brief presentation of early background research. Lastly, an overview of the project will be presented alongside an outline of each chapter.

TTM is often described as a poorly understood disorder (Woods et al, 2006). The definitions asserted by researchers over the last few decades have varied to some extent; Stevens (1984) stated that TTM is a behaviour disorder associated with excessive hair-pulling, several years later, Palmer et al (1999) described it as a behavioural disorder associated with repetitive hair-pulling resulting in alopecia. In 2009, Chamberlain et al described TTM as a disorder which is associated with repetitive hair-pulling, which often results in noticeable hair loss and functional impairment, stating that the pathology of TTM exists in the focus, duration and extent of the hair-pulling behaviour, as well as the subsequent experiences of impairment.

This project will use the currently accepted definition of TTM; that TTM is characterised by the recurrent pulling out of one's own hair resulting in hair loss, with repeated attempts to decrease and/or stop hair-pulling behaviours. Furthermore, trichotillomania involves hair-pulling which commonly results in clinically significant distress or impairment across all aspects of life (e.g. social, occupational), and that TTM and its subsequent hair loss are not attributable to another medical condition or mental disorder (DSM-5; American Psychiatric Association, 2013). The DSM-5 is described by the American Psychiatric Association as a handbook widely used by healthcare professionals around the world as an authoritative guide to diagnosing mental disorders.

1.1 History of Trichotillomania

The concept of hair-pulling has been evident for thousands of years; it has been referenced in the Bible (Old Testament, book of Ezra) where Ezra describes hair-pulling in verse 9:3, "and when I heard this thing, I rent my garment and my mantle, and plucked off the hair of my head and of my beard".

Similarly, Homer's the Iliad (800 B.C) makes several mentions of hair-pulling, one of which occurs in Book X line 11, where Agamemnon pulls out his hair in desperation: "When he looked upon the plain of Troy he marvelled at the many watchfires burning in front of Ilius, and at the sound of pipes and flutes and of the hum of men, but when presently he turned towards the ships and hosts of the Achaeans, he tore his hair by handfuls before Jove on high, and groaned aloud for the very disquietness of his soul". Many centuries later, hair-pulling is mentioned within the work of William Shakespeare's play "Much Ado About Nothing"

> Claudio "Then down upon her knees she falls, weeps, sobs,
> beats her heart, tears her hair, prays, curses; 'O
> sweet Benedick! God give me patience!".
> (Shakespeare, 1599, 2.3. 960 - 963)

One of the earliest references of trichotillomania within medical literature was made by Hippocrates, who made reference to a person who “plucks his hair” in Epidemics 1 (Chadwick and Mann, 1983). In the late 18th century, Baudamant (1777–1779) referred to a TTM-related phenomenon, trichophagia (eating of hair) and a subsequent complication of this, by noting a trichobezoar (large mass of ingested hair) in a 16-year-old boy. However, ‘trichotillomania’ was not directly discussed, and was only overtly acknowledged much later in the 19th century where it was described as a discrete medical syndrome.

In 1889 the term ‘trichotillomania’ was introduced by French dermatologist Francois Hallopeau, who described it as a compulsion to pull out hair (Hallopeau, 1889; cited in Chamberlain et al 2009). Hallopeau thought that patients who displayed this compulsion were otherwise sane. However, dermatologists later suggested that TTM had a psychogenetic origin. Hallopeau considered the behaviour to be chronic and lacking a cure (Hallopeau, 1894; cited in Chamberlain et al 2009). Sadly, over a century later, no significant progress has been made in the field, as the disorder still presents as a chronic condition and lacks a definitive ‘cure’.

1.2 Overview of Trichotillomania

This section will highlight onset, sub-types and subsets of TTM, alongside histology, presentation of TTM and its confusion with alopecia.

Onset and Sub-Types of TTM

Sah, Koo and Price (2008) outline three sub-types of hair-pulling associated with age of onset. In pre-school age children, TTM often presents as a habit similar to thumb sucking. Children in this category are often younger than five years old, pull mainly from the scalp, often engage in hair-pulling unconsciously and may pull when asleep. The pre-adolescent to young adult age is the most common age of onset and the most common subtype; Sah, Koo and Price (2008) cite several researchers between 1991 – 2006 who suggest the mean age of onset is between 9 – 13 years, with females accounting for between 70% - 93%. There appears to be more episodes of chronic hair-pulling and relapsing within this subtype. Lastly, the adult subtype indicates the onset of TTM has occurred during adulthood. The onset of TTM at an adult age may be due to an underlying psychiatric condition, and in this case, psychiatric treatment to treat the underlying condition should take priority (Sah, Koo and Price, 2008). These three subtypes outlined by Sah, Koo and Price (2008) do not take into account the possibility of early onset in babies or young infants. Although less common, ‘baby trich’ has been discussed by several researchers; Swedo and Rapoport (1991) stated that ‘baby trich’ may constitute a separate and distinct entity, while Woods et al (2006) suggested that it is believed to be a short-term phenomenon that may be linked to attachment issues and covarying oral habits.

Woods et al (2006) also states that the average age of onset is between 9 – 13 years, with this group experiencing a more chronic form of TTM and that response to treatment is more challenging in this age group. Several years later, Duke et al (2010, p184) stated that “later onset is considered to be of increased severity, more treatment resistant, and more often associated with comorbid psychopathology”.

Three subsets of TTM; Automatic, Focused and Early Onset

Further to the three sub-types detailed above, there are three further subsets of TTM related to the nature of hair-pulling: automatic, focused and early onset. TTM was previously divided into two categories of hair-pulling: automatic and focused. Automatic (or unconscious) TTM is often seen in children and automatic hair-pullers do not recall pulling their hair. Christenson et al (1994) described the automatic state of hair-pulling as 'trance-like' and stated that 75% of adult chronic hair-pullers in their study had experienced phases of automatic pulling. Automatic pulling occurs outside of conscious awareness, it commonly takes place during sedentary activities and is highly responsive to tactile antecedents (e.g. touching head with fingertips). In contrast, focused TTM is commonly linked to affective or cognitive antecedents (Franklin et al, 2011). Focused (or conscious) hair-pulling often involves specific rituals, such as searching for specific hairs which may be wavy, bumpy, have a different texture, or different colour. Focused TTM is characterised by urges and tension which is often associated with obsessive compulsive disorders (Duke et al, 2010). There may also be oral rituals involved, such as biting off the hair bulb, chewing or swallowing the hair (trichophagia).

The differences between automatic and focused hair-pulling have not been widely investigated. Flessner et al (2008) has stated that previous research has attempted to examine the differences between focused and automatic TTM; with focused hair-pulling having a compulsive element and automatic hair-pulling having decreased awareness, but these constructs were not assessed using reliable measures. Results from the Flessner et al (2008) internet survey indicated that people with high levels of automatic hair-pulling reported more severe TTM and greater stress, compared to people with low levels of automatic hair-pulling. People with high levels of focused hair-pulling also reported more significant issues with depression and functional impairment in comparison to people with low levels of focused hair-pulling.

Early onset hair-pulling has been more recently introduced as a third subset of TTM. Duke et al (2010) stated that early onset TTM commonly occurs in children aged 8 or younger and is usually self-correcting without requiring intervention. It is important to note that these three subsets of TTM; automatic, focused, and early onset, are not exclusive and it is possible that a person may experience co-occurring subsets at any point (Duke et al, 2010).

Histology, Presentation of TTM and Confusion with Alopecia

The histology of TTM can be helpful towards diagnosis and on examination, increased numbers of catagen (transitional phase) and telogen (resting phase) hairs are noticed. Chronic hair-pulling induces a catagen phase in the cycle of hair growth; catagen phase is a transitional phase that comes directly after hair growth (anagen phase), whereby hair stops growing. In people with TTM, empty anagen follicles are noted and torn or damaged follicles are often seen alongside remnants of hair bulbs (Sah, Koo and Price, 2008). Perifollicular haemorrhage near the hair bulb or between the root sheath and connective tissue sheath is used to diagnose chronic TTM.

The DSM-5 (American Psychiatric Association, 2013) states that skin biopsy and dermoscopy (or trichoscopy) is able to differentiate TTM from alopecia. A dermoscopy on a person with TTM typically shows a range of specific features associated with pulling out hairs, such as a decrease in hair density, short vellus hairs, and broken hairs with different shaft lengths. According to the DSM-5 (American Psychiatric Association, 2013), TTM may occur from any part of the body, with the most common sites being the scalp, eyebrows, and eyelids, while less common sites are axillary, facial, or pubic regions. Additionally, hair-pulling can take place short episodes scattered throughout the day or during longer and more sustained periods that can continue for hours, with this type of hair-pulling often lasting for months or years. The physical presentation of TTM is described by Sah, Koo and Price (2008) as patients often having areas of different hair lengths, broken hairs, and tapered ends. TTM may result in various bald patches, or in severe cases the Friar Tuck pattern is noted (indicated by very short hair in the crown area, and longer hair at the back).

Trichotillomania may be confused with alopecia areata if a patient is not honest with their healthcare professional and denies the self-inflicted nature of hair-pulling. Thus, the healthcare professional would not have a full description of the issue and the hair loss would present itself as alopecia of an uncertain aetiology. TTM of the scalp often presents itself with thinning hair, or bald spots with stubble from recently pulled or recovering areas, whereas alopecia areata presents as bald spots which are completely bare. However, presentation of TTM of the eyelashes and/or eyebrows may be easily confused with alopecia areata, as patients with alopecia areata often exhibit patchy hair loss of the eyebrows and eyelashes (Shelleh, 2006).

1.3 Aetiology and Epidemiology of TTM

Duke et al (2010) has stated that the knowledge surrounding the aetiology of TTM is largely speculative, and due to this unclear understanding, there have been many experimental theories proposed by researchers. Davidson et al (1985) has stated that there are no epidemiologic studies exploring the incidence and prevalence of TTM. This has remained the same several decades later; Franklin et al (2011) stated that comprehensive and large-scale epidemiological studies have yet to be conducted.

Prevalence

The prevalence of TTM varies significantly; early research indicated that TTM was a ‘rare’ disorder, with Schacter (1961) estimating prevalence at 0.05%. Woods et al (2006) has stated that the estimated lifetime prevalence of TTM in adults can ranges between 0.6% - 3.4%. Duke et al (2010) has said that prevalence is between 1% and 13.3%, Duke discussed this large variance by stating that the current estimated prevalence levels for TTM are largely from student surveys which may not represent the clinical or general populations. More recently, the DSM-5 (American Psychiatric Association, 2013) has reported that TTM in the general population has a 12-month prevalence estimate in adults and adolescents between 1% - 2%. Overall, it has been suggested by Diefenbach et al (2000) that the incidence of TTM is on the rise, which should signify the urgent need for increased attention to fulfil the escalating needs of those individuals struggling with this disorder.

Gender

Stevens (1984) has previously suggested that TTM occurs more frequently in females and children than among males. For example, Christenson et al (1991) found that 93.3% of a sample of 60 chronic hair-pullers were female. This is also echoed in later research which suggests that TTM is disproportionally represented by females (Chamberlain et al, 2009; Diefenbach et al., 2008; Flessner et al 2008). It can be argued that TTM is disproportionally represented by women because women may seek help and treatment more often than men. Men may attribute their TTM to male pattern balding; they may also shave their heads if they are in denial about having TTM. There is agreement that hair-pulling is equally represented between gender in the younger population (Tay et al, 2004; Duke et al, 2010). However, it is understood that far more female adults report having TTM than their male counterparts.

Ethnicity

Ethnicity seems to play a role in the pull site, with Caucasians engaging in hair-pulling more often from eyelashes and eyebrows than other races (Neal-Barnett et al, 2010). TTM still remains an under-recognised disorder in the general population and also within ethnic minority groups. Walther et al (2010) states that research on the cross-cultural impact of TTM is very limited. Neal-Barnett et al (2010) discusses this further by stating that this is partly due to limited access to ethnic minority participants. There is a very limited amount of cross-cultural and racially diverse research on TTM; one of the only large-scale studies (Neal-Barnett et al, 2010) involved an online study comparing 103 ethnic minorities and 1290 Caucasian participants. Results from this study indicated that ethnic minorities participants reported increased levels of disruption in home management due to TTM and were less likely to participate in treatment. No differences between ethnicity were noted regarding the efficacy of treatment. Although it is clear that there is a paucity of research involving non-Western participants, the DSM-5 (American Psychiatric Association, 2013) has stated that TTM appears to manifest similarly across cultures.

Physiological Aspects

There is very limited evidence or studies exploring TTM using magnetic resonance imaging (MRI) and functional magnetic resonance imaging (fMRI) equipment. Chamberlain et al (2007) discussed a decreased cerebellar volume in patients with TTM, but no abnormalities in the caudate nucleus (as is the case with OCD patients). Thus, suggesting that TTM may not be part of the OCD spectrum, as currently categorised. Zuchner et al (2006) has also conducted genetic testing on TTM and it has been noted that several mutations (SLITRK1 gene) may contribute towards hair-pulling behavior.

The heterogeneity of TTM alongside the possible genetic and familial links has been explored by Novak et al (2009) in a twin concordance study; among a sample of 24 monozygotic twin pairs and 10 dizygotic twin pairs, results revealed that respective concordance rates for monozygotic and dizygotic twin pairs were significantly different at 38.1% and 0% for DSM-IV-TR (American Psychiatric Association, 2000) criteria for TTM.

More recently, the DSM-5 (American Psychiatric Association, 2013) has stated that there is evidence for a genetic vulnerability to TTM and that it appears to be more common in people with obsessive compulsive disorder (OCD) and their first-degree relatives, than in the general population.

Trauma

Very early research has suggested that TTM may be linked to early childhood physical and/or sexual abuse (Singh and Maguire, 1989). However, this is purely speculative, and based on a single case study where the authors say a "possible causal connection" may exist between TTM and the case's previous experience of sexual abuse. A study involving 60 female TTM patients revealed that only 18% had a history of childhood sexual abuse (Christenson et al, 1991), however, the rates were not significantly different from the general female population, being 12.8 – 24% (Chamberlain et al, 2009).

It has been previously suggested that experience of a traumatic event and/or post-traumatic stress disorder (PTSD) may possibly be linked to the aetiology of TTM. However, the aetiological underpinnings linking TTM to trauma is very limited. Gershuny et al (2006) assessed the prevalence of trauma and PTSD in a sample of 42 patients, approximately 76% of patients reported a history of at least one traumatic event, with 19% meeting criteria for PTSD. Findings also suggested that the prevalence of PTSD in patients with TTM may be higher than that of the general population. Gershuny et al (2006) also suggest that in traumatised patients, TTM may represent a method of coping via the use of self-soothing behaviours. In contrast to this, although some clinicians have speculated that the TTM may be a direct response to trauma, Woods et al (2006) has stated that only 5% of patients have comorbid TTM and PTSD.

Townsley-Stemberger et al (2000) noted issues associated with low self-esteem, secretiveness, shame and issues engaging in social activities among people with TTM. They suggested that these negative affects should be conceptualised as a cluster, which should be considered in the aetiology of TTM. There is no singular 'cause' of TTM and it can be generally accepted that TTM may occur through multiple pathways. Diefenbach et al (2000) suggests that the aetiology of hair-pulling is likely to involve a complex interaction of biological, psychological and social factors. Still, over the last several decades, many hypotheses have been proposed by researchers, with limited consensus over the cause of TTM. Therefore, the aetiology of TTM remains largely speculative, and there is a lack of epidemiological studies on the topic (Chamberlain et al, 2009). The aetiology of TTM is important to its classification; however, as there is a limited number of empirical research studies and knowledge regarding the aetiology of TTM is very limited. This could explain why TTM remains a misunderstood disorder that has been reclassified several times in the Diagnostic and Statistical Manual of Mental Disorders (DSM).

1.4 Affective, Cognitive and Environmental Factors

Duke et al (2009) investigated the phenomenology of hair-pulling in a large community sample of 830 participants (age range between 17–43 years old), where participants were actively recruited from the wider community in a south-eastern city in the USA. Results revealed several cognitions associated

with TTM, participants reported hair which “feels coarse” (53.3%), “doesn’t feel right” (30.0%), “is curly” (26.7%), and “doesn’t look right” (23.3%). Participants reported the environments they associated with hair-pulling behaviours as being: “while reading” (38.9%), “while watching television” (37.0%), and “in class” (35.25%). Duke et al (2009) is the first large-scale study examining the phenomenology of hair-pulling, in a large-scale community sample. Results revealed the most commonly endorsed rituals associated with TTM were “must pull out the root” (51.9%), “examine the root” (33.3%), “roll the hair between fingers” (27.8%), and “pull with certain fingers” (20.4%). Duke et al also note a decrease of other affective states across the hair-pulling cycle including feeling; anxious, depressed, bored, sad, angry, embarrassed, frustrated and lonely. Affective states of “calm” and “relieved” increased, and “indifferent” remained stable throughout. The affective state of “happy” was only evident during the hair-pulling activity. Interestingly, the mean age of onset in the Duke et al study (15.92 years) is higher than the previously reported average age of onset, between 9 – 13 years of age (Sah, Koo and Price, 2008). It is important to note that, within the Duke et al study, only 5 of the 830 participants met the full diagnostic criteria for TTM, thus giving an estimated prevalence of 0.6% for the people who met full diagnostic criteria. Although the Duke et al (2009) study was the first of its kind in utilising a large-scale sample, anonymous questionnaires were used and clinical assessment to confirm a diagnosis of TTM were not performed. Given the very low number of participants who met full diagnostic TTM criteria in this study, generalisation would prove problematic.

In terms of cognitive function, Chamberlain and Sahakian (2006) have stated that functional impairments and depression have been associated with TTM. Several investigations into cognition and TTM have revealed no evidence of cognitive deficits in TTM patients versus control (Coetzer and Stein, 1999), but treatment status was not confirmed (Chamberlain et al 2009). Early research (Christenson et al, 1993) involving a study of 75 individuals with TTM found that negative affective states and low self-esteem were common antecedents for hair-pulling. People with TTM are said to experience significant levels of distress, including high levels of anxiety, shame, depression and impairment across many areas of life (Woods et al., 2006), which may impact their health and wellbeing. Of the 1697 participants in the Woods et al study, most reported receiving TTM treatment (n = 1048), with many participants reporting unfavourably on the treatment they had received; 28.1% (n = 295) described a lack of TTM knowledge from their healthcare provider, 27.7% (n = 290) felt their healthcare provider had only heard about TTM, thus largely representing inadequate levels of TTM treatment among treatment-seeking patients. Of the participants who described receiving treatment, only 5% (n = 52) reported their symptoms as being “very much improved” (Woods et al., 2006).

Health and Wellbeing Impact

There are numerous ways in which TTM impacts an individual’s health and wellbeing, two of the broad areas are physical health and wellbeing, and psychological health and wellbeing. There are several physical complications associated with TTM, which include skin infections, bleeding, irritation, and inflammation from excessive hair-pulling (Duke et al, 2010). Sah, Koo and Price (2008) corroborate this and suggest that secondary infections can occur when an individual picks and/or scratches their scalp and/or skin. Christenson et al (1991) has stated that 48% of people with TTM

have an oral fixation with their hair and may run the hairs over their lips. If an individual eats the roots of their hairs or the entire hair, severe complications can occur. Patients who have a history of trichophagia (ingesting hair) may experience pain and nausea, with a risk of having a trichobezoar (large hair ball) which can prove fatal if not removed via surgical intervention.

It is common for TTM to exist in parallel with other issues and comorbidities. Davidson et al (1985) has stated that TTM is an overlooked disorder, that is difficult to treat and often has a poor prognosis. There is a tendency for TTM to be overlooked, as there are high comorbidity rates with other psychological disorders (Mulinari-Brenner and Bergfield, 2001). Further to this, psychiatric comorbidity is common, this may include anxiety disorders, mood disorders, substance use disorders (Lanoue et al, 2003) eating disorders (Christenson et al, 1991) and personality disorders in adults (Christenson et al, 1992) as well as anxiety and disruptive behavior disorders in youth (King et al, 1995). Due to this high rate of comorbidity, TTM is often overlooked and may not considered a long-term issue in its own right.

People with TTM frequently experience issues with depression and anxiety (Christenson and Mansueto, 1999). This is echoed by Duke et al (2009) who discusses a positive correlation between TTM and depression, as well as a correlation between TTM and anxiety in females (Duke et al., 2009). Treating TTM with comorbid disorders is also difficult, as Naylor and Grossman (1991) presented a case of a 16-year-old patient with TTM and comorbid depression; the depression responded to pharmacological treatment with fluoxetine, but the TTM did not respond. King, et al (1995) found that “as a group, hair-pulling subjects had substantial comorbid psychopathology, and a parental history of tics, habits, or obsessive-compulsive symptoms was common”.

Social Impact

One of the diagnostic criteria in the DSM-5 (American Psychiatric Association, 2013) states that TTM causes clinically significant distress or impairment in social and occupational areas. Significant impairment may also occur across different areas such as: social, occupational, academic, and leisure. Diefenbach, Tolin, Hannan et al (2005) also found that people with TTM reported more severe psychosocial impairment compared to control patients, as TTM severity predicted lower life satisfaction and lower self-esteem ($p = .05$), with participants also noting current and lifetime issues associated with grooming, physical health, social interactions, recreational activities and work productivity. These findings are generally consistent with other research which has highlighted impairment on daily functioning (Keuthen et al, 2002; cited in Diefenbach, Tolin, Hannan et al, 2005). Due to the wide scale impairment associated with TTM, Diefenbach, Tolin, Hannan et al (2005) have suggested that it is vital to improve resources in order to support the clinical care of patients with TTM. Interestingly, some previous research has found low clinician ratings of impairment and interference in daily functioning for TTM patients (Stanley et al, 1993), contradictory to growing support which recognises patient impairment in TTM; this could potentially be attributed towards a lack of clinician understanding around TTM at a time when rigorous research was limited.

It has been reported that chronic hair-pullers experience significant levels of depression, anxiety, shame, embarrassment, feelings of unattractiveness, and low self-esteem (Townsley-Stemberger et al, 2000). The issues surrounding self-esteem and feelings of unattractiveness seem to be ongoing in relation to TTM; Townsley-Stemberger et al (2000) used a clinical sample of 67 patients, their charts indicated the negative affective states evident in the treatment-seeking patients which included feeling unattractive (87%), low self-esteem (77%), secretiveness (83%), shame (75%).

Various studies have explored the social implications of TTM and have found that patients suffer pronounced impairment (Franklin et al, 2008, Wetterneck et al, 2006). Avoidance of social activities is common amongst people with TTM, as they attempt to maintain secrecy and avoid embarrassment. The activities commonly avoided are: haircuts, physical activities such as sports, outdoor activities, and sexual intimacy, with between 22 – 63% of patients with TTM avoiding these common activities (Townsley-Stemberger et al, 2000). Flessner et al (2008) also found people with TTM reported an impact on social activities as they participated in fewer social events and highlighted lower quality and quantity of friendships and romantic relationships. Diefenbach, Tolin, Crocetto et al (2005) and Diefenbach, Tolin, Hannan et al (2005) have both indicated patients have strong feelings of shame and embarrassment and will use various methods of concealment such as wigs, makeup, hats to disguise the effects of hair-pulling. Stemming from the idea of embarrassment, comes the concept of avoidance behaviours, with O'Sullivan et al (1996) stating that this may limit the patients desire to seek help. TTM has also be associated with family functioning impairment, as it can contribute towards family arguments and secrecy which may often result in an increase in stress, that can subsequently exacerbate TTM (Townsley-Stemberger et al, 2000). However, research is unclear whether family difficulties cause TTM, or are consequent to the development of TTM. Hence, longitudinal research and qualitative research is needed.

TTM also has numerous functional outcomes, adults have reported impairment in school, work, social functioning, lowered career aspirations (Diefenbach, Tolin, Hannan et al, 2005; Seedat and Stein, 1998 cited in Franklin et al, 2011; and Woods et al, 2006), with adults often spending a lot of money on methods of concealment and possible treatments (Wetterneck et al, 2006). Diefenbach, Tolin, Hannan et al (2005) examined the effects of TTM on lifetime work productivity, results indicated that TTM impacted the areas of any work productivity (78.6%), productivity at home (35.7%), concentration levels (60.7%), and lateness (25%). The concept of interrupted concentration has also been raised by Wetterneck et al (2006) who stated that people with TTM may often experience difficulty focusing, this can have an impact academic or occupational work and career advancement. An internet-based survey done by Franklin et al (2008) also revealed that TTM impairs the social and academic world of older children and adolescents. Franklin et al (2011) stated that many adolescent TTM sufferers have expressed fear that their classmates and peers would discover their hair loss and/or bald patches and evaluate them negatively. This fear may be well founded; Boudjouk et al (2000) found that developmentally normal teenagers who viewed videotaped clips of actors portraying individuals with TTM, chronic tic disorders (CTDs) or neither condition rated the social acceptability of those with TTM and CTDs as significantly lower than those without TTM or CTD.

One of the largest-scale TTM studies to explore the impact of TTM was conducted by Woods et al (2006). This involved an internet survey which was completed by 1697 people. The sample self-reported their symptoms which were consistent with TTM (as outlined in the DSM-IV-TR; American Psychiatric Association, 2000). The survey assessed various aspects including social, occupational, academic, psychological impact, treatment-seeking experiences, and phenomenological experiences. All 1697 participants reported mild to moderate impact and impairment in social, occupational, academic and psychological functioning; more than 20% reported avoiding vacations, 23% reported interference with employment, and 24% reported missing school. Thus, the study indicates that the impairment TTM sufferers feel has a significant impact on their daily lives. There appeared to be a correlation between impairment and TTM symptoms, as impairments became more pronounced if TTM symptoms became more severe. Impairment appears to worsen over time, with mild to moderate social and interpersonal impairment also evident in childhood (Franklin et al, 2008), this often progresses to moderate to severe impairment in later life (Woods et al, 2006)

1.5 Psychological Models of Trichotillomania

Over the years, there have been various models associated with TTM; some of these models have used reinforcement as a potential explanation of TTM, while others have discussed models of behavioural treatment and stimulus regulation. Ferster and Skinner (1957) and Skinner (2011) discussed reinforcement in relation to TTM. Positive reinforcement aims to strengthen a behaviour by providing a consequence which a person may find rewarding, thus providing a positive consequence which strengthens a preceding response. Mansueto (1991 cited by Chamberlain et al, 2009) conducted a study which included 30 patients, of which 39% reported a feeling of pleasure from the act of hair-pulling, thus implying that positive reinforcement may influence symptom mediation. Negative reinforcement involves the removal of an unpleasant reinforcer that may strengthen a behaviour, by removing the negative stimulus which is rewarding to the individual. In a large-scale study involving 1697 people, 40% reported feelings of anxiety, and they wished to reduce these negative feelings by engaging in hair-pulling (Woods et al, 2006).

Mansueto's (1999) ComB model (Comprehensive Model for Behavioural Treatment) is a model containing five modalities that act as cues and feedback that maintain hair-pulling behaviours. Mansueto states that the ComB model is a Cognitive Behavioural Therapy (CBT) approach used to treat TTM and other body focused repetitive behaviours. Its primary aim is to identify a target behaviour and create a targeted replacement, through the identification of five modalities that act as cues and feedback that maintain hair-pulling:

Cognitive	(individual's thoughts and beliefs about TTM)
Affective	(emotional states, emotional triggers, and subsequent consequences)
Motoric	(physical actions associated with TTM)
Sensory	(sight, touch, sound)
Place	(external / environmental)

Penzel's Stimulus Regulation (SR) Model of TTM (2002) assumes that the mechanisms which are responsible for balancing internal levels of stress do not work efficiently in people with TTM, with the

most likely reason for this being an underlying genetic predisposition involving serotonin and dopamine systems. Penzel's observations have indicated that people engage in hair-pulling when they are overstimulated (i.e. stress / positive or negative excitement) or understimulated (i.e. bored). He suggests that hair-pulling may be an external action by a genetically prone individual to regulate an internal state of sensory imbalance, and patients need to find an alternate way to regulate him/herself. Penzel describes the three types of activities providing stimulation:

Tactile	(touch, stroke, tug at hair, pull hair, handle / manipulate hair / run across face)
Visual	(watch the hair being pulled / examine pulled hairs / examine hair characteristics)
Oral	(chew / bite hairs, oral manipulation / ingestion)

Penzel has stated he believes his Stimulus Regulation model interfaces well with Mansueto's ComB approach; working with various biological, behavioural and cognitive tools to help TTM patients make recoveries that they can maintain. Penzel goes on to suggest that the part 'habit' plays in TTM can't be ignored. Additionally, due to the biological components of TTM, he suggests that psychiatric medication should be used more effectively.

There are some limitations to psychological models of TTM. These models may offer an explanation for the presence, maintenance of, and potential treatment of TTM, but they do not account for the initial development or manifestation of TTM. A model may explain how TTM is maintained; perhaps an individual describes relief of unpleasant emotions or tension relief, but it does not explain why people engage in hair-pulling behaviours rather than engaging in other more constructive or beneficial behaviours. It would be advantageous to explore biological or neurological models alongside participants' individual motivations and process of hair-pulling, as this information may highlight a more complete explanation for the development and maintenance of TTM which may impact the delivery of a treatment intervention. Furthermore, the two TTM models above do not take other cognitive elements into account, such as perfectionism or beliefs about self-control (Roberts, 2014). Other aspects such as an individual's core beliefs and personality traits are not taken into consideration.

It is clear that there may be multiple independent or interrelated factors that can contribute towards hair-pulling behaviours. Duke et al (2010, p. 186) succinctly states that it is likely "genetic influences impose a vulnerability to emotional dysregulation through biological processes; hair-pulling is learned to reduce associated discomfort (provide nervous system homeostasis), rewarding a behavior pattern that becomes classically conditioned to associated stimuli over time".

1.6 Early Research on Neurobiologic, Pharmacologic, Behavioural and Dual-phase Approaches

This section will aim to provide background information on early TTM research, which has encompassed a wide range of investigations on pharmacologic, neurobiologic, behavioural and dual approaches in an attempt to understand TTM and trial different forms of treatment. The early research

provided in this section will aim to provide background context on key treatment approaches noted before 2010, before proceeding onto a more structured and focused literature review chapter.

In terms of the potential neurobiologic basis in TTM, neuroimaging on patients with TTM have revealed a reduced volume in the left inferior frontal gyrus (Grachev, 1997) as well as a smaller left putamen (O'Sullivan et al, 1997) compared with control patients. In the Grachev (1997) study 10 females with TTM and 10 female control participants were used to investigate if there were any volumetric changes in the neocortex. Results showed that TTM patients displayed significantly reduced left inferior frontal gyrus volume of 27% ($p = 0.04$) and enlarged right cuneal cortex volume of 40% ($p = 0.03$) compared to normal controls. In the O'Sullivan et al (1997) MRI study, volumes of the brain structures were compared with a sample consisting of 10 females with TTM and 10 normal control females, matched for gender, age, handedness and education. Results revealed that the left putamen volume was significantly smaller in TTM patients. A decade later, an fMRI study measuring brain activation during implicit sequence-learning was conducted by Rauch et al (2007); findings revealed no significant differences in brain activation between TTM patients and control participants. A further MRI study (Chamberlain et al, 2008) investigating changes in neural circuitry using 18 TTM patients and 19 control, results revealed that patients with TTM patients exhibited grey matter density increases in several brain regions linked to habit learning, cognition and affect regulation. Brain imaging studies provide mixed support at best when examining volumetric differences in TTM patients versus control patients.

There have been investigations into the genetic basis for TTM; Greer and Capecchi (2002) reported that mice with disruptions and loss-of-function allele of Hoxb8 have shown excessive grooming behaviours leading to hair loss and lesions. Their observations being that excessive and pathological grooming by the mice results from CNS (central nervous system) abnormalities, and further state that Hoxb8 is expressed in regions known as the OCD circuit. Greer and Capecchi highlight the importance of future research on human patients with TTM exploring any defects in the Hoxb8 gene, or in paralogous genes (Hoxc8 and Hoxd8). Interestingly, the brain regions involved in the Greer and Capecchi study share noteworthy overlap with the neural regions reported to be structurally abnormal in one of the largest MRI studies of TTM patients (Chamberlain et al, 2008)

Early research on serotonergic interventions have been largely ineffective (Swedo et al, 1993). This has encouraged researchers to investigate other pharmacologic approaches, including:

- atypical antipsychotic (e.g. olanzapine)
- dopamine blocker (e.g. pimozide)
- opioid antagonist (e.g. naltrexone)
- inositol (a type of carbohydrate)
- tricyclic antidepressant (e.g. clomipramine)

Olanzapine has received some attention in the possible treatment of TTM, with the efficacy of using an atypical antipsychotic medication being examined by (Van Ameringen et al, 2006); 25 patients were randomly assigned to a 12-week trial of olanzapine or placebo, a flexible dose was administered

starting at 2.5mg/day, increasing up to a maximum dose of 20mg/day by week eight. Results indicated that Olanzapine improved symptoms of TTM (compared with placebo). Clomipramine is suggested to be superior to Desipramine for adult TTM patients, with further suggestion that results for Fluoxetine in adults remain inconclusive (Palmer et al, 1999). Fluoxetine has been examined in two randomised controlled trials (Christenson et al, 1991b; and Streichenwein and Thornby, 1995) both indicating that treatment was not efficacious. However, Riddle et al (1993) has previously suggested that Fluoxetine has safely and effectively been used to treating OCD behaviours within the paediatric population. Various other pharmacologic interventions have been tried, including the use of anti-depressants (selective serotonin reuptake inhibitors / SSRI's, and tricyclic antidepressants / TCA's). However, the use of anti-depressants can be considered risky as most come with a black box warning to patients younger than 25 years old, this warning indicates a potential increase or risk of suicidal ideations and behaviours. As Sah, Koo and Price (2008, p19) succinctly state "with a black box warning and lack of convincing results, the use of antidepressants must be weighed versus other treatment modalities for initial therapy – especially in patients who may have comorbid depression". Naltrexone (an opioid antagonist) has also been explored as a potential treatment for TTM with mixed results; O'Sullivan et al (1999) performed a placebo-controlled, randomised double-blind trial which lasted for 6 weeks, with 7 of 17 patients receiving 50mg Naltrexone per day. Results were favourable and individuals noted a decrease in TTM symptoms whilst on Naltrexone, but the results failed to reach statistical significance which could be attributed to the small sample size.

Pharmacological trials have their limitations which primarily are the use of small sample sizes, in the studies which do show treatment benefits or significant results, long-term follow-up data is sparse. Double-blind trials with long-term follow-up are needed in order to further examine the abovementioned medications and other potentially useful pharmacological treatments, this will inform TTM treatments so that firmer treatment algorithms can be generated (Chamberlain et al, 2009). There have also been other pharmacologic approaches researched, but these have largely been on individual cases or open-label uncontrolled and unpublished trials and are therefore largely unreliable (Duke et al, 2010).

Early research on behavioural treatment of TTM has involved a range of different behaviour-based interventions including habit reversal therapy (HRT), cognitive behavioural therapy (CBT), acceptance and commitment therapy (ACT), and decoupling. Bloch et al (2007) has suggested that the strongest evidence points toward HRT as a first line behavioural treatment for TTM. A landmark study by Azrin and Nunn (1973) is often considered to be the most researched and most effective HRT in the area, with the three main elements underpinning HRT as:

awareness training	(encouragement to be cognizant of hair-pulling behaviours)
competing response training	(doing a task that is incompatible with hair-pulling)
social support	(support to identify hair-pulling, and redirect to other behaviours)

Walther et al (2010) has said that counsellors will often add in another element, stimulus control, into HRT. One of the earliest studies to explore HRT and TTM (Azrin et al, 1980), where 19 patients

received HRT and 15 patients received negative practice training. These patients were randomised and received a two-hour session of either method. Results indicated HRT to be more effective than the punitive method, with a 91% reduction in TTM at 4-month follow-up. Long-term follow up at 22 months revealed that 75% of HRT patients reported a remission of TTM compared to 25% of the negative practice group. Moritz et al (2011) introduced a self-help method called “decoupling” which shares similarities with the HRT method. Where HRT aims to stop the behaviour, decoupling places the focus on behaviour deviation (e.g. instead of pulling hair from the scalp, deviate this behaviour to massaging the scalp). Decoupling has been presented as an alternative to HRT.

A different option for behavioural therapy is acceptance and commitment therapy (ACT). The core idea of ACT is acceptance of thoughts rather than reducing or eradicating thoughts and urges to engage in hair-pulling. Walther et al (2010) describes the four main components of ACT as:

- acceptance and awareness of thoughts, urges, and feelings that may cause discomfort
- rejection of emotional control that prevents growth toward life goals
- addressing the behaviours that prevent growth toward life goals
- cognitive defusion

There has since been research into using ACT and HRT as a dual therapy approach; Woods et al (2006b) conducted a randomised controlled study which examined the efficacy of using ACT and HRT as a dual therapy. Of the 25 patients, 12 patients who completed the ACT/HRT reported favourable results, compared with a control group. The ACT/HRT combination group reported a 58% reduction in the number of hairs pulled per day, and reductions in hair-pulling were generally maintained at follow-up three months later. Decreases in experiential avoidance were noted alongside improved treatment compliance, these aspects were significantly correlated with overall reductions in the severity of TTM. This suggests that targeting experiential avoidance may be useful in the overall treatment of TTM.

The last form of behavioural therapy within TTM research is cognitive behavioural therapy (CBT). Diefenbach et al (2006) compared group CBT with group supportive therapy with a sample of 12 patients in each group. Behavioural therapy consisted of eight sessions. Overall results indicated that the CBT group showed more TTM symptom reduction compared to the support therapy group. However, follow-ups scheduled at one, three and six months showed a significant worsening of treatment gains for the CBT group. Although there is no definitive method outlined for using CBT to treat TTM, a study by Flessner et al (2010) found that counsellors implemented CBT as a primary TTM treatment method. However, additional studies are needed to provide more support and evidence for current treatment approaches, behavioural approaches often utilise different protocols and implementation methods, which makes it inappropriate to compare results from different studies (Duke et al., 2010).

There has been limited research using a dual approach to treat TTM, in studies which have compared behavioural interventions and medical treatments (Ninan et al, 2000), cognitive behavioural therapy (CBT) and habit reversal therapy (HRT) techniques have demonstrated improvement over hair-

pulling. In Ninan et al's randomised parallel treatment placebo-controlled trial, patients in the medical treatment aspect of the trial received either placebo or clomipramine alongside weekly psychiatric sessions. Patients in the behavioural intervention (CBT) showed more improvement in comparison to other patients who took clomipramine (p=.016), or placebo (p=.026). The Dougherty et al (2006) study randomly assigned participants to treatment with sertraline or placebo, following 12 weeks of monotherapy, participants who did not demonstrate improvements had HRT added into their treatment. 13 participants completed monotherapy (either sertraline or HRT) over a 22-week period, and 11 participants received both modalities (sertraline and HRT). Results revealed larger gains in the dual modality group, indicating that a combined approach utilising both pharmacotherapy and psychotherapy may be effective in treating TTM.

It is evident that there have been efforts in early TTM research to explore pharmacologic, behavioural and dual-phase treatment approaches. However, it is important to note that there appears to be no formal clinical guidance from the National Institute for Health and Care Excellence (NICE) that outlines how people with TTM should be treated or supported. No information is currently listed on the NICE website under guidance and advice in relation to TTM; this speaks volumes as NICE provides guidance and advice to improve health and social care across the United Kingdom, and is a key organisation for providing essential information to key groups such as general practitioners (GP's) and health professionals.

This chapter has offered a historical perspective, introduction and background into TTM alongside early research to provide context on what research has previously been conducted to understand and treat TTM from a neurobiologic, pharmacologic, and behaviour-based perspective. Although there have been efforts to explore the causes of TTM, and efforts made to further our understanding of TTM, there is still no consensus on the aetiology or epidemiology of TTM. The next chapter will utilise a systematic approach to the literature review to provide a focused perspective into more recent TTM research, highlighting gaps in the literature and a rationale for the current project.

1.7 Structure of the Thesis

Chapter one has introduced TTM, presented the history of TTM and provided a broad overview of TTM onset and sub-types, affective, cognitive and environmental factors. Lastly, aetiological and epidemiological aspects have been presented, and the impact associated with TTM on social, health and wellbeing levels are highlighted. Lastly, early research involving neurobiologic, pharmacologic and behavioural background research has been presented.

Chapter two will present a systematic approach to the TTM literature over the last ten years; search terms will be detailed alongside a PRISMA diagram. The need for qualitative research will be discussed, leading into a rationale for the current project. The aims and objectives of the study will be presented at the end of this chapter.

Chapter three will provide a discussion around ontology and epistemology in relation to the current study, followed by a methodological discussion whereby five methodological perspectives will be presented alongside a rationale for choosing the adopted methodological approach. The chosen methodological approach (a generic qualitative approach) will then be discussed alongside the four elements of a well-designed research framework (Crotty, 1998).

Chapter four will focus on methods and will present phase one (asynchronous email interviews) and phase two (blog posts) of the study. Engagement with service users to inform the study design, and a commentary on the process of applying for ethical approval is discussed. Ethical considerations of each phase will be presented, alongside a discussion around researchers and the internet, netiquette and rapport. The chosen method of data analysis, Braun and Clarke's thematic analysis, will be discussed, alongside information power in qualitative research and sampling hard to reach populations. Additionally, reflexive pauses will be utilised at different points to signpost decision making processes, as reflexivity is a central aspect of qualitative research.

Chapter five will include a presentation of findings from the asynchronous email interviews and blog post data. Participant experiences, opinions and perceptions of TTM will be presented. Participants' experiences of previous treatments alongside their perceptions and opinions of an ideal TTM treatment strategy will be highlighted. Blog post data will explore blog users' experiences, opinions and perceptions of TTM. Extract quotes will illustrate each theme and sub-theme while aiming to show the breadth of participants within the interview.

Chapter six will include a critical discussion around the DSM criteria in conjunction with the current findings. Themes and sub-themes will be discussed in turn, linking to previous literature in the area and relevant theory, where possible. A reflexive account of the research process will be presented, reflections on the sample and recruitment will be highlighted and reflections on the email interview method will be discussed. The 'insider perspective' will be presented and using the internet for research will be discussed alongside how the internet can be used to create an online connection for people with shared conditions. Strengths and limitations of the project will be highlighted, professional relevance and implications will be discussed alongside participant responses to their ideal TTM treatment strategy. Recommendations for future research will be discussed and contribution to knowledge will be presented.

Chapter seven will conclude the project by outlining an overarching summary of the research alongside key aspects for consideration including the need for additional TTM training among healthcare professionals, and future research to develop and pilot a treatment intervention, as the overarching findings have indicated intermittent and severe, often lifelong impairment, frequent experiences of comorbid disorders, with the effects of TTM often feeling debilitating.

Chapter Two: Literature Review

This chapter will firstly provide a brief discussion on previous review papers in an attempt to provide context on what the previous reviews have found, followed by presenting a systematic approach to the literature review for the current project. Findings from the literature review will be synthesised and gaps will be identified to provide a rationale for the study. Chamberlain et al (2009) has said that there are no formal treatment guidelines for treating TTM, with the evidence base being very limited. The overall prognosis for TTM is poor, Woods et al (2006) has stated that approximately half of people with TTM access treatment, and only 15% of the people who access treatment report a moderate to large reduction in symptoms. Although there have been significant efforts made to investigate and explore TTM (as evidenced in the various reviews by Bloch et al 2007, Duke et al 2010 and Slikboer et al 2015), there is still very little known about the causes, epidemiology or aetiology of TTM, with treatment of TTM yielding mixed results at best. This further emphasises the need for additional research into the area so that people with TTM have better hope in understanding and treating their TTM.

A previous systematic review of behavioural and pharmacological treatments by Bloch et al (2007) compared the efficacy of three interventions (habit reversal therapy / HRT, selective serotonin reuptake inhibitor / SSRI and clomipramine) in randomised clinical trials. Seven studies were included in the review, meta-analysis showed that HRT was superior to treatment using clomipramine, and there was no evidence demonstrating SSRI's were more effective than placebo (Bloch et al, 2007). A further review was conducted by Duke et al (2010) and discussed a wide range of factors including prevalence, onset, neurobiology, comorbidity, and forms of behavioural and pharmacological treatment. The review was described as a "broad and thorough synthesis" of TTM literature, which aimed to provide a resource for healthcare professionals seeking information on TTM. Duke et al (2010) included a variety of studies, both controlled and open trials, and discussed psychological and psychiatric treatment options, stating that literature has consisted of primarily small and uncontrolled studies and more rigorous studies have involved behavioural therapy or pharmacotherapy. Duke stated that behaviour-based treatments demonstrate superiority over pharmacotherapy; further suggesting that a first-line TTM treatment approach should consist of CBT with HRT, but multi-site randomised clinical trials comparing behavioural treatments are absent in the area. Additionally, with very minor exceptions, treatment utilising HRT has undergone limited evolution in the last 30 years; stating that it is vital to advance theoretical frameworks in order to understand and treat TTM. This was further echoed by Franklin et al (2011) who discussed an overview of current treatments and outlines recommendations about existing and new clinical strategies, stating that that most studies involving treatment outcomes have focused on behavioural therapies and/or pharmacological intervention; with the collective findings being mixed, specifically regarding the efficacy of medication.

The most recent systematic review and meta-analysis in this area was done by Slikboer et al (2015) who aimed to assess the efficacy of behaviour-based interventions and pharmacological interventions

for TTM. Slikboer stated that other reviews in the area have not been systematically performed, with a very small number of controlled trials produced over 26 years of reviews being testament to the difficulties of low prevalence and secrecy associated with TTM. The systematic search performed by Slikboer et al (2015) included various databases (i.e. Cochrane library, EBSCOhost, MEDLINE before 1966, and Google Scholar). The database searches aimed to identify randomised controlled trials. The systematic search resulted in 462 records, twelve studies were included in the quantitative synthesis and nine studies in meta-analyses. Findings of the Slikboer et al (2015) review indicated that fluoxetine was ineffective in the treatment of TTM, while N-acetyl cysteine (NAC), clomipramine and olanzapine demonstrated potential in the treatment of TTM. However, psychotherapy and behaviour-based treatments were shown to be far more efficacious in treating TTM, in comparison to passive control groups. The review also highlighted that when behaviour-based treatments were compared to an active control (e.g. progressive muscle relaxation), both behaviour-based treatment and active control groups showed similar rates of efficacy. TTM is associated with high relapse rates, which was not taken into account in the review. Furthermore, the Slikboer review did not account for comorbidity which may be problematic as it is very rare to treat a patient with TTM who does not have a comorbid disorder (Woods et al, 2006). In summary, the Slikboer et al (2015) review indicated that behaviour-based therapy has the most evidence as an effective treatment for TTM, when administered by trained healthcare professionals. Slikboer et al (2015) concluded by stating that more randomised controlled trials are needed in the area that specifically investigate pharmacological treatment, psychological therapy and a combination of the two. None of the three reviews discussed above expressly included or discussed qualitative based research on TTM.

2.1 Systematic Approach to the Literature Review

The rationale for utilising a systematic approach to the literature review is to overcome any subjectivity that may result from a standard narrative review, by aiming to use an objective approach in order to reduce potential bias (Bruce and Mollison, 2004). This systematic approach to the literature review will aim to methodically search relevant databases, identify relevant literature through the use of explicit inclusion and exclusion criteria, and aim to read, critically assess and summarise findings of the included studies. An audit trail was kept to track the searches and articles, by clearly outlining the search terms, inclusion and exclusion criteria, this allows for reproduction of the database searches by other researchers. Polit and Beck (2006) state that it is important to summarise and evaluate evidence, highlight any similarities or differences and offer potential reasons if any inconsistencies are found. The stages for conducting a review have been outlined by Bruce and Mollison (2004) as involving a comprehensive identification of relevant literature, using clearly outlined inclusion and exclusion criteria, followed by a critical evaluation of included studies, summarising data in an informative way and interpreting findings.

Liberati et al (2009) has stated that systematic reviews are often done with the purpose of answering a specific and often narrow research aim or question. The most recent systematic review and meta-analysis paper (Slikboer et al, 2015) provided insight into behavioural and pharmacological TTM treatments. As the Slikboer et al review was published in 2015, the aim of the current review is to

provide a more focused perspective on any further TTM treatments in the last decade, and to further explore the area by including broader search terms of 'perceptions', 'experiences', 'opinions', 'therapy', 'treatment' and 'intervention', with the hope that peer-reviewed research papers would provide a more well-rounded insight into what different treatments have been trialled in the last decade, alongside TTM participants' direct perceptions, experiences or opinions about having TTM.

Search Terms

The search terms "trichotillomania" (abstract) AND "treatment OR intervention OR therapy" (anywhere) AND "perceptions OR experiences OR opinions" (anywhere) were used to search for peer-reviewed publications in three databases; PsychArticles, PsychInfo, and Medline, within an approximate 10 year time frame between 01 January 2010 – current date of search (04 December 2019). Following the review and screening of relevant articles for this review, in order to keep the review as up to date as possible, an alert system was set up on each database to notify the researcher if any further articles which met the search criteria were published.

Inclusion and Exclusion Criteria

Inclusion Criteria:

- Primary research articles which conducted a study exploring direct participant perspectives of treatment / intervention or therapy of TTM
- Primary research articles which directly explored TTM participant's opinions / experiences or perceptions of having TTM

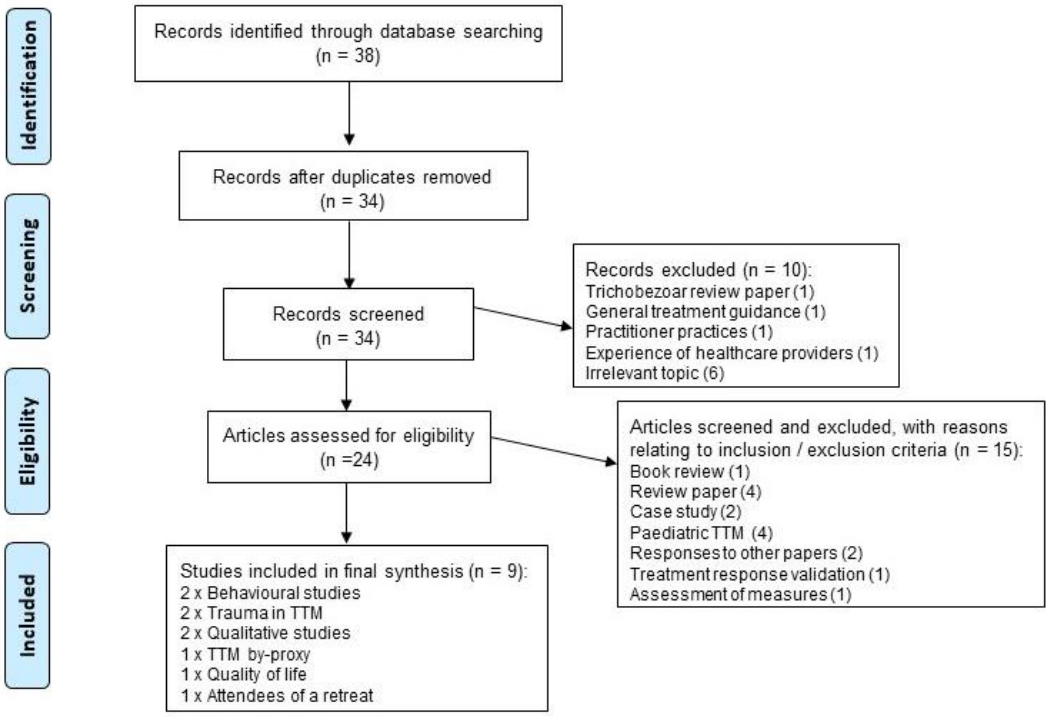
Exclusion Criteria:

- Duplicate articles and articles not written in English.
- Review papers and responses to other papers
- Papers which only involved a paediatric sample, as it has been previously asserted that hair-pulling in young children may constitute a distinct clinical entity (Swedo and Rapoport, 1991), that is often self-limiting without requiring intervention (Chamberlain et al, 2007).
- Any irrelevant articles, alongside any papers which detailed clinician / practitioner experiences or practices of treating TTM, as these did not provide a direct perspective of people living with TTM (as described in the inclusion criteria above).

In summary, articles were removed if they did not relate to TTM, did not discuss any direct participant treatment of TTM, or outline direct participant experiences of having TTM. The initial searches resulted in 38 articles. The abstracts of all 38 articles were screened against the inclusion / exclusion criteria. The screening and eligibility process can be viewed on the PRISMA diagram below. Of the 38 articles found, nine were included in the final review; these studies involved various topics including trauma, behaviour-based treatment, TTM by-proxy, quality of life, attending a retreat, cognitions and beliefs of TTM. The review has not utilised an appraisal tool; Grant and Booth (2009) have stated that a systematised review may or may not include a quality assessment tool but does provide a critical discussion on uncertainty of findings and study limitations. The current systematic approach to the literature review has largely followed the steps outlined by Bruce and Mollison (2004) and will present

key themes from the nine studies, provide a critique of the methods and sample alongside commentary on strengths and weaknesses, conflicting findings and generalisability of findings.

PRISMA Flow Diagram



Template Located on the Prisma Website and Adapted From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

2.2. Literature Review Findings

Analysis of the nine studies included in the review resulted in the identification of three themes: behaviour-based treatment approaches, cognitions in beliefs in TTM, and trauma. These will be discussed in turn in this section. First, however, the key characteristics of the nine papers are presented. Table 2.1 (below) provides an outline of all nine studies included in the systematic approach to the literature review; study description, demographic details, recruitment, measures and results are presented. The table below aims to provide a descriptive summary of each study to highlight key findings within the last decade, relating to participants' direct experiences of TTM treatments and participants' direct perceptions, experiences or opinions about TTM.

Table 2.1 Key and Descriptive Characteristics of the Nine Review studies

Study and Country of Origin	Study Description	Sample Description and Recruitment	Measures	Key Findings
Lee et al (2018) USA	Randomised controlled trial of Acceptance and Commitment	An active treatment condition (n = 12) was compared to a	- Miniature International Neuropsychiatric Interview (MINI) - Massachusetts General Hospital Hair Pulling Scale (MGH-HPS)	Reductions in TTM severity from pre-treatment to post-treatment, compared to the waitlist condition.

	Therapy (ACT) Enhanced Behaviour Therapy, using Telepsychology 10 weekly one-hour sessions.	delayed treatment waitlist control (n = 10). The average age was 32.5 years old 86.4% were women 95.5% of the sample were Caucasian Recruited from multiple university campuses, mental health providers, and advertising via internet	- Quality of Life Scale (QOLS) - The Acceptance and Action Questionnaire for TTM (AAQ-TTM) - Experience of Shame Scale (ESS) - The Working Alliance Inventory-Short Revised (WAI-SR) - Client Satisfaction Questionnaire-8 (CSQ-8)	Changes in psychological flexibility from pre to post treatment significantly correlated with changes in severity (p = .016). Perceived shame indicated non-significant improvement (p = .084) and Quality of life did not improve (p = .183)
Özten et al (2015) Turkey	Quantitative study investigating Trauma	23 patients with TTM (78.3% female, mean age 32.7) 44 patients with skin picking disorder (75% female, mean age 31.9) 37 health controls (64.9% female, mean age 30.7). Recruitment via Hospital Outpatients.	- Clinical interview to assess demographic and clinical data - Beck Depression Inventory (BDI) - Traumatic Stress Symptoms Scale (TSSS) - Dissociative Experiences Scale (DES). - List of traumatic life events (prepared by author).	No significant difference between all three groups on Dissociative Experiences Scale scores (p = 0.07). BDI and TSSS for the TTM and Skin Picking were higher than the control group. Patients with diagnosed TTM or Skin Picking reported higher numbers of traumatic and negative events in childhood, compared to control group.
Houghton et al (2016) USA	Cross-sectional study investigating Trauma and TTM	85 participants (mean age=35.39); 91.8% female, 82.4% Caucasian Recruitment via newspaper adverts, flyers, website adverts, and clinical referrals to a University based TTM clinic.	- Structured Clinical Interview for DSM-IV patient version (SCID-P), also included listing traumatic experiences and a screening for symptoms of PTSD - Massachusetts General Hospital Hair Pulling Scale (MGH-HPS) - Clinical Global Impressions Severity Scale (CGI-S) - National Institute of Mental Health Trichotillomania Severity Scale (NIMH-TSS) - Beck Anxiety Inventory (BAI) - Beck Depression Inventory (BDI) - Quality of Life Inventory (QOLI)	Participants who experienced trauma had more depressive symptoms, greater TTM severity, and increased avoidance. Over half the sample reported experiencing a traumatic event, with common types of situations being sexual assault (18.8%), witnessing violence (11.8%) and physical assault (10.6%). Trauma was associated with greater global TTM severity, and poorer quality of life.
Slikboer et al (2018) Australia	Qualitative semi-structured interviews exploring reward and punishment in TTM, using Theoretical Thematic Analysis	16 female participants; mean age range of 31.5 years old. Recruitment occurred via a local mental health organisation and TTM internet support groups	- National Institute of Mental Health TTM Impairment Scale (NIMH-TIS) - Massachusetts General Hospital Hair-Pulling Scale (MGH-HPS) - Depression Anxiety Stress Scale (DASS-21) - Semi-structured interview either in person, by telephone or teleconferencing. Interview centred heavily around the various states and behaviours associated with bio-	Three concepts identified relating to reward and punishment (behavioural activation system, behavioural inhibition system, fight, flight, freeze system and constraint). Participants perceived themselves as highly sensitive to punishment and generally distrustful

			behavioural systems linked to reward and punishment (i.e. behavioural activation system, behavioural inhibition system, fight, flight, freeze system, and constraint).	and/or suspicious of positive and rewarding life experiences. Participants experienced minimal reward or pleasure in life on a cognitive level. Anxiety was related to stress, fearing negative judgement and negative beliefs about appearance.
Rehm et al (2015) Australia	Qualitative study exploring cognitions and beliefs in TTM, using Interpretative Phenomenological Analysis	8 female participants (mean age 29.88) Ethnicity unknown. 4 participants from Australia 2 participants from UK 1 participant from Europe 1 participant from Asia Recruitment via adverts to mental health organisations and online peer support forums.	- Massachusetts General Hospital Hair-pulling Scale (MGH-HPS) - Obsessional Beliefs Questionnaire – Revised (OBQ-44) - Obsessive-Compulsive Inventory – Revised (OCI-R) - Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q). - Psychiatric Institute Trichotillomania Scale (PITS) - Yale-Brown Obsessive-Compulsive Scale: Trichotillomania version (YBOCS:TM) - Brown Assessment of Beliefs Scale (BABS) - Minnesota Trichotillomania Assessment Inventory– II (MTAI-II) - Mini-International Neuropsychiatric Interview- version 5 (MINI) - Semi-structured interview contained questions relating to the context in which hair-pulling occurs, experience of urges, physical sensations, affects, thoughts and behaviours, reflections on the function of hair-pulling.	6 of 8 participants demonstrated significant obsessive-compulsive symptomatology. Participants report living at 52.5% of their maximum quality of life. 7 of 8 participants reported seeking prior treatment for TTM, with no improvements. Six key themes identified: negative self-beliefs, control beliefs, beliefs about coping, beliefs about negative emotions, permission-giving beliefs and perfectionism. Findings suggest cognitions play a role in TTM phenomenology.
Falkenstein and Haaga (2016) USA	Survey exploring relationship functioning in TTM, by-proxy hair-pulling, symptom accommodation and self-disclosure.	670 participants, 96% female, 90% of the sample were Caucasian. 63% of survey respondents between 18 and 34 years old. Mean age unknown. Recruitment via TTM website, Facebook page and electronic newsletters relating to TTM.	- Massachusetts General Hospital Hairpulling Scale (MGH-HPS) - Trichotillomania Diagnostic Interview-Revised for DSM-5 self-report format (TDI-DSM-5-Self), an unpublished measure by the same authors - Trichotillomania-by-proxy scale (TTM-BP), also created by same authors - TTM-BP-C (current) and TTM-BP-L (lifetime) Versions of the scale above; these measures are unpublished scales by the same authors. - Milwaukee Inventory for Sub-types of Trichotillomania- Adult Version (MIST-A) - Relationship Assessment Scale (RAS) - Risk in Intimacy Inventory (RII) - Perceived Criticism Measure (PCM) - Social Interaction Anxiety Scale – Short From (SIAS-6) - The Multi-dimensional Scale of Perceived Social Support (MSPSS) - Frost Multi-Dimensional	TTM by-proxy urges reported by 54% of participants, while 37% reported having pulled hair from other people. Higher levels of TTM-by-proxy urges were associated with “focused” pulling (d = .37) and perfectionistic thinking (d = .16 to .20). More than one-third of respondents had pulled hair from others. Clinical levels of social interaction anxiety were endorsed by 51% of the sample. TTM severity was correlated with greater perceived criticism.

			Perfectionism Scale (FMPS) - Sheehan Disability Scale (SDS) - A series of open-ended and close-ended questions to ascertain symptom accommodation, symptom prevention, and self-disclosure	
Singh et al (2016) USA	Survey examining relationship between shame, quality of life and symptom severity in people with TTM, Excoriation Disorder (also known as Skin Picking) and Obsessive-Compulsive Disorders	OCD (n = 152) TTM (n = 248) Excoriation Disorder (n = 142). Of the total sample, 76.4% were female and 82.1% were Caucasian, mean age was 30.3 years old. Recruitment via websites related to OCD-related disorders, and various related self-help websites.	- Wetterneck Hart OCD screener (WHOS) - The Trichotillomania Checklist; heavily influenced by questions from the Structured Clinical Interview for DSM disorders (SCID) - Skin Picking Checklist was used (convert from TTM checklist above) - Dimensional Obsessive-Compulsive Scale (DOCS) - Massachusetts General Hospital Hair Pulling Scale (MGH-HPS) - The Skin Picking Scale (SPS) - The World Health Organisation Quality of Life (WHOQOL-BREF) - Experience of Shame Scale (ESS)	TTM, Excoriation Disorder and OCD were significantly correlated with shame. Shame was negatively correlated with quality of life for all three disorders. Gender was a significant predictor of quality of life in the TTM sample, with men reporting greater quality of life compared to women.
Rogers et al (2014) USA	Stepped care model for improving access to treatment. Step 1 (10 weeks online self- help), Step 2 (8 sessions voluntary in-person behavioural therapy with a student therapist, under supervision).	60 participants (95% female, 75% Caucasian) with a mean age of 33.18 years old. Recruitment via various adverts and clinician referrals.	- Structured Clinical Interview for DSM-IV-TR (SCID-I/P) - Trichotillomania Diagnostic Interview (TDI) - Massachusetts General Hospital Hairpulling Scale (MGH-HPS) - Psychiatric Institute Trichotillomania Scale (PITS) - The Alopecia Rating - Client Motivation for Therapy Scale - Client Satisfaction Questionnaire (CSQ-8) - Sheehan Disability Scale (SDS) - World Health Organisation Quality of Life - Brief Version (WHOQOL)	Treatment satisfaction was high; CSQ-8 scores averaged 25.13 (SD = 4.70) after Step 1, 28.54 (SD = 4.52) after Step 2, and 28.00 (SD = 4.49) at follow-up. 76% enrolled onto Step 2. 36% made clinically significant improvement in self-reported TTM symptoms. Reduction in symptoms, alopecia and impairment was noted alongside increased quality of life. However, some relapse occurred at 3-month follow-up.
Lochner et al (2013) USA	Survey exploring attendees' impressions of and experiences from attending a retreat for people with TTM and other Body-Focused Repetitive Behaviours (e.g. Nail biting / Skin Picking, etc).	62 participants (57 female; mean age 32.4 years old), Caucasian (n = 56). USA participants. 55 reported 1 or more disorder. 6 were attendee family members. 1 reported TTM in remission. Of the 62 participants, 11% had TTM, 53% had TTM and another body-focused repetitive disorder. Recruitment at the Retreat.	Survey consisted of Likert-type scales that assessed if attendees' needs were met by attending the retreat, and if the retreat format (e.g. lectures / groups / practical sessions) were effective. Survey was available in both paper and online formats.	92% of participants largely enjoyed the retreat (n = 57), and enjoyment of the social activities (n = 59). 57 participants largely agreed the retreat was well organised. 85% reportedly increased motivation to stop hair-pulling and/or picking.

Behaviour-based Treatment Approaches

Analysis of the nine studies revealed a theme of 'behaviour-based treatment approaches', within this theme, two studies explored behaviour-based treatment and one study explored experiences of attending a retreat. Lee et al (2018) utilised a randomised controlled trial of acceptance and commitment therapy enhanced behaviour therapy, using telepsychology to deliver treatment. Telepsychology refers to delivering traditional psychological support services using technology-assisted means. This appears to be the first study of its kind to treat TTM using telepsychology methods. Lee et al (2018) compared an active treatment condition (n = 12) to a delayed treatment waitlist control (n = 10). Intake and treatment sessions all utilised telepsychology methods, and all participants received treatment within their homes via video conferencing software. Treatment consisted of 10 weekly one-hour sessions, and a blend of traditional HRT techniques and more contemporary behavioural elements of ACT (using techniques to influence urges and cognitions). Participants were measured using a wide range of various measures (see table 2.1), some of which reported good internal consistency; the Massachusetts General Hospital Hair Pulling Scale (MGH-HPS) demonstrated internal consistency (α = .75), Quality of Life Scale (QOLS) demonstrated (α = .86), Experience of Shame Scale (ESS) reported α = .95, and the Working Alliance Inventory-Short Revised (WAI-SR) also demonstrated good internal consistency (α = .98).

Results from Lee et al (2018) indicated significant reductions in TTM severity compared to the waitlist condition. Treatment effects on TTM severity remained significant at 12-week follow-up, and improvements were also noted on psychological flexibility and perceived shame. However, quality of life did not improve. Although the authors conclude that ACT-enhanced behavioural therapy can be delivered successfully via online telepsychology methods, the data collected relied heavily on self-reporting measures and were not assessed by an independent evaluator. This may lead to inaccurate evaluations of TTM severity and an imprecise view into the overall treatment progress. Utilising an independent evaluator that is blind to the study aims would have been beneficial. Additionally, the authors did not assess for technical issues associated with telepsychology methods and barriers that clients may encounter during the treatment sessions (i.e. technical issues, loss of signal or interruptions with internet connection), a significant limitation given that the entirety of the study utilised online methods. Furthermore, 86.4% of the participant sample were women and 95.5% of the sample were Caucasian, signalling issues with generalisability to the wider population. Using a more socioeconomically diverse sample would have provided a clearer perspective on the use of telepsychology methods in delivering treatment.

Rogers et al (2014) aimed to test a stepped care model for improving treatment access. Sixty participants (95% women) participated, the sample were randomly assigned to either immediate or waitlist conditions for step one, which involved 10 weeks of online web-based self-help sessions, after which participants could decide if they wanted to take part in step two, which involved eight sessions of in-person habit reversal training (HRT). Various measures were used to screen participants and diagnose TTM (a full list of measures can be viewed in table 2.1). Some of the diagnostic measures were assessed by a second rater; 20% of the Trichotillomania Diagnostic Interviews (TDI) were coded

by a second rater with high agreement. While 20% of the Psychiatric Institute for Trichotillomania (PITS) were also coded by a second rater with single rater reliability being high (r = .95). Massachusetts General Hospital Hairpulling Scale (MGH-HPS) showed results in the sample as alpha .74. No significant differences were noted between step one and step two in self-report measures of TTM symptoms, alopecia, impairment or quality of life. Overall, step one appeared more efficacious for participants who frequently utilised the website. Stepped care was highly acceptable, treatment satisfaction within this step was high and 76% of participants chose to take part in step two (in-person HRT sessions). It was found that more symptomatic participants chose to enrol onto step two (HRT), and 36% were found to have made clinically significant improvements on self-reported symptoms of TTM. Step two treatment adherence was measured by the HRT therapist who assessed homework after each session. The HRT therapist was assessed on a further checklist by two raters and rater reliability for therapist adherence was high. During the behaviour-based therapy phase (step two), eight sessions of weekly HRT were administered by one of seven doctoral student therapists (under supervision). Treatment satisfaction was high, as evidenced by CSQ-8 scores which averaged 25.13 (SD = 4.70) after step one, 28.54 (SD = 4.52) after step two, and 28.00 (SD = 4.49) at follow-up. Following the stepped care program, participants experienced a reduction in TTM symptoms, alopecia and impairment, as well as an increase in quality of life. However, it was noted that quality of life and TTM symptom severity did experience some relapse when assessed at 3-month follow-up.

Rogers et al (2014) provided an insight into a stepped care method of treating TTM, by utilising online self-help strategies with the option of participating in in-person behavioural therapy. However, the waitlist control group was only maintained through step one and not throughout the entire study, leaving step two results based on an uncontrolled study. Overall, this two phase stepped care model was fairly simple and each step relied solely on patient self-selection. Although this program did provide evidence that stepped care can improve treatment access, the stepped care program did not take relapse rates into account, a significant limitation as relapse rates in TTM are common. Furthermore, Rogers et al (2014) stated that it may be beneficial to add an additional phase (step three) consisting of a specialised behavioural intervention that incorporates additional elements of acceptance and commitment therapy (ACT) or dialectical behavioural therapy (DBT).

Lochner et al (2013) assessed attendees' impressions of and experiences from attending a retreat. The annual retreat is run by an organisation in the United States and consists of a three to four-day event involving programs for adults, parents and children with TTM and other body focused repetitive behaviours and their significant others. The primary aim of this annual retreat is to provide education to service users and their significant others on aspects relating to their disorder. Attendees voluntarily attended the retreat and the retreat was not hosted or arranged by the researchers. The attendees, people with TTM and/or other related body-focused repetitive behaviours and their significant others, took part in an anonymous survey. 62 participants (57 females) completed the survey; 55 participants reported experiencing a form of body-focused repetitive behaviour, while 6 participants were family members of the attendees, and one participant reported TTM in remission. Of the 62 participants,

11% had TTM, while 53% had TTM and another body-focused repetitive disorder (e.g. skin picking / nail biting / cheek biting, etc).

Participants in Lochner's study completed a survey which consisted of Likert-type rating scales that assessed if attendees' needs were met by attending the retreat, and if the retreat format (e.g. lectures / groups / practical sessions) were effective and was available in both paper and online format. Results from the survey revealed that 92% of participants largely enjoyed the retreat (n = 57), with many referencing enjoyment of the social activities (n = 59). 57 participants largely agreed the retreat was well organised, with some giving a response of 'strongly agree' (n = 37). The survey ended with an open-ended section allowing more detail for any complaints or suggested improvements on future retreats. Participants largely found that attending the retreat was a helpful intervention that provided support and information about their disorders, attending the retreat also resulted in reduced stigma, shame and loneliness, and 85% reportedly increased motivation to stop hair-pulling and/or picking. Some participants with skin picking disorder (dermatillomania) provided critique that the retreat focused too heavily on TTM, describing that they felt their disorder was not as equally represented. Although the survey provided evidence that attending a retreat may be used as an innovative therapeutic tool, there was a relatively low response rate (60%) of the survey. The survey respondents were primarily adults, therefore the findings may not be applicable to all age groups. Young people may require different methods of intervention, which may have been illuminated by a more age-representative survey sample. Attending the retreat may only be a realistic option for a small section of society. Therefore, findings may not be generalisable, specifically to younger people who may benefit from different formats of support. The authors only provide a general description of the retreat content as involving lectures and sessions by healthcare professionals, consumers and other related professionals (e.g. hair stylists), there is no specific detail about the intervention content. The paper format of the survey was administered on the final day of the retreat, pre-retreat measures were not obtained making the ability to compare and contrast how people felt before and after the retreat not possible. The sample consisted solely of Caucasian participants all from the USA, signalling potential issues with generalisability to the wider population. Furthermore, a follow-up survey would have been useful to implement, to ascertain if any gains from attending the retreat (i.e. increased motivation and reduced stigma, shame and loneliness) were sustained over time.

Taken together, the findings from this theme suggest that online methods may be a potential treatment option for people with TTM, as Lee et al (2018) utilised telepsychology methods to deliver a behavioural intervention (ACT-enhanced behavioural therapy). Although there may be barriers to care using technological methods, Lee et al (2018) showed reductions in TTM severity from pre-treatment to post-treatment compared to waitlist condition, but no improvements were evident on quality of life among participants. Although the sample was of very limited ethnic and socioeconomic diversity and relied heavily on self-report measures, Lee et al (2018) concluded that ACT enhanced behavioural therapy can delivered successfully using an online method (telepsychology). Containing similar facets (behavioural therapy and online methods), Rogers et al (2014) involved a two-step treatment plan for TTM, online self-help followed by in-person habit reversal therapy. Treatment was more efficacious

for people who used the website more frequently. Treatment satisfaction was high, participants reported a reduction in TTM symptoms, alopecia and impairment, and an increase in quality of life. Rogers et al (2014) did provide evidence that stepped care can improve treatment access; however, the study failed to account for any long-term relapse rates which are common in TTM. Lochner et al (2013) explored attendee experiences of a retreat and largely found that retreats involving behaviour-based interventions can be used as a potential therapeutic tool, as participants largely reported that attending the retreat reduced stigma, shame and loneliness, while providing support and information to learn more about their disorders. This could arguably contribute towards an improvement in quality of life (although quality of life was not formally assessed within the survey).

Cognitions and Beliefs in TTM

Analysis of the nine studies revealed another theme, 'cognitions and beliefs in TTM'. Within this theme, two studies explored cognitions and beliefs from a qualitative perspective and two studies utilised surveys.

Slikboer et al (2018) explored how reward and punishment are experienced by people with TTM, by performing qualitative semi-structured interviews with 16 female participants who had a clinical diagnosis of TTM. Several measures were used in order to provide descriptive details related to TTM severity, impairment, anxiety and depression (see table 2.1). Results from the scales reported moderately severe TTM symptoms and impairment that was evident to peers and family members, severe depression (≥14), moderate anxiety (6-7) and severe stress (≥17). One author drafted a semi-structured interview, which was further refined by the co-authors. Participants took part in the interview, either in person, by telephone or teleconferencing. A theoretical thematic analysis based on the behavioural activation system, behavioural inhibition system, fight, flight, freeze system and constraint were used to provide details about how people with TTM experience reward and punishment. Slikboer et al (2018) results revealed three concepts relating to reward and punishment:

- The selection of rewarding stimuli was described as a top-down process (executive control) as opposed to an internal drive process (biological control)
- Activation of the behavioural inhibition system appeared to be linked to reward (hair-pulling) and punishment (life stressors)
- Freeze and fight behaviours were minimal, but avoidance behaviours were dominant

Overall, results from Slikboer et al (2018) revealed that participants in the sample perceived themselves as sensitive to punishment and generally distrustful and/or suspicious of positive and rewarding life experiences. Participants often explained experiencing very minimal pleasure in life on a cognitive level; this suggests that TTM may be relevant to the whole self, as opposed to being viewed as a separate behaviour (Moulding et al, 2016). For participants in the study, anxiety was linked to various factors: stress, fearing negative judgement and negative beliefs regarding appearance. Slikboer et al (2018) participants described hair-pulling as a means to regulate both anxiety and distress, but the resultant hair loss lead to further worry about being negatively evaluated which lead to further anxiety. Although Slikboer et al (2018) provided an insight into how people with TTM perceive reward and punishment and provided three important concepts, the study did not

clinically assess for TTM as the primary disorder within the sample and Slikboer did state that separating TTM from anxiety and depression was difficult. The study involved a solely female sample, given that the study explored reward and punishment from several key facets of the behavioural system, it is likely that the absence of male participants in this sample influenced the overall findings by possibly reducing the likelihood of “fight” behaviours that may have emerged from the data.

Rehm et al (2015) aimed to explore cognitions and beliefs that lead toward the onset and maintenance of trichotillomania. A sample of eight females took part in a semi-structured interview which explored their cognitions and beliefs before, during and after a hair-pulling episode. Rehm et al (2015) utilised both clinician-administered and self-report measures (table 2.1 contains a full list of measures used). Results from the measures revealed moderately severe TTM symptoms, and moderately severe functional impact. The sample experienced clinically significant symptoms of OCD; 6 of 8 participants demonstrated significant obsessive-compulsive symptomatology. Participants also reported living at 52.5% of their maximum quality of life, and 7 of 8 participants reported seeking prior treatment form TTM, with no TTM improvements. The semi-structured qualitative interview was developed by the authors, the interview contained questions relating to the context in which hair-pulling occurs, experience of urges, physical sensations, affects, thoughts and behaviours, reflections on the function of hair-pulling. Interviews were analysed using interpretative phenomenological analysis (IPA), findings revealed six key themes: negative self-beliefs, control beliefs, beliefs about coping, beliefs about negative emotions, permission-giving beliefs and perfectionism. These findings suggest that the cognitions experienced by people with TTM play a vital role in understanding the phenomenology of TTM. The implicit beliefs that were revealed in the interview could be useful in understanding the onset and maintenance of automatic hair-pulling behaviours; Rehm et al states that, given the significant levels of TTM automaticity, future research should aim to explore the role of cognitive processes that lie beyond conscious awareness. The study found that an individual’s cognitions play an important role in TTM phenomenology, and that the implicit beliefs exhibited by a person with TTM could be useful in understanding the onset and maintenance of an individual’s hair-pulling behaviours. Although these cognitions may play a key role in understanding TTM, the sample of 8 unmarried women limits the generalisability to the wider population. Utilising men within the sample may have provided different cognitions and beliefs, providing a more well-rounded perspective into TTM. Participants also reported high levels of comorbidity, raising questions about the resultant cognitions and beliefs being specifically linked to TTM. Although comorbidity within individuals with TTM may be high, it would be helpful to distinguish between the thoughts and cognitions relating to TTM and other comorbid disorders. Rehm et al (2015) suggested that quantitative research which further explores cognitions and beliefs utilising larger samples would be beneficial in order to advance cognitive-behavioural models and treatments.

A survey by Singh et al (2016) examined the relationship between shame, quality of life and symptom severity in non-referred people with TTM, excoriation disorder (also known as skin picking) and OCD, under an umbrella category of obsessive compulsive and related disorders. Although this study looks

at three different disorders, and not solely TTM, it was included in the current review as TTM is listed as an obsessive-compulsive and related disorder in the DSM-5 (American Psychiatric Association, 2013) and the researchers involved a group of people who self-reported as having TTM (n = 248). Data were collected from 3109 participants; 1592 participants were excluded for incomplete responses. Survey responses were screened to assess likely diagnoses of either OCD, TTM or excoriation disorder. 975 participants were excluded due to comorbidity. The sample relied on self-reported diagnoses consisting of OCD (n = 152), TTM (n = 248) and Excoriation Disorder (n = 142). Of the total sample, 76.4% were female and 82.1% were Caucasian, with a small amount of other racial backgrounds. A battery of various measures was utilised (see table 2.1). Most of the measures used reported favourably, the Dimensional Obsessive-Compulsive Scale (DOCS) had good internal consistency (α = 0.93), the Massachusetts General Hospital Hair Pulling Scale (MGH-HPS) reported (α = 0.87), the Skin Picking Scale (SPS) reported (α = 0.88), as did the World Health Organisation Quality of Life (WHOQOL-BREF) reporting (α = 0.89) and the experience of Shame Scale (ESS) also demonstrating good internal consistency (α = 0.94).

Initial linear regression analysis in Singh et al (2016) highlighted that gender was a significant predictor for quality of life ($p < 0.05$), gender was controlled for in all subsequent analyses. Results also indicated that TTM, excoriation disorder and OCD were significantly correlated with shame, while shame was negatively correlated with quality of life for all three disorders. Results highlighted that gender differences were evident in relation to shame and quality of life, while regression analyses showed that shame was strongly related to quality of life compared to symptom severity for all three disorders. Overall findings indicate that people with OCD and related disorders are likely to experience shame and diminished quality of life. Although gender played a significant role when relating to separate variables in the study, gender was not a significant predictor of quality of life for the OCD or skin picking participants. In contrast, gender was a significant predictor of quality of life for participants with TTM, and males reported greater quality of life compared to females. Although this study did provide a perspective into shame, symptom severity and quality of life within these category-related disorders, the study relied solely on self-report measures done via an online survey. The overall effects of the study findings were small. An observational study may uncover different data, as the self-reporting nature of the measures used heavily rely on an individual's perception of themselves. Additionally, although validated measures were used, no formal diagnoses were obtained, replicating this study using an outpatient sample may be beneficial.

Falkenstein and Haaga (2016) investigated relationship functioning in TTM, by-proxy hair-pulling, symptom accommodation and self-disclosure. Data from adults with TTM were collected via survey (n = 670); 96% of the sample was female, 90% of the sample were Caucasian and 73% of the sample were from the United States. A full list of measures can be found in table 2.1. Several open-ended and close-ended questions were included to ascertain symptom accommodation and symptom prevention by family members and other close friends. Two additional questions (developed by the authors) were included to ascertain self-disclosure of TTM in close relationships. Findings indicated that approximately a quarter of the participants had not disclosed their TTM to their close friends, and

one fifth had not disclosed TTM to their romantic partner. Results also revealed that TTM symptom severity was correlated negatively with relationship satisfaction and perceived social support. TTM symptom severity was correlated positively with perceived criticism, perceived risk in intimacy and social interaction anxiety. 54% of participants in the sample reported experiencing TTM by-proxy urges, while 37% reported they had pulled hair from other people. TTM-by-proxy hair-pulling urges were notably higher for people who engaged in "focused" hair-pulling behaviours (d = .37) and for people who experienced perfectionistic thinking (d = .16 to .20), yet by-proxy urges were not associated with functional impairment. More than one-third of participants had pulled hair from others, and many reported keeping TTM a secret and not disclosing their disorder to close friends and even romantic partners. 51% of the sample reported experiencing clinical levels of social interaction anxiety. TTM severity was correlated with greater perceived criticism. A small correlation was evident between greater TTM severity and lower relationship satisfaction, this suggests that people who experience severe TTM behaviours are less satisfied in their relationships. Participants reported issues related to social interaction anxiety, 51% of the sample reported high scores that would warrant a formal diagnosis of social phobia.

Falkenstein and Haaga (2016) is one of limited number to use a large-scale survey to examine TTM, however, as the nature of the study involved an internet survey, self-reported symptoms of TTM were given and a clinician would not be able to confirm diagnosis of TTM. The study did use a significant number of self-report measures, three of which were unpublished measures created by the authors which lends to potential issues with validity and reliability. The sample consisted of limited diversity, signalling potential issues with generalisability. The study demonstrated that TTM by-proxy urges are linked to focused hair-pulling and perfectionistic cognitions. The results indicate that TTM has far reaching implications; but relied heavily on self-report measures (including some unpublished scales) from an internet survey. The authors did not differentiate if TTM symptoms were exacerbated by relationship difficulties, exploring these issues from a qualitative perspective may provide a deeper insight into the impact of TTM.

Taken together, the findings from this theme suggest that there are cognitions and beliefs associated with TTM. Slikboer et al (2018) identified that people with TTM perceived themselves as sensitive to punishment and distrustful of positive life experiences. Falkenstein and Haaga (2016) identified that people with TTM often experience by-proxy urges and perfectionistic thinking, and many engaged in keeping their TTM a secret. Singh et al (2016) found that participants may experience shame and diminished quality of life. Containing similar facets relating to perfectionistic thinking and quality of life, Rehm et al (2015) revealed that people with TTM reported living at 52.5% of their maximum quality of life, and also identified negative self-beliefs and perfectionism beliefs within the sample. Participant cognitions and beliefs can play a role in advancing our understanding in the phenomenology of TTM and can be used to understand the onset and maintenance of TTM.

Trauma and TTM

Analysis of the nine studies revealed a theme of 'trauma and TTM', within this theme, two studies explored the links between trauma and TTM. Özten et al (2015) aimed to investigate if there were any links between traumatic life events, symptoms of post-traumatic stress disorder and dissociation in people with TTM and skin picking disorder. 23 patients with diagnosed TTM, 44 patients with diagnosed skin picking disorder and 37 health controls comprised the sample. The full sample involved more female than male patients; 78.3% in the TTM group, 75% in the skin picking group, and 64.9% in the control group. After three psychiatrists conducted clinical interviews, patients then completed various self-reported measures assessing depression, traumatic stress and dissociative experience (see table 2.1 for a list of measures used).

Participants completed a list of traumatic life events in order to ascertain any exposure to traumatic events (Özten et al, 2015). The types of traumatic events included a list involving; natural disasters, fire explosions, traffic accident, physical attacks, sexual assault, war, exposure to torture, death incidents, serious illness or unexpected death of a loved one, domestic violence, economic difficulty. All the data were compiled, and a clinical psychologist evaluated the data diagnosis-blind. Patients were excluded if they had a coexisting mental illness (other than TTM or skin picking). The measures assessing depression and traumatic stress symptoms for TTM and skin picking were higher than the control group. Özten et al (2015) reported that patients with TTM or skin picking experienced significantly higher numbers of traumatic and negative events in childhood, compared to the control group. Therefore, Özten et al (2015) conclude by stating that trauma may play a role in the development of both TTM and skin picking. Findings from this study also highlighted an increase in the duration of hair-pulling or skin picking which was correlated with a decrease of PTSD symptoms. However, the study failed to establish whether trauma and/or PTSD or TTM and/or skin picking preceded the development of the mental health disorder. Additionally, the study relied heavily on self-reported scales, the reliability of these scales completed by a patient without clinician intervention is lower than that of more structured clinician administered measures. The sample size was small, and based on their findings, a conclusion cannot be adequately made that suggests TTM may serve a dissociative or anxiety-relieving function.

A year later, Houghton et al (2016) stated that it has been previously asserted TTM may be triggered by traumatic events, but there was a lack of reliable evidence to confirm this. Houghton et al (2016) explored the links between trauma and TTM by utilising a cross-sectional sample of adults with TTM. The sample comprised 85 participants (91.8% female; mean age=35.39), most of the sample being Caucasian (82.4%). Various measures were administered to assess traumatic experiences, hair-pulling severity, global impairment, anxiety, depression and quality of life (table 2.1 contains a list of measures used). Results indicated that participants who had experienced trauma reported higher levels of depressive symptoms, greater TTM severity and increased avoidance. Of the self-reported traumatic experiences, over half the sample reported experiencing a traumatic event, with the most common types of situations being sexual assault (18.8%), witnessing violence (11.8%) and physical assault (10.6%). However, the presence of a traumatic event history did not relate to hair-pulling

symptom severity in the past week. Findings in this study revealed that trauma was associated with greater global TTM severity, marginally greater experiential avoidance as indicated by the AAQ ($t(81)=1.96$, $p=.054$), and poorer quality of life compared to participants who had not reported a history of traumatic experiences. Results from Houghton et al (2016) have suggested that trauma is not directly related to TTM, but rather linked to overall symptoms and associated impairment. Further to this, trauma and global TTM severity were both mediated by depressive symptoms, thus suggesting that people who engage in hair-pulling behaviours who have experienced trauma may subsequently experience negative affect, which results in greater TTM severity. Houghton et al (2016) did not provide a dimensional assessment of trauma severity and relied on participants to self-report traumatic events. Furthermore, the definition of 'trauma' is likely to vary considerably between participants, which is likely to lead to over-reporting or under-reporting. A clearer view on the extent to which participants have been affected by any traumatic event would have been achieved if the researchers had provided a more rigorous dimensional assessment of trauma severity.

Although there were two studies exploring the links to trauma and TTM, results from both studies were in conflict and no consensus was achieved to indicate that trauma and TTM are interlinked. To compare these two studies exploring trauma and TTM: Özten et al (2015) relied heavily on self-report measures, included a small sample and did not establish whether trauma and/or PTSD or TTM and/or skin picking preceded the development of a mental health disorder, Özten et al conclude by stating that trauma "may play a role" (p. 1209) in the aetiology of both TTM and skin picking disorder and that people with TTM or skin picking reported higher levels of traumatic events in childhood. However, findings from Houghton et al (2016) cast doubt on the idea that TTM is directly linked to trauma, instead it is suggested that pathological TTM may be exacerbated by those who may have a history of traumatic experience, and not that their TTM is a direct manifestation of trauma. Only half the Houghton et al sample reported a meaningful traumatic event, although Houghton did not assess trauma severity or provide a standardised definition of trauma for their participants, the findings suggest that trauma is not a universal precursor of TTM. As these two studies had conflicting results, significantly more robust research is needed to further explore whether traumatic events exacerbate symptoms of TTM.

Review Summary

Although there have indeed been review articles published in the area (with three presented at the beginning of this chapter), there is still very little known about the causes, epidemiology or aetiology of TTM, with treatment of TTM yielding mixed results at best. This indicates the need for additional research into the area so that people with TTM have better hope in understanding and treating their TTM. These sentiments have also been echoed by other researchers; Chamberlain et al. (2009) stated that additional research is needed to explore TTM treatments. In their view, there is a paucity of rigorous research and a lot of unchartered territory regarding potential TTM treatments. Chamberlain et al (2009) says that the understanding of TTM in terms of its phenomenology, neurobiology and treatment remains incomplete. Franklin et al (2011) suggested that it is vital for

clinically oriented TTM researchers to aim to meet the demand for more rigorous information and TTM training, in order to do this, Franklin suggested that research in the next five years should focus on the development of optimised models as a means to address the major shortage of therapist expertise in TTM that is evident globally. Previous review papers have focused primarily on treatments for TTM, with treatments largely falling into two categories: behavioural and pharmacological treatments. Overall findings from the Slikboer et al (2015) systematic review and meta-analysis revealed that behaviour-based therapies are more efficacious than pharmacologic methods in treating TTM. This overarching conclusion is also noted by Duke et al (2010) who stated that randomised trials have demonstrated that behaviour-based treatment approaches are more superior to pharmacotherapy.

As there are already three previous reviews on TTM (Bloch et al 2007, Duke et al 2010 and Slikboer et al 2015), a decision was taken to run a focused database search strictly within the last decade utilising broader search terms. It is acknowledged that this database search strategy may reflect some limitations, including the possibility that relevant literature may have been available prior to 2010. It is also possible that articles may have been missed that focused solely on intervention *or* experiences. The chosen search terms included Boolean operators to account for variation in wording, as research articles often use phrases (e.g. intervention, treatment, therapy) interchangeably. As previously mentioned, the current review aimed to further explore if any other treatments have appeared in the area over the last decade, while also aiming to provide a broader view on TTM by including any papers that discuss experiences, opinions or perceptions of TTM from the perspective of the individual themselves. The search terms utilised in the current review aimed to provide a deeper perspective into TTM, as previous systematic review papers have primarily focused on behavioural and pharmacologic treatment of TTM. This goal was achieved, with the inclusion of these two qualitative studies in the current review. In relation to the nine studies included in the review, it is noted that the availability of empirical research in the field over the last decade is sparse. Additionally, this review has shown that there are limitations which affect the quality of available evidence, with the evaluation of some interventions being underpowered.

The nine studies included in this review have utilised samples of fairly limited diversity and a very limited number of qualitative studies. The review clearly highlights the wide-ranging implications associated with TTM. Analysis of the nine studies resulted in the identification of three themes: behaviour-based treatment approaches, trauma and TTM, and cognitions and beliefs in TTM. Findings of the nine studies have revealed that behaviour-based treatments can be useful and can work well within a combined approach (online methods and behaviour-based therapy). Additionally, the links between TTM and trauma are tenuous at best and require significantly more rigorous research to explore if traumatic events exacerbate TTM. Furthermore, the ‘cognitions and beliefs in TTM’ theme has provided insight into how TTM may be maintained through various perceptions, cognitions and beliefs, which can be considered when treating TTM. Findings from the literature review have emphasised that many people with TTM may experience by-proxy hair-pulling urges, and that people with OCD and related disorders (including TTM) may experience shame and diminished

quality of life, but that attending a retreat may serve as a useful therapeutic tool in reducing stigma and shame.

2.3 The need for Qualitative Research and Rationale for the study

TTM is known to be a debilitating and distressing disorder, it has been commonly linked to great secrecy and shame, a lack of understanding about the availability and efficacy of TTM interventions further contributes toward poor prognosis and routine outcomes (Slikboer et al, 2015). Most TTM research has focused on pharmacological and behavioural research, with the majority of previous literature being quantitative in nature (Franklin et al 2011, and the systematic review of behavioural and pharmacological interventions by Slikboer et al, 2015). The current systematic approach to the literature review (see summary table 2.1) has highlighted a range of other research on different topics (e.g. qualitative research, trauma, by-proxy hair-pulling, quality of life). There has also been some research on the effects of TTM: in the Woods et al (2006) study, all 1697 participants who took part in the TTM survey reported mild to moderate life impairment (including social, occupational, academic psychological areas). However, qualitative research which fully explores these impairments from the perspective of the TTM patient is lacking. As there has been an over-reliance on quantitative methods when investigating and exploring TTM, with many studies reporting mixed results in treating TTM, qualitative methods seem an appropriate step forward in the area. In this respect, the current study aims to fill this gap, by providing an in-depth contextual qualitative account.

Franklin et al (2011) reported that much previous research surrounding TTM has been conducted through open and uncontrolled trials. Duke et al (2009) has previously stated that using large, geographically diverse samples would be a factor in advancing the understanding of hair-pulling behaviours. Some other studies, such as Flessner et al (2008) have used the internet to recruit and survey large participant samples. These are quantitative surveys that lack the depth which qualitative research can provide, quantitative surveys may highlight that people with TTM report life impairment or disruption in daily life, but by using a qualitative approach these issues can be further explored to ascertain how and in what ways TTM affects people. The current study aims to address this gap.

Studies in this field have placed emphasis on utilising quantitative methods and qualitative studies are few and far between. There is a large amount of quantitative research on TTM which focuses on biomedical and behavioural topics, this does indeed provide vital information on TTM but fails to provide an in-depth and well-rounded insight into the topic. Although quantitative research is important in providing a focused and statistical perspective into a topic, qualitative research can provide a broader perspective which is rich in participant perception and experience; something which a measurement scale would be unable to provide. Thus, a broad internationally-inclusive qualitative study is absent in this area, and the proposed research aims to contribute to this area through recruitment of an international and geographically diverse sample, as TTM occurs across the world and incorporating an international approach could generate new and relevant insights.

In contrast to people experiencing impairment associated with TTM, Stanley et al (1993) noted low clinician ratings of impairment for TTM patients; this contradicts accumulating evidence which highlights the negative consequences associated with TTM and further emphasises that TTM is a misunderstood disorder. TTM is under-recognised in the general population (Odlaug et al, 2010) and in ethnic minority groups (Neal-Barnett et al, 2010). Furthermore, as Walther et al (2010) states, the availability of research exploring the cross-cultural impact of TTM is sparse, and there is an absence of multicultural considerations that multi-culturally experienced therapists should take into consideration when treating people with TTM (McDonald, 2012). These assertions heavily influenced the decision to recruit an international and geographically diverse sample in the current study.

In summary, this project aims to address the abovementioned gaps in previous research by providing an in depth contextual qualitative account which explores participant perceptions, experiences and opinions of TTM, via recruitment of an international and geographically diverse sample. It is envisaged that this will generate new and relevant insights into many different facets of TTM. In order to achieve a full exploration of participant perceptions, opinions and experiences of TTM from an internationally diverse sample, the study will involve gathering data from asynchronous email interviews and blog posts which will be analysed using Braun and Clarke's thematic analysis. The methodology and methods chapters will unpack this further, alongside the associated ethical implications and relevant steps taken towards data analysis.

2.4 Aims and Objectives

As the literature review has shown, there is an abundance of quantitative research in the area, with very limited qualitative studies available. TTM is considered an under-researched topic with unexplored and limited qualitative enquiry about perspectives and experiences. Thus, the current study aims to address this gap, by providing an in-depth contextual qualitative account utilising an international and geographically diverse sample. The primary aim of this project is to explore the opinions, perceptions and experiences of people with TTM (including any overall effects relating to social, health and wellbeing implications).

One of the objectives was to explore what participants envisage their ideal TTM treatment would consist of, this stemmed from the suggestion that TTM is an underdiagnosed disorder and when it is eventually clinically diagnosed, it is often treated ineffectively (Duke et al, 2010). By identifying participant treatment preferences to potentially inform or develop an intervention, this may fill a gap in the existing literature, as Duke et al (2010) states there is an inadequate supply of counselors who are trained or specialise in the treatment of TTM, this scarcity in fully equipped professionals means that people with TTM are likely underserved. Additionally, given the dearth of qualitative research exploring TTM, several questions were included to seek participant opinions on participating in the asynchronous email interview, by exploring aspects of acceptability and feasibility of gathering data from an international and graphically diverse sample using online methods.

Alongside the primary aim (to explore the perceptions, opinions and experiences of people with TTM), the project has three objectives:

- Explore participant experiences, opinions and perceptions of TTM via asynchronous email interviews and blog post data.
- Identify participant treatment preferences, to potentially inform or develop an intervention
- Consider implications for future development and delivery of support / services for people with TTM.

Chapter Three: Methodology

This chapter will provide a discussion around ontology and epistemology in relation to the current study, followed by a methodological discussion and justification of using a generic qualitative approach alongside the four elements of a well-designed research framework (Crotty, 1998). Creswell (2012) states that researchers should have a firm grasp of the various philosophical assumptions (e.g. ontology, epistemology, methodology) that underpin qualitative research and be in a position to adequately articulate them within a research study or presentation. Within research, a researcher brings to the inquiry a "basic set of beliefs that guides action" (Guba, 1990, p. 17), these may be certain paradigms or perspectives that may frame or influence their actions. Huff (2009) has suggested that acknowledging philosophical perspectives in research can shape how the problem is examined, how research questions are studied and how researchers seek information to answer the research questions / aims of a study. This suggestion is also noted by Denzin and Lincoln (2011) who stated that philosophical assumptions are important concepts that are folded into the interpretive frameworks used in qualitative research. This chapter will therefore begin with a consideration of the philosophical concepts that underpin this research.

3.1. Ontology

Within research, scientific paradigms are determined by ontological positions, with the adopted ontological position establishing the process of "knowing" which subsequently leads to an epistemological position that is concerned with the nature and scope of knowledge (Slevitch, 2011). Ontology involves the process of understanding what can be known and the nature of reality (Crotty, 2003), and is used to inform the explanation of reality. Realist ontology asserts that our world is composed of various structures which have a cause-effect relationship on each other. In contrast, relativist ontology is known to place emphasis on the diversity of interpretations.

This project has adopted a relativist ontological position, this position acknowledges the idea that our understandings of the world are diverse and unstructured (King and Horrocks, 2010). A relativist ontological position puts forth a belief that reality is a subjective experience (Denzin and Lincoln, 2005), this suggests that reality and human experience are closely interlinked. This position acknowledges the existence that multiple interpretations of an experience may come with multiple realities, and researchers utilising this position should aim to understand the subjective experience of a participant's reality and the multiple truths that may exist (Levers, 2013). Becker (1992) has stated that experience is the source of all knowing and forms the foundation of our behaviour, and that these experiences constitute the basis of knowledge about ourselves, other people, and the world.

Most of the study aims and objectives involved investigating the experiences, opinions and perceptions of people with trichotillomania, this informed the position of the current study as the sample consisted solely of people with TTM, but the experience of each individual person was unique to them. The assertion by King and Horrocks (2010) describing the existence of multiple and diverse realities and perspectives, directly informed the decision to involve a diverse range of participants

from various geographic locations. In a similar vein, Polit and Beck (2008) have also stated that multiple interpretations of one reality may exist in an individual's mind, and no process exists that is able to determine if these constructions are viewed as true or untrue. This project acknowledges that multiple interpretations of one reality may exist, and by including a diverse sample of people living with TTM who all may have different experiences with their TTM, it is hoped that similarities and differences would be more noticeable when exploring the realities of this TTM sample group.

3.2. Epistemology

Epistemology uses ways to describe how we know what we know (Sprague, 2010), it offers a perspective into the nature of knowledge and the different ways of understanding and learning about reality, epistemology is succinctly defined by Crotty (1998, p3) as "the theory of knowledge embedded in the theoretical perspective and thereby in the methodology". This project has adopted a constructivist position which asserts that knowledge does not exist in a state awaiting discovery (Gordon, 2009) but that humans construct knowledge through meaningful interactions with the world (Morcol, 2001). This is further discussed by Robson (2002) who stated that the term constructivism aims to identify the core assumption that reality is socially constructed, and is a relativist position that signifies no external reality exists that is independent of human consciousness. This aligns with the current study as people with TTM actively spoke about their experiences of TTM alongside their opinions and perceptions of TTM. The study sample all disclosed they had a TTM diagnosis and their direct experiences of having TTM would subsequently have an influence on their reality and social experiences.

As mentioned above, where ontology involves the process of understanding what can be known and the nature of reality (Crotty, 2003), epistemology describes how we know what we know (Sprague, 2010). Ontology and epistemology sit beside each other and provide a perspective into what the researcher believes to be the nature of truth (Berryman, 2019), they work together to shape a study and have informed the theoretical positioning of this study.

3.3 Choosing a Methodology

There are many commonalities of qualitative research; all qualitative research aims to understand data that are complex (Morse and Richards, 2002). Qualitative methods offer an insight into individual experiences and the way in which meaning is constructed (Patton, 2002). Furthermore, qualitative methods are commonly used in the exploration of topics where little is known, one of the central aims of qualitative methods is to investigate and understand complex situations, this ultimately results in gaining a complex insight of the phenomena in question (Morse and Richards 2002).

Choosing a qualitative research paradigm can be challenging and a researcher may become too preoccupied in epistemological underpinnings, rather than choosing a methodological approach focused on meeting the study aims (Sandelowski, 2000). One way of understanding qualitative approaches is to consider the overall purpose of a methodological approach, this can be divided into three broad groups. When considering the use, meaning or role that language plays in research, this

may involve the description and interpretation of participant data and subsequent development of theory (Tesch, 1990), the approaches that aim to develop theory are typified by grounded theory (Glaser and Strauss, 1967). Socio-linguistic perspectives may be used to explore how language is used, this commonly involves discourse analysis (Potter and Wetherell, 1987) and conversation analysis (Schegloff, 2007). From a different perspective, when the research goal involves the description and interpretation of participants' views, qualitative approaches such as phenomenology, content analysis and thematic analysis are commonly used to achieve these goals.

Qualitative research commonly utilises approaches that are flexible and sensitive to the social context of the topic under investigation, and recognises the idea that multiple truths may exist. The different approaches listed above are useful when aiming to investigate issues where the evidence base is limited. This allows for the acquisition of new and relevant insights into a phenomenon. The methodological choices a researcher makes will be dependent upon whether the primary focus of a study is within a specific paradigm and examining a topic through a particular lens, or if the primary objective is on health service research, the main priority would be to find the best suited approach in order to investigate a specific issue. Methodological choices largely depend on whether a researcher chooses to focus their study through a particular lens, or if the focus is on health service research the main priority would be finding what the best suited approach would be, in order to investigate or address a specific issue.

Smith et al (2011) stated that designing a study that explores how people make, interpret and understand their experiences of health and illness can be challenging, as there is a diverse range of approaches to choose from. For a researcher to make an informed decision, it is essential to have an understanding of the similarities, differences and underlying principles of the main qualitative methodological perspectives (Morse and Richards, 2002). There are a diverse variety of qualitative methodological approaches available to use; as Gale et al (2013) have discussed, the approaches which pay close attention to language and how language is used in social interactions (discourse analysis, Fairclough (2010) and ethnomethodology, Garfinkel (1996). The approaches which are concerned with experience and meaning (phenomenology, Merleau-Ponty 1962) and narrative methods, Reissmann (2008), and the approaches which seek to develop theory derived from the data (grounded theory, Glaser and Strauss 1967). These various methodological approaches are often underpinned by philosophical ideas which shape the process of data collection and analysis.

This following section will provide a discussion on five core qualitative traditions outlined by Creswell (1998, 2012), followed by an explanation of the methodological choices made that resulted in adopting a generic qualitative approach. Creswell (1998, p15) offers his definition of qualitative research which focuses on the methodological nature and its nature of naturalistic enquiry:

> "Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in natural setting."

In 1998, Creswell listed the five core traditions of qualitative research as ethnography, case study, grounded theory, biography (later renamed as narrative), and phenomenology. In order to contribute towards rigour and to clearly outline the methodological decisions which contributed towards the final approach used in this study, the five core traditions outlined by Creswell will be discussed further below.

Ethnography

Ethnography focuses on investigating a network of social groupings, social customs, beliefs, behavior, practices, that may define a culture. This perspective is primarily interested in the social-cultural realm of qualitative research. Morse and Richards (2002) state that ethnography provides a means to explore cultural groups (or the beliefs, values and behaviours of a cohesive group of people). Within a cultural group, behaviours are often patterned and vales are shared. Ethnography is a holistic approach that aims to be contextual and reflexive, and is presented from the emic perspective (Boyle, 1994). Ethnography can be used to study smaller subcultural units (e.g. people a shared illness or condition), and it believes that knowledge is socio-culturally constructed in relation to circumstance. However, Morse and Richards (2002) state that ethnographic research is best conducted by researchers who are not part of the cultural group; if a researcher shares the participants' culture it can be argued that it is difficult for the researcher to clearly see the beliefs, values and behaviours shared by the participant sample. After considering an ethnographic approach, it was decided that the current study was not well suited toward using ethnography, as the aim was not to investigate social customs or practices of TTM that may define a culture (or subcultural unit).

Case Study

Case study often involves a highly detailed exploration of a single case, using multiple methods alongside a variety data sources. Percy et al (2015) define a "single case" as having a clearly recognisable boundary that differentiates the case from any other collection of instances. The case study approach can pose difficulties as the researcher needs to recognised that there may be several possible candidates for selection, and if the study at hand would be best suited to include a single case or multiple cases; as a study involving multiple cases may dilute the overall analysis by lacking adequate depth of a single case. In this case, the researcher would choose between using multiple cases for a move towards generalisability, at the potential expense of diluting the depth of a single case. Case study would not have been a suitable approach to use within the current study, as it was an aim to try and capture experiences, opinions and perceptions from a fairly large and diverse sample of people with TTM.

Grounded Theory

Grounded theory originated from symbolic interactionism and puts forth a viewpoint that reality is negotiated between people and regularly evolves (Blumer, 1986). Within this methodological perspective, there is an aim to analyse data in order to understand the ways that reality is socially constructed. The researcher aims to explore the data with theoretical sensitivity and construct a theory that is grounded in the data. Glaser and Strauss (1967) advocated that theory should be

developed “in intimate relationship with data, with researchers fully aware of themselves as instruments for developing that grounded theory” (Strauss, 1987, p.6). As the core goal of grounded theory is to develop a theory derived from the data, a study using this approach will likely offer a core concept and its attendant theory. After consideration of grounded theory, it was decided that this may not be an appropriate method to use in the current study, as it was not an explicit aim to develop a theory on TTM but rather to explore participant experiences, perceptions and opinions of TTM.

Narrative Approach

Creswell (2012) describes narrative research as focusing solely on one or two individuals, gathering data through the collection of stories and experiences and often involves gathering data through many different forms. Originally referred to as ‘biography’ in the 1998 edition but has since been revisited and re-labelled. This tradition may be challenging as the researcher needs to collect extensive amounts of information about the subject, as the researcher should aim to give a multi-layered and diverse context of their life. Additionally, the researcher should have a good understanding of historical and/or contextual material, so the subject can be adequately framed within larger societal or cultural trends. This approach was not well suited to use within the current study, as it was not an aim to seek historical or biographical accounts from each participant.

Phenomenology

Phenomenology primarily investigates the ‘lived experience’ (or pre-reflexive conscious experiencing) of various psychological phenomena. The key interests of a phenomenological researcher commonly involve exploration of the inner dimensions, textures, qualities and structures (or essences) of cognitive processes, and not in external content (Percy et al, 2015). As Van Manen (1990, p9) succinctly stated “phenomenology differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world pre-reflexively, without taxonomizing, classifying, or abstracting it”.

As Morse and Richards (2002) discussed, phenomenological reflection takes place within four existentials, namely temporality (lived time), spaciality (lived space), corporeality (lived body), and relationality or communality (lived human relation). In phenomenology, the terms ‘experiencing’ and ‘experiences’ can be contrasted: phenomenology is interested in the ‘experiencing’, which focuses on the inward and ongoing task of understanding a phenomenon (Percy et al, 2015). Whereas, ‘experiences’ focuses our attention outwardly. The phenomenological approach aims to develop an accurate and complete description and understanding of a particular experience, with researchers often attempting to ‘bracket’ their presuppositions.

Some of the perceived limitations of the phenomenological approach include: the language and terms used in existential-phenomenological philosophy are usually complex, and this may miss information about broader experiences, if the study focuses on a specific time period or moment. By focusing on one aim (e.g. a rich description of experience), other important factors may be missed (e.g. what led to that experience, the consequences of the experience). Participants need to be carefully selected or

screened, as they will need direct experience with the phenomenon under investigation. Phenomenology would have been the closest 'fit' to use in the current project and will be discussed alongside a generic qualitative approach in the next section.

Phenomenology vs. The Generic Qualitative Approach

After reflecting on the underpinning theoretical perspectives of Creswell's five core traditions, it was clear that adopting one of these approaches would not fully align with or enhance the study aims and objectives. Out of the five core traditions, a phenomenological approach could have been used as it was largely aligned with exploring participants' direct experiences within the current study. Some of the aims, objectives and interview schedule questions focused on direct answers and/or opinions, acceptability and feasibility of participation and not on the participants perceptions or experiences. Therefore, a generic qualitative approach is an appropriate way forward.

Percy et al (2015) has stated there are some topics that simply cannot be underpinned with traditional qualitative methodological designs. In such situations where there is an imperfect fit, a generic qualitative design can be used. Percy et al (2015, p78) advised that, after deciding your topic and interest points within the topic, if the questions focus on the "actual opinions themselves, the life experiences themselves, the participants' reflections themselves, and less on the inner organisation and structure of the participants' experiencing processes, then phenomenology would not be appropriate, but a more generic qualitative analysis would be".

Percy et al (2015) has stated that the most difficult distinction to make is differentiating between using a generic inquiry or phenomenology. This was indeed the case in the current study, as it was originally envisaged the study would be underpinned using a phenomenological perspective, by exploring the lived experiences of individuals with TTM. However, as the study developed and following a review of literature, the scope of the project expanded. This was possible, as the asynchronous email interview involved an in-depth interview schedule with many email exchanges. The email interview schedule was adjusted to include aspects of acceptability and feasibility, as well as asking participants their opinions on what their ideal TTM treatment plan would be. A phenomenological approach would be concerned with inner organisation (with the phenomenological interest being in the internal subjective structures of the experience itself). If the focus is on the outward (e.g. the content of opinions, actual life experiences, participant reflections of themselves, reflection of occurrences in the past) a generic approach would be better suited for this. The current study involves a focus on the outward aspects, detailed above, which better aligns with a generic qualitative approach.

Percy et al (2015) has stated that the primary goal of generic qualitative research is to gather data from representative groups of people, with the aim to explore their real-world events, processes and/or experiences. Additionally, generic qualitative research investigates subjective opinions, attitudes, beliefs, reflections on people's experiences of events that take place in the outer world. Percy et al (2015) offered some guidance on using the generic qualitative approach as a

methodological approach and asserted that it is an appropriate approach to use if the following criteria apply:

(1) The research problem and/or research questions require a qualitative methodology.
(2) Ethnography, case study, grounded theory, or phenomenology are inappropriate to use because the focus of the study, or content of data do not fit those approaches.
(3) The researcher has a body of pre-knowledge about the topic that he/she wants to be able to more fully describe from the participants' perspective.

The generic qualitative approach often requires the use of semi- or fully structured interviews, questionnaires, surveys, or participant observation. Generic qualitative research aims to collect data from specific groups of people about real-world events and processes, or about their experiences (Percy et al, 2015). Therefore, in relation to the current study, the three abovementioned criteria outlined by Percy solidify that the generic qualitative approach is suitable to use in the current study.

3.4 Adopting and Using a Generic Approach

The current study involved an in-depth asynchronous email interview, with between 8 – 10 email exchanges. The interviews would be used to explore the experiences of individuals living with TTM, as well as acceptability and feasibility aspects of participating in the interview. Participants were asked what their ideal treatment would be, in the hope of using this information to suggest a future intervention strategy. By including these aspects, although questions were posed in a way of asking participants their opinions and perceptions, it was clear that, although a large portion of the interview schedule did focus on participants lived experiences, there were questions that did not fully align with the phenomenological perspective of exploring the 'lived experience' (as some questions were more perception and opinion based).

Adopting a generic qualitative approach can assist a researcher in making sure that the methods of data collection and data analysis best suit the research questions of a study, as opposed to attempting to fit the question to a particular philosophical stance (Morse and Richards 2002). This can arguably enhance the credibility of a research project, as the researcher is more focused on accurately describing participant experiences, keeping the findings data driven while making their own interpretations transparent compared to researchers who are overly focused on adopting a traditionally theoretical approach (Sandelowski, 2000). Established methodologies do offer robust and rigorous literatures with important methodological debates for generic studies. However, researchers may feel the need to avoid the restrictions caused by over-reliance on these established traditional methodologies. In addition, there are advantages to using generic qualitative approaches; Lim (2011) has stated that a tendency towards a flexible approach is common for researchers conducting research on a topic where few theories or empirical studies exist.

Caelli et al (2003) has stated that, given the quantity and breadth of potential questions, it would be naïve for researchers to assume that the traditional and more established methodologies would account for every possible question. However, researchers still feel obliged to underpin their research with an established methodology, despite an imperfect fit. There are likely to be cases where using an

established traditional methodology will not provide a perfect solution for exploring questions which lie in-between methodologies. Becker (1993) has stated that it is less worrying to focus on correctly using method and methodology, than to focus on the philosophical constructs of science. If academics and researchers have not settled epistemological debates definitively in 2000 years, these debates will probably never be definitively settled; that concerns about the philosophy of science should be left to the people who adopt "philosophical and methodological worry as a profession" (p. 226). Merriam has highlighted that the aim of generic studies is the same of all qualitative research, to seek and understand how people interpret, construct, or make meaning from their world and their experiences. Merriam also argued that generic qualitative studies are epistemologically social constructivist and focus on "(1) how people interpret their experiences, (2) how they construct their worlds, and (3) what meaning they attribute to their experiences" (Merriam, 2009, p. 23). Furthermore, Merriam (2009) has stated that the generic qualitative approach can also stand alone as a researcher's articulated approach.

Over immersion in the epistemological and ontological perspectives that underpin a specific methodological approach is likely to result in theoretical perspectives becoming the dominant focus of a research study, instead of placing importance on the research questions used (Sandelowski, 2000). By examining a specific topic, a researcher should decide whether their main focus is examining that topic through a particular lens, or if the focus is finding the best approach to adequately explore the topic. Smith et al (2011) has stated that within health service research, if the focus is on finding the best approach to address a specific research question or problem, researchers should be confident that qualitative methods can stand alone as their articulated approach, without needing specific epistemological underpinning. Qualitative research provides us with functional explanations of language, behaviour and action, while inviting reflexivity throughout the research process; a stage which quantitative research is likely to avoid. Many studies in qualitative research explore and report people's subjective opinions, attitudes, beliefs, or experiences of things that occur in the world. Smith et al (2011) has stated that the merits of adopting a generic approach versus a traditionally theoretical approach has polarised qualitative researchers. Smith et al (2011) draw on these challenges and argue that over-adherence to the philosophical origins of qualitative methods (e.g. phenomenology, ethnography) has the ability to undermine the valuable role that qualitative research contributes towards evidence-based studies.

As qualitative inquiry evolves, the methods used to undertake qualitative research should stand alone without requiring the need to be underpinned by a theoretical perspective or having a definite allegiance to a traditional philosophical stance (Patton 2002). Reeves et al (2008) stated that traditionalists support the idea that qualitative research should be driven by a clear theoretical framework, and that qualitative research which lacks a theoretical framework will potentially negatively affect a study's validity (Morse et al, 2002). As Thorne (2000) noted, qualitative researchers used to assert that reliability and validity were irrelevant to qualitative enquiry but demonstrating rigour is essential and will be further discussed in section 3.5. From a different perspective, many researchers share the viewpoint that a poor understanding and application of theoretical underpinnings will likely

contribute towards the devaluation of qualitative methodologies (Maggs-Rapport, 2001). Despite the suggested polarisation of qualitative researchers into those who advocate for adopting a specific methodological approach, as opposed to researchers who support a theoretically flexible approach that is guided by the research questions, there still appears to be overwhelming agreement that the issue of quality is central to the credibility of qualitative research (Braun and Clark, 2006; Morse et al, 2002).

Although parameters for generic research have been offered, generic qualitative studies still remain largely ill-defined (Kahlke, 2014). Caelli et al (2003) has argued that researchers who use a generic approach should clearly articulate their theoretical position, by clearly outlining their motivations for the research, outlining congruence between methodology and methods, and discussing strategies to establish rigour. Generic approaches tend not to declare allegiance to a specific approach (e.g. ethnography), but clarity in generic work is highly important and there are ways to express clarity and create a convincing account of the work in order to attain rigour. Caelli et al (2003) suggests that a generic qualitative approach can blend already established approaches in an attempt to create something new, or claim no formal methodological framework whatsoever. For example, in a generic qualitative study, researchers could aim to use grounded theory without aiming to derive a theory (Lim, 2011); this walks a line between prescriptive and flexible research.

The generic approach is described by Caelli et al (2003, p4) as research that "is not guided by an explicit or established set of philosophic assumptions in the form of one of the known [or more established] qualitative methodologies". Generic qualitative research is often subdivided into various categories of interpretative and descriptive qualitative work (Caelli et al, 2003). It is possible that a researcher finds themselves with research questions or research aims that do not fit *neatly* into the confines of a single methodology (Caelli et al, 2003), in this instance, a generic approach is an ideal opportunity to use as it allows a researcher the space to explore the data and make advances in the field by deviating from methodological prescriptions. This was the case in the current study, as some questions from the interview schedule did not fit neatly into a single methodology.

The process of developing a research project may seem like an easy and straight forward task. Firstly, to decide on an appropriate epistemological position (e.g. constructionist), then subsequently choosing a suitable theoretical perspective (e.g. phenomenology or feminism). Prior to choosing a methodological position (e.g. grounded theory), and a specific method for data collection (e.g. interviews). However, researchers frequently find that their study does not neatly fit into an established methodology. It is highly probable that novel and interesting research questions or interview questions may arise that lie "in-between" methodological spaces. These questions may involve topics that have yet to be explored, and often do not appear neatly as a "phenomenology question". Instead, supporters of generic qualitative approaches argue that these questions can and should drive the methodology, rather than the other way around (Caelli et al, 2003, Annells, 2006).

The core focus of the generic approach is often on the external and real-world, as opposed to internal and psychological (Percy et al, 2015). This is in line with the current study, which used semi-

structured asynchronous email interviews to explore participant perceptions, experiences and opinions on the health, wellbeing, and social implications of TTM. Instead of focusing a study through the lens of an established methodological approach, the aim of generic qualitative studies is to either combine aspects of several methodologies or claim no specific methodological viewpoint at all (Caelli et al, 2003). This lack of allegiance to one set methodology does present challenges for generic research, the most important challenge is the lack of debate about how to do a generic study well. In this regard, Caelli et al offer four requirements for conducting a generic study well:

(1) Noting the researchers' position (alongside a researcher's motives, presuppositions, and personal history that may influence a particular inquiry).
(2) Distinguishing method and methodology.
(3) Clearly outlining the approach to rigour
(4) Identifying an analytic lens

In order to contribute towards clarity and rigour, this project will be taking the four elements of a well-designed research framework (Crotty, 1998) into consideration, this involves discussing and demonstrating use of the four aspects below:

(1) Epistemology
(2) Theoretical framework or philosophical stance
(3) Methodology (outlining the research strategy)
(4) Methods (outlining techniques used for data collection and analysis)

In line with Crotty's four elements of a well-designed research framework guidelines, this chapter has attempted to discuss ontological and epistemological underpinnings related to the current project. As mentioned, this project has adopted a relativist ontological position which asserts that there are multiple realities that may exist as our understandings of the world are diverse. This is in line with the current study, as the experience of TTM for each participant was unique to them and may consist of multiple realities and perspectives. This project has adopted a constructivist position which asserts that knowledge is constructed by humans through purposive interactions with the environment (Morcol, 2001). These positions actively reflect the idea that the people with TTM in the current study spoke about their TTM alongside their opinions, experiences and perceptions of TTM and that their direct experiences of having TTM would influence their reality and social experiences. Furthermore, a generic qualitative approach has been selected as a methodological approach, alongside the use of collecting data via asynchronous email interviews and blog posts, and analysing the data gathered using Braun and Clarke's thematic analysis (this will be further discussed in chapter four: methods).

3.5 Establishing Rigour - Trustworthiness in Qualitative Research

Lietz et al (2006) has stated that researchers should consider raising awareness of the needs of underprivileged populations and that qualitative studies can be used as a tool to accurately reflect the thoughts and experiences of these populations as closely as possible. Sandelowski (1993, p1) has stated that "there is an inflexibility and an uncompromising harshness and rigidity implied in the term 'rigour' that threaten to take us too far from the artfulness, versatility and sensitivity to meaning and context that mark qualitative works of distinction". Rigour has been discussed by Gambrill (1995; cited

in Lietz 2006) who suggested that qualitative inquiry does not require inflexible procedures (in contrast with quantitative inquiry which has rigid procedures), the primary aim of qualitative inquiry is to increase confidence that the findings accurately represent what participants have presented during data collection. Padgett (1998) has asserted that following a set of procedures in order to increase rigour will assist in the management of reactivity and bias, which in turn will legitimise qualitative findings. Rigour is achieved when the study findings reflect participant data as closely as possible (Lincoln and Guba, 1985).

Rigorous qualitative work often employs activities where the researcher aims to give priority to the meanings of participants. In order to do this, efforts should be taken to manage the potential issues of reactivity and bias, thus ensuring that researchers are able to describe qualitative data in a credible way. Utilising a rigorous thematic approach can contribute towards an informative and in-depth analysis that answers a predetermined research question. Holloway and Todres (2003) have highlighted that it is of great importance to choose a method that appropriately addresses the research question or research aim, instead of falling victim to "methodolatry" which can happen when a researcher is more committed to method, as opposed to exploring the topic or content of research questions. Guba and Lincoln (1989) have stated that, a study is credible when it provides clear descriptions, if any differences are noted, the researcher should be in a position to adequately evidence how each theme was derived from the data itself, as the findings and conclusions in a study should be grounded within the original data or explained in conjunction with the researcher's defined interpretative scheme. Clarity in generic work is highly important and there are ways to express clarity and create a convincing account of the work in order to attain rigour. This is echoed by Mertens (1998) who stated that methodological trustworthiness can be achieved by ensuring the logic of enquiry, procedures and measurement instruments are clearly described.

Qualitative research has employed several standards or measures of quality, these are known as validity, rigour, trustworthiness, fairness, authenticity and credibility (Morrow, 2005). In many traditional research approaches, aspects such as validity, reliability and generalisability are generally accepted as the constructs that demarcate good research, with these aspects often referred to as a "scientific holy trinity" (Kvale, 1996, p.229). Using methods to establish rigour and trustworthiness can increase overall confidence that findings accurately reflect the data and the voice of the participants is heard. Trustworthiness can be established through several ways; member checking, prolonged engagement, peer debriefing, triangulation, audit trail and reflexivity (Creswell, 1998).

Reflexivity is defined by Horsburgh (2003, p308) as "active acknowledgement by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation". A researcher's background will have an influence on the topics they choose to investigate, as well as the angle of the investigation (Malterud, 2001). Therefore, it is important to acknowledge how a researcher's identity can help, hinder or influence their interpretations of the data at hand (Reich, 2003). MacBeth (2001, cited in Lietz et al 2006) has stated that the act of reflexivity involves the deconstruction of how our beliefs, experiences and identity may

overlap with that of the participant. Reflexivity should not be considered a single use strategy, done at one point during the research process, it should be viewed as an on-going process throughout the duration of the research project (Guillemin and Gillam, 2004), this has been included in the current project though the use of several reflexive pauses at various stages. Reflexivity is a vital role in qualitative research because it encourages researchers to reflect on their role and consider the ways in which who they are could possibly help or hinder data analysis (Guillemin and Gillam, 2004).

Koch (2006) has suggested that trustworthiness can be achieved if the reader is able to audit the events, influences and actions of the researcher. Keeping an audit trail whilst in the data analysis stage can be a helpful tool to contribute towards rigour and the audit trail should clearly describe the steps and decisions the researcher took and a description of reflexivity within each step. Utilising an audit trail enables a researcher to record and follow their own research procedures, this has the ability to help facilitate critique by the wider research community as the procedures are fully and accurately outlined (Lietz et al, 2006). Koch's study fully revealed her personal and professional 'prejudices' through the use of a journal during the data collection process, and the discussion around the process of data collection highlighted the way in which a decision trail can be incorporated in qualitative research, thus contributing to the overall rigour of the study.

Peer debriefing is another strategy which contributes towards rigour, this involves engaging in dialogue with colleagues who are not involved in the research project but who have some experience with the topic / population or methods used (Creswell, 1998; Lincoln and Guba, 1985). Triangulation has been described as a procedure that contributes towards validity whereby researchers look for convergence among multiple data sources in order to derive themes or categories (Creswell and Miller, 2000).

Member checking can also be used to establish rigour, this is when the study findings are shared with the participants in an attempt to verify if the results are accurate. Member checking has also been referred to as respondent validation, as it allows the sample to review study findings so that they may either confirm or challenge the accuracy of the researcher's data analysis. This has the ability to ensure that the study findings are an accurate representation of the reality of the participant, rather than the reality of the researcher (Creswell, 1998; Maxwell, 1996).

Prolonged engagement has roots in anthropological fieldwork where researchers spent prolonged periods of time with the participants in their studies, thus establishing rapport which encourages participants to be more open with their responses (Creswell, 1998). Collecting more data from participants and spending prolonged periods with participants increases the likelihood of reaching information power.

This study has used reflexivity, prolonged engagement and an audit trail to establish rigour. The aspect of prolonged engagement is relevant as the asynchronous email interview was extensive and took place over 8 – 10 email exchanges (the range of time participants took to respond to each email exchange was between 1 day – 4 weeks; the process was flexible), thus developing a rapport with

participants. Reflexivity was an ongoing task which has resulted in a reflexive piece (see sensitivity and reflexivity, page 75) and several shorter reflexive pauses at various stages. Furthermore, an audit trail was also used to contribute towards rigour, by keeping a journal, this aimed to record my own personal preconceptions throughout the data collection process and discuss the data collection process alongside any decisions made (Koch, 2006). Contributing towards the audit trail, the entire data analysis phase was frequently discussed in supervision meetings and several drafts of the findings chapter were presented for review; thus all members of the supervision team reviewed and commented on the process of analysis and all decisions relating to this were discussed during supervision meetings.

3.6 Introducing Asynchronous Email Interview and Blogs

This section will introduce the two phases of the study; asynchronous email interviews and blog posts. Each of these phases will be discussed in further detail in methods chapter four (see page 63) in relation to the method and associated ethical implications.

Researchers and the Internet; Introducing Email Interviews

Research involving email communication is commonly referred to as computer-mediated communication, this generally involves interactions that take place on a computer (Cleary and Walter, 2011). Computer-mediated communication can either be synchronous (real-time) or asynchronous (not subject to time constraints) in nature. There are numerous benefits of interviewing participants via email, these include allowing the participant a greater amount of time to think about questions and reply at a time convenient to them while in comfortable surroundings (Kralik et al, 2005). Email correspondence is said to contribute toward participant automony (East et al, 2008), it is also considered to be a cost effective technique. Possible disadvantages of using email interviews include the potential for technical difficulties (McCoyd and Kerson, 2006), and any affects on data quality that may be linked to participant comprehension levels (Cleary and Walter, 2011). The email interview approach has demonstrated effectiveness (Bampton and Cowton, 2002) and is an approach that can be used to collect sensitive and richly detailed data (McCoyd and Kerson, 2006).

Introducing Blogs and the 'Blogosphere'

A blog is commonly thought to be a community-based online tool that comprises an interactive personalised web page, the web page can be instantly and chronologically updated with a wide range of information including text, imagery, audio files, video files, and hyperlinks (Newson et al, 2008). Blog entries are called 'posts', and blog entries can be published by anyone that is registered to post on the site. One of the key features of blogs is interactivity, as blog readers have the choice of leaving comments on the content of a blog post. Blogs are considered only minimally intrusive, as a user can access their blog whenever they need to, similar to a traditional paper-based diary (Alaszewski, 2006). Additionally, blogs can facilitate data collection across several geographical locations simultaneously, which aligned with the current study which aimed to gather data from a wide and geographically diverse range of locations.

Blood's (2002) definition of a blog is a frequently updated, author-driven website with the capability of reader feedback. There are different types of blogs; personal blogs are written by an individual and share resemblance to a diary, while organisational blogs are primarily used for business purposes (Wright and Hinson, 2008). TTM blogs can be classed as a personal blog, as they reflect the experiences, opinions and personality of the author. As blogs are multi-modal, it can be argued that they honour participant voices and the numerous ways blog users may find and use their voices. Blog users may express themselves through the use of text, narratives and poetry (Newson et al, 2008). McCabe and Foster (2006, p195) have stated that "a person's identity can be communicated through narrative". Therefore, the content written on TTM blogs has the potential to reveal much about a writer, how they perceive themselves and how they experience their environment. It can be argued that blog data can be less impacted by biases (such as social desirability), while providing an authentic perspective into blog user's experiences (Banyai and Glover, 2012). It has been asserted that the "blogosphere" provides a unique location where blog users can exercise freedom of expression (Argyle, 1996).

The rise in popularity of blogs mean that they are more frequently used in health research, and have been described as "unsolicited narratives that offer a naturalistic entrée into the illness experience unconstrained by time" (Eastham, 2011, p 353). Further to this, Heilferty (2009) has suggested that nowhere are illness narratives discussed more than in blogs. Hookway (2008) has stated that blog posts can be viewed as an online extension of diary research, with blog posts often viewed as online "self-narratives" where intimate and/or personal content is posted (Herring et al, 2004). Harricharan and Bhopal (2014) have stated that online research methods (ORMs) were developed in response to the growth of the internet, with the internet becoming embedded in people's daily experiences. Participants' lives have therefore become centered around technology, with the online world becoming embedded within society, as such qualitative methods should embrace this aspect by using the internet to explore blog users' perspectives.

The popularity of blogs in the United States alone was responsible for a significant decrease in newspaper readership; from 52.6% of adults in 1990 to 37.5% in 2000 (Goldman, 2008). The number of internet users on a global scale have increased ten-fold between 1999 and 2013 (Internet Live Stats, 2015). To highlight the increasing popularity of the internet over the years, a survey by the Pew Internet and American Life Project indicated 12 million adult bloggers in the USA, and approximately 57 million blog readers in the USA (Lenhart and Fox, 2006). Most of these bloggers utilised their blogs for personal means, such as writing about their life and experiences. Other research (Banas, 2008) has indicated that the internet has become a popular tool for communicating health information. Blogs are thought to be one of the fastest growing and types of internet-based web pages, as at 2006, there were more than 70 million blogs available on the internet (Sifry, 2006). As suggested by Softwarefindr (2018), the number of blogs on the internet in 2018 has since increased to an estimated 505 million. In terms of daily usage, it has been reported that over two million blog posts are written on a daily basis (Internet Live Stats, 2015), given the global increase of internet users and the popularity of the

asynchronous nature of blogs, the participation potential increases significantly (Wilson et al, 2015). Therefore, it can be argued that blogging can be viewed as an affordable, global and instantaneous way of collecting data (Hookway, 2008).

It can be argued that bloggers who freely post information about themselves or their lives on a public internet-based forum are rendering blog posts similar to online diaries. Both Hookway (2008) and Williams and Merten (2008) have found that the online contributors may reveal more information than other more traditional data collection methods (e.g. interviews, focus groups). Therefore, blogs can provide an innovative and novel data source, and as they are posted on a publicly accessible forum, this allows a researcher to unobtrusively read and observe blog post content without outside intrusion or interference by a researcher.

3.7 Chapter Summary

This chapter has presented the development of a theoretical position within the project by applying and discussing an ontological and epistemological position in relation to the study. There tends to be a preference for using established methodologies in psychological research, such as the five core traditions previously outlined by Creswell (1998), but there are limitations to using an established methodology when the research inquiry is broad, as in the current study. This chapter has established that the generic qualitative approach was a suitable approach to use in the current study as some of the project's aims and interview questions did not fit neatly into the confines of a single methodology. Merriam (2009) stated that the aim of this approach is the same as all qualitative research; to seek an understanding about how people understand, interpret, and construct their experiences. In order to contribute towards rigour and transparency, the project has been discussed in conjunction with Crotty's four elements of a well-designed research framework (Crotty, 1998). Lastly, the two phases of the study, email interviews and blog posts, have been introduced and will be further discussed in relation to method and ethical implications in the next chapter.

Chapter Four: Methods

This chapter will present phase one (asynchronous email interviews) and phase two (blog posts) of the study. Data were collected in two phases as they had originated from two separate populations and different findings may have emerged from each phase. As such, each phase will be discussed separately. Engagement with service users to inform the study design will be highlighted. Ethical considerations will be applied to phase one and phase two, followed by methods of data collection for phase one and two. Lastly, the chosen method of data analysis for the whole dataset (Braun and Clarke's thematic analysis) will be presented. This chapter will begin with a reflexive pause, which acknowledges my personal interest in this topic.

Reflexive Pause – Early Development of the Project

I have utilised the idea practiced by Walker (2006) to include several reflexive pauses throughout the project, a further piece on sensitivity and reflexivity (see page 75) will also be presented. This project developed after having been a member of an online TTM support group and regularly reading online posts about the frustrations that other people had with TTM. Coupled with my own frustrations at attempting to seek treatment and often not being taken seriously, a look into key papers revealed a need for qualitative research which gives a voice to those with TTM. The many thousands of online TTM support group voices detailing their journey and struggles with TTM were undeniably strong, it seemed unbelievable that their individual voices and stories were not being heard within TTM research. After identifying a lack of qualitative research in the area, a research proposal was submitted to the university of Huddersfield.

Engagement with Service Users to Inform Study Design

Having had intermittent phases of TTM throughout life, I attended a support group meeting in England for a chance to meet other people with the disorder. After discussing TTM for several hours, I asked some of the attendees about their willingness to participate in TTM research. The answers I received were conclusive, only one would consider taking part in a face-to-face interview and three would consider doing a focus group. Others said it would make them feel uncomfortable, with one person saying it may be too stressful and that the stress may act as a 'trigger', resulting in more hair pulling. Telephone interviews were an alternative, but there were reservations about time constraints and interference in their daily routines. Therefore, an asynchronous email interview (McCoyd and Kerson, 2006) has been used in the current study, as this method is convenient for participants (from a wide range of geographical locations). Participants can answer interview questions in their own time and think about their responses before replying. They can participate in a surrounding which is comfortable and safe, without any potential feelings of embarrassment. Taking this feedback into consideration, the idea of using blog posts that explore TTM came after the decision to utilise email interviews; in keeping with the online and electronic nature of data collection, it was decided that examining TTM blog posts could potentially provide a deeper insight into TTM as well as possibly highlighting different themes from an online population.

4.1 Ethical Considerations

This section will outline general ethical considerations in qualitative research, the process of receiving ethical approval and an outline of the ethical considerations of both phases of the study. Orb et al (2001) has stated that relationships and power dynamics between researcher and participants are embedded in qualitative research, with participation dependent upon a participant's willingness to share their experience on the topic at hand. Ethics in qualitative research involve navigating around issues about privacy, while encouraging honest interactions, with the key ethical concerns being towards anonymity, confidentiality and informed consent (Sanjari et al, 2014). Informed consent is held in very high regard, as researchers need to specify how data will be collected and used prior to commencement of participation.

Ethical Approval

This project has followed the ethical guidelines outlined by the British Psychological Society Code of Ethics and Conduct (BPS, 2009), alongside the Guidelines for Ethical Practice in Psychological Research Online (BPS, 2007). These two ethical protocol guidelines were used to inform a comprehensive ethical approval application which was submitted to the university's school of human and health sciences research ethics panel (SREP). Ethical approval was received from SREP (original application SREP/2015/118 approved on 15 February 2016) following several minor amendments. A revised ethics application was submitted several months later, as a few participants offered to submit photographic evidence of their trichotillomania. Therefore, it was deemed necessary to include a separate consent form for photographs (SREP/2015_118_Rev1_200616) which was approved on 29 June 2016. The ethical approval applications included both phase one and phase two of the study (see appendix one on page 172 and appendix two on page 175). Important detail was provided on the ethical approval applications which included a discussion around recruitment, data collection procedures, confidentiality, informed consent, anonymity and debriefing. The ethical considerations for each phase vary and will discussed further below.

Ethical Considerations Phase One – Email Interview

This section will be presenting a discussion around the information sheet and informed consent for email interview participants. The consent form will be highlighted, alongside confidentiality, anonymity, debriefing and safety protocols that took place during the email interview exchanges.

Information Sheet and Informed Consent

Participants who signaled an interest in participating in the study were given an information sheet and were informed that their participation would be in the form of an email interview with 8 – 10 email exchanges. Participants were informed that there would be several questions per email exchange, and they were provided with information detailing that they could answer the email interview questions at a convenient time. Participants were informed that I was interested in their experiences, opinions and perceptions of trichotillomania, and were regularly encouraged to provide as much rich detail as they were able. Additionally, informed consent was sought at every email exchange, this was achieved by checking back with each participant after every individual email exchange. This aimed to

provide on-going consent whereby each interview participant was able to re-affirm their willingness to continue the email interview.

Participants were given a detailed information sheet which provided a comprehensive explanation of the procedure for data collection. The information sheet provided the aims of the project alongside the expectations involving their participation in the interview. The information sheet clearly outlined that participation was voluntary and participation may be withdrawn, with the deadline for withdrawing their participation being 01 February 2017. Participants were regularly encouraged to provide detailed responses during the email interview exchanges and participants were reminded that their identity would be kept confidential at all times. Participants were made aware that they did not have to answer any questions that made them feel uncomfortable, and their data would be anonymised of any identifying details (e.g. names / locations / school names) and that their identity would not be disclosed to any third parties. Furthermore, participants were informed that their data would be stored on a password protected server and destroyed at a later date. Participants were notified that the findings may be published in a journal or report and it would be necessary to use their words within the presentation of findings, but their privacy and anonymity would be ensured throughout.

Consent Form

Consent forms are a useful means to gain participant consent. Contact with the email interview sample had taken place solely via an electronic basis, as such, the consent form was emailed and returned in the same manner. Participants were encouraged to read the consent form, raise any questions or concerns before signing and returning the consent form. Once the consent form had been signed and returned formal participation in the study could commence. As outlined by the Code of Ethics and Conduct (BPS, 2009) and the Guidelines for Ethical Practice in Psychological Research Online (BPS, 2007), participants were advised that they could exercise their right to withdraw from the interview at any point and participants were ensured that their identities would remain anonymous throughout the study. Additionally, in order to ensure internet security, the 8 – 10 email exchanges took place on a secure web server (this was indicated by the presence of “HTTPS” in the web bar). The consent form contained a list of points which required participants to tick / place an “x” in the box to confirm their agreement for each point.

The points covered by the consent form also aimed to incorporate the inclusion / exclusion criteria to facilitate the researcher in identifying which participants were suitable to participate. This included confirming if the participant was over the age of 18, that they understood the aims of the project and consented to taking part, that they understood their right to withdraw, giving permission for their words / quotes to be used in conjunction with a code / pseudonym to protect anonymity. Agreement that their data would be anonymised and kept in secure conditions and acknowledgement that they did not consider themselves to be a vulnerable adult. The consent form also included several questions to confirm their TTM, as based on the criteria outlined by the DSM (specifically, that they have had on-going issues with TTM, have had reoccurring episodes of TTM resulting in hair loss, TTM that causes distress, their TTM is not due to another medical condition, and repeated attempts to decrease or stop the TTM).

Several participants suggested they would like to submit photographic evidence of their TTM / hair loss. It was deemed necessary to re-submit a revised ethics application to include a separate consent form for photographs. With the intention of maintaining ethical rigour, the separate photo consent form (see appendix four – page 181) included a similar tick box / place an "x" in the boxes to indicate agreement and included the participants confirming that they had willingly provided photos for use in the study, that they understood the photos would be anonymised (through the use of blurring / cropping) identifying features, with the original photo being deleted after this had taken place. Participants also acknowledged that any personally identifying features (e.g. tattoos) would be edited out and gave their permission for their submitted photos to be used within the project.

Confidentiality and Anonymity

It was a primary aim to ensure that each email interview participant had the right to confidentially participate throughout the study. Data was stored in compliance with the protocols outlined by the university of Huddersfield. Participants were reminded that their data would be anonymised, that their participation would remain confidential, and that no personally identifying information would be shared with third-party members. Participants were notified that their interview responses would only be discussed within the research team, consisting of the researcher and degree supervisors. In order to adhere to ethical protocols, all email interview data was cleansed of personally identifying features. Participants were assigned a unique code which they could use to withdraw from the study. The cleansing of identifying features in the data set (e.g. location names, names of individuals) aimed to further protect participant identities.

Debriefing and Safety Protocols

Participants were provided with a debrief sheet (appendix five, page 182) in the final email interview exchange, alongside thanks for their cooperation. The debrief sheet contained a deadline to withdraw data (01 February 2017). A list of support measures was provided within the debrief sheet, the support measures were tailored to include each participating country and included a telephone helpline and website link for each respective country, alongside a referral to their own designated heathcare provider. In addition to participant safety, the topic of researcher safety was highlighted, and I was made aware of support services at the university should the need have arisen to seek wellbeing support. Additionally, the supervision team played an active role in providing support for any psychological challenges that may have arisen from reading potentially emotive data and ensured safety by signposting to relevant support options available on campus.

Ethical Considerations for Phase Two – Blog Posts

The emergence of computer-mediated communication (CMC) has introduced a significant body of academic writing, this academic writing has primarily been concerned with interpreting the interactions that now exist in a cyberspace environment (Wellman et al, 2001). Researchers have become increasingly more interested in how cyberspace can be used to expand research (Mann and Stewart, 2000). It has been previously asserted that the issues associated with online research methods are largely unexplored (Mann and Stewart, 2000) and it has been generally recognised and accepted that

cyberspace offers a unique frontier for research. One area that has recently been developed as a possible source of qualitative data is the weblog. A weblog (commonly referred to as 'blog') refers to a website that consists of various posts, usually written by one author, that are listed in reverse chronological order (Bar-Ilan, 2005). To my knowledge, TTM research has not involved the analysis of blogs from a qualitative perspective. Thus, this will fill a gap in the existing literature. The next section will highlight the ethical implications associated with using blogs in research

Anonymity and Privacy

Blogs provide a publicly available and affordable data collection technique. Blogs offer immediate and naturalistic data and eliminate the need for tape recorders and lengthy transcription. The anonymity of this online world ensures that bloggers may remain relatively unselfconscious about the content of their posts. Blogs are often freely and publicly available on the internet. As research using internet-based data is relatively new, there are limited perspectives on the ethical implications that may arise. However, Jones and Alony (2008) have highlighted several ethical considerations surrounding blogs; in relation to copyright, the content of online blogs can be viewed as a freely accessible product that exists within the public domain of the internet, these freely accessible details can be studied within the boundaries of copyright. In relation to the current study, I have chosen not to inform the TTM blog authors, as the blog post content found was freely accessible and was uploaded online voluntarily and consciously.

The British Sociological Association has previously claimed that the ethical issues involving internet research were underdeveloped (BSA, 2004, p.5-6). Many researchers have encountered a consistent issue during online research in relation to protecting the anonymity of participants. This is a problematic issue when attempting to gain informed consent, as most researchers do not know the identity of these online participants (Markham, 2008). However, the anonymous nature of the internet can and should be perceived as a strength when collecting online data. For example, Mann and Stewart (2000) demonstrated that anonymous online reflections have the ability to result in rich in-depth perspectives, in comparison to face-to-face interviews. Furthermore, Tidwell and Walther (2002) have stated that the anonymity of the internet has been shown to reduce the anxiety that may result from feeling judged and can therefore increase self-disclosure which may motivate deeper introspection.

As Harricharan and Bhopal (2014) have stated, anonymity and privacy are important in research, but with the internet, data is publicly available. Qualitative research largely depends on participant quotes in order to validate the study and empower the voices of the sample. However, the content of a blog post can be traced if an internet search using a published quote is conducted (Markham 2008). Therefore, it may be difficult to maintain 100% anonymity and privacy in these cases, when the content of blog posts is publicly available on the internet. Within the current study, in terms of blogger privacy, all blogs which required a password or membership were excluded (Lingetun et al, 2017, and Eastham, 2011). All identifying information, such as names of people / places were anonymised in aiming to ensure privacy was upheld.

Beaulieu and Estalella (2012) have stated that doing online qualitative research may result in unique ethical issues due to the 'traceability' of quotes, in some cases, the data collected online may contain sensitive content which may potentially impact the members of these online communities. The associated ethical implications will likely depend on the purpose of the research and type of online environment data is accessed from. It has been argued that websites which don't contain password protection should be classed as public spaces; this is highlighted by Rodriguez (2013) who received feedback from an ethics review board that their study on illness narratives found on internet postings did not meet the definition for human subject research, and was therefore exempt from ethical approval. Holtz et al (2012) have advocated against exact quotes, as a method of reducing potentially identifiable details being found on internet searches. In this vein, other researchers have developed strategies to avoid the traceability of quotations: Hewitt-Taylor and Bond (2012) allocated pseudonyms to participants, and made minor changes to quotes so they were untraceable on internet searches, thus protecting the privacy and anonymity of online individuals.

It is important for researchers working in the online world to decide if they need to gain permission from bloggers, or if they consider blog posts as academic fair game. Although there is no consensus on this topic, the issue about what is considered private or public tends to fall into three camps (Hutchinson, 2001). Firstly, some researchers take the position that publicly available archived content does not require consent (Sudweeks and Rafaeli, 1995; Walther, 2002). Other researchers claim that although blog content is publicly accessible, blog users have written them with an expectation of privacy and the blog posts should be treated as such (Sharf, 1999). Lastly, some researchers argue that online interactions defy clear cut prescriptions as either public or private, this is succinctly stated by Waskul and Douglass (1996, p131) who discussed cyberspace as being "publicly-private and privately-public". This aspect was echoed in later research, as Roberts (2015) stated many ethical considerations disappear if a researcher chooses to view an online community or website as a public space.

As Donath (1996) has argued, blog users should be considered as pseudonymous, because blog readers will often recognise the online names or usernames of bloggers. In response to this, some researchers choose to alter the blog users screen names. For the current project, I have removed blog page details and redacted any names / identifying information within the blog posts in order to help preserve anonymity. Furthermore, supporting quotes from blog post data used to illustrate themes and sub-themes have been assigned an anonymised reference (e.g. B1 for Blog 1). As Paccagnella (1997) and Bruckman (1997 cited in Jacobson, 1999) point out, researchers who conduct internet-based studies often have differing opinions on ethical protocols. There have been examples of studies using data from chatrooms and other online community settings without gaining informed consent (Paccagnella, 1997), in contrast to this, other researchers have sought permission to use online transcripts (Sharf, 1999). Nevertheless, the evolution of the internet has highlighted that there is a growing value to explore these new environments, this suggests that making exceptions to

rigid ethical guidelines should be considered, especially if it provides insight into hard to reach populations and the data content is not sensitive.

When conducting internet-based studies, researchers should have an awareness of copyright law. In Australia, the United Kingdom and the United States of America, the content found on the internet is automatically copyrighted (Australian Copyright Council, 2005; UK Patent Office, 2006; US Copyright Office, 2000, cited in Hookway, 2008). Copyright exists as a means to protect original 'works', including a range of literary, musical or artistic content that is posted on the internet. In terms of blog research, when a blog post is uploaded onto a blog website (or content management system), it is automatically protected by copyright. This would ordinarily be a significant limitation for researchers working in the online world, but special provisions have been implemented into copyright acts to account for "fair dealing" for the purposes of research (Hookway, 2008).

Informed Consent

Research which takes place in the "blogosphere" can be complex and the area of consent is a controversial one. Eastham (2011) has stated that ethical approval can be considered as an unnecessary task, as the content exists in the public domain and is fully and freely accessible. Blogs have been described as being simultaneously private yet public, thus challenging researchers to design studies that consider suitable protections for participants (Eastham, 2011). The issue of informed consent for using publicly available, but private material has remained a contested topic as the division that exists between these two domains is obscure (Lunnay et al, 2014). Guidelines for research on the internet has presented challenges, particularly regarding informed consent and maintaining anonymity. Text (including blog posts) which are openly published on the internet can be considered public (Bruckman, 2002**,** and Bradley and Carter, 2012). By making text in the form of blog posts publicly accessible, blog owners give an "implied consent". Therefore, in relation to the current study, the researcher refrained from seeking informed consent, as the blog post data was accessible within the public domain. In support of this position, it has been asserted that if the content is freely accessible to the public, it can be perceived as a public place (Sudweeks and Rafaeli, 1995). It may be easy to forget that messages and blog posts can be stored and are retrievable for a long time after being published. Since a researcher cannot know whether blog users perceive their internet environment as public or not, the researcher should think it over and consider if the information that they are quoting and publishing in their research can be safely used without the risk of causing harm.

Many blog researchers have adopted the 'fair game – public domain' position (Ackland, 2013) and it can be argued that although blog posts may contain private content, they are indeed knowingly published in a public domain, and should therefore be considered as 'fair game'. Hence, it is argued that the necessity of gaining consent should be waived. Blogging has been described as a public act of writing content for an implicit audience, and researchers have stated the public nature of blogs also exists in how they are defined by blog users (Waskul and Douglass, 1996). If a blogger feels that one of their blog posts is 'private', they can set their privacy settings for that particular blog as 'friends only'

and not ‘public’. Therefore, publicly accessible blogs may contain material of a personal nature, but they are not private.

As evidenced above, tension is noted among online researchers regarding identity protection and acknowledgment of blog authorship (Hookway, 2008). In relation to the current study, the position of moderate disguise has been adopted. This position favours the protection of participant identities over providing credit to the blog author (Bruckman, 2002). As such, any pseudonyms or blog usernames noted in the blog post data have been altered and data has been cleansed to remove identifying information.

4.2 Asynchronous Email Interviews

This section will focus on providing a discussion surrounding phase one of the study: asynchronous email interviews. Inclusion and exclusion criteria will be presented alongside commentary on sampling hard to reach populations. The email interview schedule will be discussed alongside data collection, timescales, transcription, and advantages and disadvantages of the method will be highlighted.

Recruiting Participants

It was an aim to collect data from as many locations as possible, for the purpose of recruiting an international sample. Walther et al (2010) has stated that there is little research on the cross-cultural impact of TTM, so the use of large geographically diverse samples would be beneficial. The researcher relied on networking skills within the trichotillomania online community to aid participant recruitment. A generic message was placed on an online forum and interested participants sent the researcher a message on Facebook with their email address. Fifty-eight people expressed interest and requested an information sheet and consent for consideration. Participants who were interested in proceeding with the email interview then completed the consent form, electronically signed and returned it via email which established formal participation in the study.

Participant recruitment began on 11 March 2016 and data collection was finalised on 24 August 2016, via semi-structured asynchronous email interviews (McCoyd and Kerson, 2006) over several email exchanges. This was a long-term process that involved between 8 – 10 email exchanges with each participant. The range of time for participants to respond was between one day and four weeks; the process was flexible. Some participants took two or three days to respond to each set of questions, while other participants took three or four weeks when answering a set of questions. The process was flexible and meant to fit around the lifestyle and availability of each participant. Four people dropped out of the interview, citing various reasons including change of mind, feeling too emotional, and time constraints. Two people were ineligible to participate which was assessed via the consent form; one said she considered herself to be a vulnerable person, while the other participant was underage. Six participants began the interview and stopped responding but did not acknowledge the email reminder or give a reason for non-responses. Within this 21-week time frame, 20 participants (7 male and 13 female) from 15 countries were recruited and participated in the email interview. A sample summary will be provided in the findings chapter.

Sampling Hard to Reach Populations

Qualitative sampling aims to consider and conform to the goals and purpose of a study in a unified logic (Marshall and Rossman, 1999), by selecting a representative sample that may best align with the aims, objectives and goals of the research. Abrams (2010) has stated that purposive sampling involves strategies whereby a researcher uses his/her own judgement when recruiting participants in order to provide the most relevant perspective on the phenomenon being studied, and then aims to recruit those people into the study. Purposive sampling strategies are carefully thought out and planned prior to commencement of the study and may be subject to change as the study progresses (Padgett, 1998). The current study used a purposive sampling strategy to specifically recruit individuals who shared a common experience of having TTM, Moustakas (1994) describes purposive sampling as a method which recruits individuals with common experiences, with the goal of generating detailed patterns and relationships of meaning. Recruiting participants via purposive sampling aligned with the study aims, and efforts were made to try recruit a diverse sample (i.e. gender, country).

Researchers often use agencies as a means to recruit hard to reach populations (Taylor, 2009), and researchers are likely to encounter barriers when recruiting a desired sample. It is important to use procedures to counter-balance these limitations; it may be necessary to include other data collection methods in order to provide different perspectives, this may highlight further evidence that can enhance the depth of findings (Padgett, 1998). This was indeed the case in the current study, as it was difficult recruiting male participants with TTM and there were several female drop-out participants in the email interview phase. Therefore, the addition of blog posts aimed to add a new layer of data to the study, with the potential to increase depth and breadth of overall findings. The scoping review done by Wilson et al (2015) found blogs have good potential as a qualitative health research tool and are particularly useful for researchers who wish to access a hard to reach population. Furthermore, by recruiting email interview participants online, this enabled the study to reach its primary aim of recruiting an international and geographically diverse sample.

Sampling – Inclusion and Exclusion Criteria

Inclusion criteria contained several screening questions, as guided by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (American Psychiatric Association, 2013) criteria for TTM. Participants were asked to confirm that they were aged 18, to avoid additional complications of needing permission from a parent / guardian, and to ensure participants could adequately answer questions relating to personal relationships, work experiences, and factors associated with health and wellbeing in association with their TTM. Other inclusion criteria were:

- recurring episodes of hairpulling
- attempts to decrease / stop the behaviour
- subsequent distress or impairment
- TTM was not caused by another medical condition

Exclusion criteria included a screening question which aimed to identify any participant who considered him/herself to be at risk. For example, a person who had recently experienced suicidal thoughts, and/or strongly believed that participating in the email interview would have a negative emotional or psychological effect were not included in the study.

Both the inclusion and exclusion criteria were clearly explained and assessed via the information sheet and consent form. As this study involved an international sample, the ability to speak and write in English was not a pre-defined criterion. However, the general message seeking participants was written in English and only participants who could read/speak English volunteered their participation.

The Email Interview Schedule

As previously mentioned, the asynchronous email interview was a highly suitable method to use in the current study. This method involved a series of 8 – 10 email exchanges, these exchanges were not subject to time constraints and participants could complete the interview questions at their convenience. As the study comprised an international sample of participants from 15 different countries, the asynchronous email interview method allowed the participants to participate in the study in a flexible manner, without relying on 'real-time' synchronous exchanges. This would have been problematic given the different time zones of this international sample. The flexibility of this approach allowed participants to respond in their own time, dependent upon each participant's schedule (Mann and Stewart, 2000). In accordance with the advantages and disadvantages of asynchronous email interviews (see page 75), the email schedule was structured to consist of seven sets of questions with approximately eight semi-structured questions in each set.

The email interview schedule was informed by background reading into the area, with the main topics aligning with the aims and objectives of the study (see page 46). The first set of questions focused on demographic information which could be used to help frame later questions. The second set of questions focused on general TTM themes, and included questions around; the process of hairpulling, feelings associated with hairpulling, environments hairpulling takes place, process of diagnosis, possible causes of TTM, and permission-giving behaviours.

The third set of questions focused on general and social TTM themes and questions included aspects of control, avoidance of situations, other habits, investment and concealment of TTM, and exclusion by peers. The fourth set of questions focused on social TTM themes and questions included the potential effects on academic life, work life, romantic relationships, and friendships. Questions also involved impact on self-esteem and self-confidence and coping with TTM.

The fifth set of questions focused on health and wellbeing TTM themes and questions included general life impact, dealing with healthcare professionals, comorbidity, and any treatments participants have tried. The sixth set of questions focused on health and wellbeing TTM themes, and questions included impulsivity, substance use, and some acceptability and feasibility questions around participating in the email interview. The seventh set of questions focused on general TTM

themes and questions included participants ideal treatment plan, ideal healthcare professions to deliver the treatment, ideal treatment frequency and duration, and opinions about their own mental health and wellbeing. There was an additional list of supplementary questions that could be used interchangeably, depending on participant responses to the interview schedule. As the email interview schedule was a considerable length, it would not be practical to present and discuss each interview question within this chapter (please refer to the interview schedule in appendix six, see page 184). The interview schedule was not piloted, and the email interview process was not piloted as the researcher had previous experience of using the asynchronous email interview method in a previous degree. The email interview did not change significantly throughout the process, except for the use of supplementary questions which were used interchangeably depending on participant responses.

This project utilised semi-structured interview questions, this aimed to receive detailed responses from participants in the sample. Semi-structured open-ended questions encouraged flexibility in an attempt to accommodate any individual differences, this allowed participants to choose the level of detail and description they wanted to share when answering interview questions. This was overwhelmingly evident, some participants provided paragraphs of rich detail while other participants answered using one sentence. The typical response length per question was three to four sentences, with the average length of the full email interview being approximately eight to ten pages per participant. Utilising semi-structured open-ended questions aimed to examine the experiences, opinions and perceptions of people with trichotillomania, this resulted in data that was largely descriptive in nature. I aimed to enter the research process with a limited number of preconceptions. However, this proved difficult, as a large amount of background reading was done which informed the construction of the interview schedule. Conducting a literature review or background reading has the benefit of highlighting gaps in previous research, this enables researchers to design studies with the potential to contribute toward knowledge and improved understandings on the topic at hand. This took place in the current project as the background reading into the area highlighted a gap in previous literature; that there is little research on the cross-cultural impact of TTM (Walther et al, 2010).

Data Collection, Timescales and Transcription

Data collection occurred via the asynchronous email interview method, with all correspondence taking place over 8 – 10 email exchanges in total. Participants who signaled their interest on a private Facebook message were sent an introductory email with an indication of the email interview process alongside an information sheet and consent form (see appendix three, page 178). Participants were informed that there would be several email exchanges and that the interview would be administered in several sets of questions. Participants were asked to return each set of questions within 2 weeks and were encouraged to contact the researcher if they needed extra time to answer the interview set. Some participants managed to return their set of questions within one – two working days, other participants needed three – four weeks to answer their interview set. As this method was highly flexible, if participants needed extra time, they could contact the researcher at any point.

After each set of questions was answered, the raw data was copied directly onto a Microsoft Word document. The asynchronous email interview successfully avoided the time-consuming aspects involving data transcription from audiotape files. This method saved considerable amounts of time which would have been spent manually transcribing data. Participant responses were read and identifying details were cleansed / removed, resulting in data that was anonymised. The file was then saved under a unique allocated code and stored in a password protected server. Only the researcher had information regarding which code related to which participant, should any participant wish to withdraw their data. Due to the fact that considerable amounts of time were saved on data transcription, all interviews were analysed by hand. This was a conscious and deliberate choice, as the researcher thought it necessary to achieve an understanding and familiarisation of the interview data. Data analysis took part in various stages, without utilising computer software. An example of an annotated interview transcript is presented in appendix seven (page 187).

Advantages and Disadvantages of Email-Interviews

There are numerous advantages associated with this method, including providing access to a specific population, while eliminating the need to travel to meet participants. With the current study, this proved ideal, as it would have been impractical to travel to 15 different countries to interview participants. The asynchronous email interview method is significantly more affordable compared to other methods (e.g. face to face interviews and focus groups across a wide range of locations), and specialist recording equipment is not required (Hamilton and Bowers, 2006). In terms of dealing with sensitive topics, this method is minimally intrusive compared to face-to-face interviews, and contributes towards participant comfort specifically when discussing emotive topics (Hamilton and Bowers, 2006).

There are some disadvantages to using this method, which includes the inability to recruit participants who do not have internet or email access, or participants who have limited computer skills. Additionally, participants may feel discouraged from participation during long-term email interviews, this was a factor in the current study as there were several dropouts in the early stages of the interview process. A more robust summary of the advantages and disadvantages (outlined by Hamilton and Bowers, 2006) associated with this method can be viewed in table 4.1 below. Based on the current study, it was overwhelmingly clear that the advantages of this method far outweigh the disadvantages.

Table 4.1: Table indicating Advantages and Disadvantages of the Email Interview Method

Advantages	Disadvantages
1 Eliminates the need to travel	1 Identity fraud is possible.
2 Provides access to specific participant groups.	2 Reliance on self-selecting participants.
3 Financially feasible than conventional methods	3 Sample is restricted to those with access to the internet.
4 International recruitment possible	4 Can be a time-consuming method.
5 Eliminates the need for separate data transcription	5 Undertaking more than one interview at a time can be problematic for the researcher.
6 Increases external validity as an audit trail is evident	6 Participant drop-out is common.
7 Flexible, participants can answer questions in their own time.	7 Lack of non-verbal communication
8 Participation can be undertaken on an international level.	
9 Participants feel less pressure as face-to-face contact is eliminated.	
10 Participation via online methods is less intrusive.	
11 Rapport is likely to develop due to the length of participation.	
12 Absence of face-to-face interaction reduces influences and/or perceptions of one another (e.g. appearance, culture, etc).	

Netiquette and Rapport

Netiquette refers to guidelines about behaviour that is acceptable when communicating with people over the internet (Mann and Stewart, 2000). One of the recommendations when engaging in online communication involves email communications that can be viewed on a single screen. This was taken into consideration when constructing the interview schedule, as each interview set comprised approximately eight questions which could be viewed on a single screen. This complied with netiquette guidelines and gave participants a manageable set of questions as well as eliminated the need to scroll up and down the web page. The email interview schedule was separated into manageable sections, this provided an opportunity to ask supplementary questions as the email exchanges progressed and aimed to contribute towards developing a rapport due to prolonged levels of interaction.

Developing a rapport with each participant was an important exercise during the email interview process. Throughout the email interview, the nature of communication naturally progressed from formal to less formal. This signified that participants felt comfortable expressing their experiences, opinions and perceptions of trichotillomania during the interview. The idea of developing rapport resulting in changes to the formality of language has been noted in previous literature (Mann and Stewart 2000, and Golding 2011).

Sensitivity and Reflexivity

It was an aim to consider reflexivity at every stage of the research process. I always knew that I wanted to conduct a research project on TTM, after conducting a review in the area to find a ‘gap’ in the literature (which revealed a lack of qualitative research), the idea of doing a project which fully investigated the experiences and perceptions of people living with TTM felt like fate. My own struggles with TTM have been the driving force behind this research project. Having had re-occurring episodes of TTM throughout my life, this could arguably give a unique insight into what questions to ask participants. My expectations were to fully engage with participants through an ongoing email

interview; I hoped that this prolonged engagement would contribute towards establishing a rapport with the participants and that they felt comfortable enough to fully explain their feelings and experiences about having TTM. As this topic is close to my heart, I expected that I may start to feel emotionally invested in the stories portrayed by the participants. My hope for this project was to let participant responses speak for themselves and that the data gathered would potentially inform others (through general awareness and possible interventions) which would help other people with TTM in the future. I endeavored to deal with reflexivity by utilising a method outlined Golding (2011), this involved reading a participant's interview responses, followed by logging off the computer for a short period of time. This strategy worked well and encouraged careful consideration of any supplementary questions as well as allowing time for self-composure in order to reply to participants in an unemotional and professional manner.

4.3 Using Blog Posts in Qualitative Research

This section will focus on exploring phase two of the study, involving the use of TTM blog posts. Advantages and disadvantages of blogs will be highlighted, and access, recruitment, inclusion and exclusion criteria will be presented.

Access and Recruitment

To locate virtual blogs, the phrase "trichotillomania blog" was typed into an internet search engine. The purpose of this exercise was to pinpoint approximately 10 blogs in the hope that some of the blog content would further contribute towards the themes which developed from the earlier interviews or illuminate new themes which the interviews did not highlight. Each search engine result was viewed, starting on page one of the search results. The results were assessed to check if they met the criteria of being a TTM blog (i.e. freely accessible, not requiring membership, with posts typically in reverse chronological order, containing a post written about a personal experience with TTM). Initially, a total of 20 blogs were examined. Blogs written by men were not excluded from this part of the project; there were simply no identified blogs written from a male perspective within the initial 20 blogs that were examined. Additionally, all 20 blogs that were initially examined were freely available with no fee-based membership. The inclusion criteria used was the blogger writing about their own TTM experiences (and not writing about the experiences of a third party). 10 blogs were excluded that merely described what TTM was, without providing direct experiences or perceptions of the blog user having TTM, this was done in order to meet the study's primary aim. Thus, by accessing pre-existing material, it is possible to access people's TTM blog posts without having direct contact with the blog authors themselves, thus allaying many ethical concerns (a similar facet which is echoed by Bradley and Carter, 2012).

Data Collection and Sample

Blog post data were collected over an approximate three week period, after the email interviews had ceased. Data collection involved reading numerous blogs and comparing against the inclusion / exclusion criteria (detailed above under 'access and recruitment'). Blog post data were copied onto a Microsoft Word document and cleansed of identifying details such as names of places, personal

images and names of people. A significant amount of blog posts merely discussed what TTM was, without talking about one's experiences, perceptions or opinions on having TTM. In line with the email interviews, blogs that included direct opinions, perceptions and opinions on having TTM were included in the final sample. Ten blog posts written by people who self-identified as having TTM comprised the final sample. These 10 blog posts resulted in 26 pages of data, averaging approximately 2.6 pages per blog post. The blogs were primarily used for gathering information about participant's direct experiences, perceptions and feelings about TTM, in line with the primary aim. As mentioned earlier, Battles (2010) has previously stated that blogs in the public domain are unlikely to have demographic information. Although 9 of the 10 blog users identified as female, there was very little other demographic details, therefore it is not possible to provide a sample summary containing the ages / locations of the 10 blog users. Dahlen and Homer (2013) have stated that blogging has been described as a fairly new form of computer mediated communication (CMC), with women often using it as a means to share personal stories, this could perhaps account for the lack of an identifiable male perspective within blog posts.

Analysis

Blog post data were analysed in the same manner as the email interviews, using thematic analysis (Braun and Clarke, 2006). This involved familiarising myself with the data, generating initial codes, searching for themes, reviewing themes, defining and refining themes. There was no need for transcription as data was already transcribed on the blog pages. After blog posts were cleansed of identifying features, the process of coding began. A full description on the steps included within the thematic analysis is detailed on page 81. As previously described, the purpose of including blog posts in this project was to further highlight people's experiences with TTM by supplementing the interview data to provide a deeper insight into TTM. Both the interview and blog post data will be presented together in the presentation of findings chapter (thematic analysis will be discussed in more depth below, alongside a step by step process of analysing the data set).

Advantages and Disadvantages of Blogs

Alaszewski (2006) have stated that blogs are minimally intrusive on participants, as they can be accessed whenever they wish, similar to traditional diaries. Blogs are multi-modal, in that they facilitate different kinds of expression; this may be through narratives, comments, poetry, text, art, video files, audio clips (Newson et al, 2008). Furthermore, anonymity of the online world can reduce anxiety about feeling judged, which in turn can motivate deeper introspection and reflection (Tidwell and Walther, 2002). Additionally, Mann and Stewart (2000) have asserted that anonymous online reflections can result in richer and deeper thought, compared to face-to-face interviews.

Using data found in the public domain can have several limitations: data is fairly limited as there is an inability to ask supplementary questions (Battles, 2010), therefore, posts should be accepted by researchers at face value (Bradley and Carter, 2012). Additionally, posts in the public domain are unlikely to contain demographic information (Battles, 2010), although it is likely that a more diverse or hard to reach sample may be accessible via this method. There are several problematic aspects

when using blogs for research, these center largely around the ethical implications of using data in a public forum, anonymity, consent, privacy, and authenticity (Ackland, 2013; Rathi and Given, 2010). If a blog post is anonymous, this can raise concerns about the authenticity of its content. However, Hookway (2008) has pointed out that manipulation of the truth can occur in a wide range of other research settings (e.g. interviews or surveys).

Establishing a blog page can be time consuming and Hookway (2008) argued that blogging can sometimes be disorienting and overwhelming while people learn to navigate the new blogging environment. There are limitations to using blogs for research, these limitations include difficulty recruiting a specific participant group or difficulty recruiting a sample with specific traits (Hookway, 2008). Additionally, the existence of spam blogs or "splogs" can significantly affect the quality of blog search results (Agarwal and Liu, 2009) with search terms often retrieving irrelevant blogs or spam content. The "blogosphere" represents an environment that frequently changes, this is recognised as a limitation as the resultant research can be viewed as a snapshot in time (Miller and Pole, 2010). Using blogs in research involves a reliance on self-report diagnoses, the diagnoses that are discussed on blog posts usually cannot be verified externally. Additionally, another limitation is the exclusion of potential participants who have no internet access and the inability to verify anonymous authors in order to ascertain authenticity. Having taken the strengths and limitations into consideration, the emergence of blogs does indeed provide vast opportunity for conducting qualitative research on a global scale. This has the ability to facilitate the collection of richly detailed and geographically diverse data, directly in line with the studies aims.

4.4 Data Analysis

This section will outline and discuss the chosen method of data analysis for phase one (email interviews) and phase two (blog posts) of the study. Thematic analysis is known to be a widely used and popular data analysis method that is commonly used within qualitative research (Braun and Clarke, 2006). Thematic analysis is a method that is largely independent of theory but is a versatile method that can be applied across a wide range of theoretical approaches. Braun and Clarke (2006) have previously asserted that thematic analysis is highly compatible with essentialist and constructionist theories within psychology. As this is a flexible method of data analysis, it is an appropriate method for the current study.

Thematic analysis has been described as a "poorly demarcated, rarely-acknowledged, yet widely used qualitative analytic method within psychology", with Braun and Clarke (2006) stating that this method provides a theoretically flexible approach, and although it shares commonalities with generic approaches, Braun and Clarke assert that it should be considered a method in its own right. The primary aim of this method is to develop and generate themes that accurately reflect participants' accounts, with the process of data analysis being an interpretative one where data is systematically analysed in an attempt to generate a meaningful description of the topic at hand. Thematic analysis offers a flexible process of analysing data, due to the flexible nature of this method, it is highly compatible with many approaches including the generic qualitative approach (Braun and Clarke,

2006). In compatibility with the chosen generic qualitative approach, Lim (2011) states that generic studies aim to provide a rich description of the phenomenon, which generally means using a highly inductive approach, and commonly using open codes, categories and thematic analysis.

Qualitative approaches are commonly used to explore issues for which there is little known, in order to gain a deeper understanding in relation to an individual's experience of a phenomenon. Choosing a suitable approach can be difficult, as it requires the novice researcher to carefully balance both the advantages and disadvantages of other approaches, and consider the study aims and objectives, before deciding on an appropriate method to use. Thematic analysis differs fairly significantly from other methods such as: thematic discourse analysis, thematic decomposition analysis, interpretative phenomenological analysis (IPA), and grounded theory. For example, approaches such as IPA attempt to search for patterns within a data set, but this approach is theoretically underpinned to a phenomenological epistemology where the primary focus is on experience (Holloway and Todres, 2003). When contrasting other methods like discourse analysis and conversation analysis, utilising a thematic analysis does not permit a researcher to make claims about the use of language or the functionality of talk (Braun and Clarke, 2006). When contrasting thematic analysis with IPA, grounded theory, narrative, discourse and conversation analysis, thematic analysis is not tied to any pre-existing theoretical framework. Thus, through thematic analysis' theoretical freedom, it provides a flexible and useful tool for qualitative data analysis by providing an account which is rich, detailed and complex, and is a suitable method to use for the current TTM study.

Inductive and Deductive Identification of Themes

Themes can be identified in an inductive (or bottom up) way, where themes are strongly linked to the data itself. Inductive thematic analysis shares minor similarity to grounded theory. If data has been collected to specifically explore a research topic, the resulting themes may bear little relationship to the questions that were included in the interview schedule. Inductive thematic analysis involves coding data without attempting to fit into a pre-existing coding frame and is not driven by a researcher's pre-existing theoretical interest; the process is data driven. In contrast to this, themes can be identified in a deductive (top down) or theoretical way and are driven by the researcher's theoretical interest on the topic, which means it is more explicitly analyst-driven. This provides a less rich description, but a more detailed analysis. The deductive thematic analysis method discussed by Boyatzis (1998; cited in Braun and Clarke, 2006) is largely driven by the researchers pre-existing interest in a specific topic. Although Braun and Clarke (2006) have stated that there is no pre-defined correct or incorrect way of performing a thematic analysis, it has been noted that an inductive thematic analysis would be enhanced if a researcher does not engage with previous literature in the early stages of analysis. Whereas, findings are likely to benefit from this in a deductive thematic analysis. While some researchers may assert that engaging with previous literature can narrow your perspective when analysing data, Tuckett (2005) has provided a different viewpoint by stating that awareness of previous literature can enhance analysis, by highlighting important data features. In relation to the current study, background reading was conducted before the study began, this aimed to further my understandings of the implications of TTM, and aimed to develop a rationale for the

current research which was used to formulate a research proposal for admission onto the course. Furthermore, this basic overview of literature in the area provided an understanding about important features in TTM research that required further exploration. This prior reading in the area influenced the types of questions included in the email interview schedule. Hence, the assertion by Tuckett (2005) is fully supported, as I too believe that having an understanding of previous literature in the area can contribute toward an enhanced analysis, as this has the ability to highlight important features and/or theories in the area.

Semantic and Latent Level Themes

Semantic (or explicit) level themes are identified within surface meanings, with the researcher not looking for anything beyond that point. Ideally, analysis shows a progression from description (where the data set is organised and summarised in order to show patterns in semantic content), to interpretation (where the researcher aims to theorise patterns in the data and provide links to previous literature in the area). In contrast to this, latent (or interpretative) level themes go beyond semantic level and attempt to identify any underlying ideas / conceptualizations or ideologies that are theorised as shaping the semantic content of the data (Braun and Clarke, 2006). Phase one and two of the current study would be suited towards using thematic analysis in an inductive way, to locate semantic level themes. The current study does have several aims and objectives, but no set research questions. Therefore, by identifying both interview and blog post themes in an inductive way, themes will be very strongly tied to the data itself, and the overall results will be data driven. Additionally, the analysis will show a progression from description to interpretation (where data will be organised and summarised to show patterns in semantic content and an attempt to theorize patterns and their broader meanings which may relate to previous literature), in line with Braun and Clarke's (2006) guidelines. This proposed method of data analysis is echoed by Lim (2011) who states that generic studies aim to provide rich description of the phenomenon and often use a highly inductive approach.

Table 4.2: Braun and Clarke (2006) Six Phase Description of the Thematic Analysis Process.

1. Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
2. Generate initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Search for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1), and the entire data set (Level 2), generating a thematic map of the analysis.
5. Defining and naming themes	On-going analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report.

Following the guidelines outlined by Braun and Clarke (2006), as detailed in the table above, analysis of the email interviews and blog posts included the following steps. These steps have been discussed at length and on a regular basis with the supervision team.

Step 1: Braun and Clarke's guidance states that phase one should involve familiarising yourself with the data by repeated reading in an active way to search for patterns and meanings. In step 1, all 20 interviews were read over once. They were then read over again, one week later, and a flow chart of my initial impressions were made. The interviews were then analysed one by one; this involved reading over the full transcript once again, then re-reading each answer again and highlighting important words / sentences and phrases. This process was repeated for each of the 10 blog posts. Some email interview participants voluntarily requested to send in photos, photos from the interview participants were not analysed, but were used to provide a visual representation of TTM to compliment their extract quotes. Any visuals on the blog posts were anonymised or redacted during analysis and coding, as the written content was used for theme development.

Step 2: Braun and Clarke's guidance recommends that the researcher should generate an initial list of ideas about what the data contains / what is interesting about the data by organising data into meaningful groups. In step 2, each interview was read over again, and notes were made in the left-hand margin (direct content related notes). Following a short break, each interview transcript was read over again, and notes were made in the right-hand margin (potential interpretations). Each interview was systematically worked through. An example of a coded data set can be found in appendix seven, page 187. After following this process for five interviews, I began compiling a summary document of data extracts / quotations. These extracts were grouped into similar themed quotes and given preliminary sub-theme titles. At this stage, there was a large volume of preliminary sub-theme titles, which would hopefully be collapsed down into larger / broader themes. Again, this process was repeated separately for the blog post data. At this stage, extract quotes and preliminary theme titles were managed on one central document.

Step 3: Braun and Clarke's guidance states that Step 3 should involve grouping similar sub-themes into broader overarching themes. This step involved re-focusing analysis at the broader level. It has involved thinking about the relationships between codes, between themes, and between levels of themes (i.e. overarching and sub-themes). This was done by reviewing the collated and coded extracts and working through the preliminary themes and sub-themes with visual help (by using tables, very large sheets of paper to collapse and collate sub-themes, and post-it notes).

Step 4: Preliminary themes and sub-themes were defined and were refined on several occasions as data analysis progressed. At the end of this step, the candidate themes and sub-themes were refined and reviewed.

Step 5: This step involved defining and naming each theme and sub-theme. This was an ongoing process whereby themes and sub-themes were collapsed and re-defined on several occasions to create a final list of candidate themes.

Step 6: Producing the report. This step involved carefully selecting extract quotes to illustrate each theme and sub-theme, providing a narrative about the findings of each theme and sub-theme and illustrating how they may be interlinked. As the interviews and blogs were analysed and coded separately, this stage focused on highlighting where the interview and blog findings differed or overlapped.

Reflexive Pause – Being Reflexive during Data Analysis

It was my aim during data analysis to hold participant responses in the highest regard, both email interview and blog post data were analysed inductively with the intention of having the emerging themes and sub-themes being strongly tied to the data itself so that the findings were data driven. This supports the primary aim of the study, to explore the experiences, opinions and perceptions of people with TTM. Data analysis was discussed extensively within the supervision team, preliminary coding of several transcripts was also discussed, in an attempt to overcome any potential research bias. Further efforts were made toward being a reflexive researcher and to be as objective as possible by noting down my own thoughts throughout the data analysis process; although, it has also been said that researchers "…are integral to the social world that they study" (Mauthner and Doucet, 2003, p 416).

4.5 Saturation vs. Information Power in Qualitative Research

Saturation in qualitative data collection is a commonly used and widely well-received method of deciding when sampling should cease. However, saturation can be a bone of contention, as it can be argued that saturation may differ between various qualitative methods, therefore these differences can result in significant variance in the resulting sample size. The primary assumption of descriptive saturation is that the researcher will find no new codes / categories / themes from the data (Rebar et al, 2011). Mason's (2010) review paper revealed that qualitative researchers often do not demonstrate adequate transparency regarding sample size and merely state saturation was achieved without providing a full explanation for their sample size. This was echoed by Newton et al (2011) who stated that most studies in their systematic review did not discuss how data saturation was achieved. Although saturation is a widely used concept and is often regarded as the *gold standard* for determining sample size in purposive samples within qualitative research studies (Guest et al, 2012), Braun and Clarke (2019) argue that the concept of data saturation is not entirely compatible with some methods of thematic analysis, namely reflexive thematic analysis. Instead, they assert that making judgements about the number of data items and when to stop data collection are subjective.

In thematic analysis (more recently referred to as reflexive thematic analysis) codes are never finally fixed, they can evolve, be redefined or renamed, collapsed with other codes or abandoned entirely. This was indeed the case in this study, codes were refined, renamed, collapsed several times before a final list of themes were derived. This process reflects the researcher's continual engagement with the data and indicates reflexive interpretation as analysis evolves (Braun and Clarke, 2019). Braun and Clarke (2019) emphasize the importance of in-depth engagement with the data in thematic

analysis and describe how coding and theme development can move back and forth recursively. Therefore, the idea that there is *no new* data is not fully compatible with thematic analysis. Information power has been offered as an alternate concept to data saturation in projects utilizing reflexive thematic analysis. However, Braun and Clarke (2019) state that data saturation may still be used by thematic analysis researchers as a pragmatic way to appease readers, particularly during the publication process. Braun and Clarke (2019) do not assert that data saturation is an invalid concept, but suggest it may not be well suited for rationale of sample size, instead they offer the view that it may merely be a matter of preference.

Malterud et al's (2016) concept of information power involves the idea that the more relevant information a sample holds, the fewer participants are required. Braun and Clarke (2019) and Sim et al (2018) advocate for a sample size which is determined on a mix of interpretative and pragmatic judgement. Malterud et al (2016) has stated that information power is influenced by the study aim, specificity of the sample, the theoretical background, quality of dialogue and data analysis strategy. Malterud et al (2016, p 1757) stated that any judgements regarding sample size should be "stepwise revisited along the research process" as opposed to being decided in advance, this assertion fits with an inductive approach to data analysis. The primary aim of this project was very broad; to explore the perceptions, opinions and experiences of people with TTM. Therefore, 20 email interview participants and 10 blog posts were recruited, in line with Malterud et al's (2016) assertion that studies with broad aims may require larger samples. As mentioned, Braun and Clarke (2019) advocate for a sample size that utilises a mix of interpretative and pragmatic judgement, suggesting the decision to stop data collection is subjective. In a similar vein, Malterud et al (2016) stated that judgements about sample size can be revisited along the research process. In this study, participant 19 spoke extensively about the installation of a hair replacement system, which no other participant had previously spoken about, so data collection continued. Data from participant 20 largely aligned with the majority of preliminary codes from previous email interview participants, a decision was therefore made to cease data collection following participant 20. Similarly, this occurred within the blog post data and data collection ceased after 10 blog posts. Sample size was not fully fixed at the outset of the study and was revisited based on the data and preliminary coding. This study has recruited a specific group of participants (people with direct experiences of having TTM) and collected data via online methods from two samples. The use of online methods has taken financial and available resources into consideration by eliminating the need to travel for face to face interviews while providing access to an internationally inclusive and hard to reach population.

Although Malterud's (2016) concept of information power can be used as an alternate to data saturation, criticisms have been noted; Malterud et al (2016) appear to assume the facets involved in information power and subsequently sample size, operate in a uniform and predictable way. A study with broad aims may require the use of a larger sample size, but the nature of the study aims should also be considered (Sim et al, 2018). Furthermore, Malterud et al (2016, p. 1756) argues "a researcher who never challenges his or her participant runs the risk of developing empirical data

holding low information power". Rather, this project holds the view that participants should be permitted to unfold their story freely and with minimal researcher intervention (see Wengraf, 2009), as a result of this standpoint and coupled with a broad primary aim, a larger sample was recruited to contribute towards information power.

4.6 Chapter Summary

This chapter has presented the process of gaining ethical approval, alongside methods of data collection for phase one (email interviews) and phase two (blog posts) and an overview of how data were analysed using Braun and Clarke's thematic analysis. In relating this chapter back to the methodology chapter; thematic analysis is often used in generic qualitative studies, as the primary aim of generic studies is to provide a rich description of the phenomenon in question which generally means using a highly inductive approach (Lim, 2011). Both the email interview and blog post data phases were analysed in an inductive way to locate semantic level themes. Inductively identifying themes would help towards assuring themes were strongly tied to the data itself and that the findings would be data driven. The next chapter will clearly highlight the themes and sub-themes that were derived from the thematic analysis.

Chapter Five: Presentation of Findings

This section will present the findings from phase one (asynchronous email interviews) and phase two (blog posts). Data were collected in two phases as they had originated from two separate populations and different findings may have emerged from each phase. As such, each phase will be discussed separately below. Participant extract quotes will be presented in their originally submitted format without any spelling or grammatical corrections, and any unclear points will be clarified using square brackets. Extract quotes will illustrate each theme and sub-theme while aiming to show the breadth of participants responses.

Demographic information will be presented first, including a summary of the email interview sample, and descriptive characteristics of the nature of their hair-pulling behaviours. A profile (table 5.1) of the sample includes 7 male and 13 female participants from 15 different countries, with an age range between 18 – 55 years old. The age range for age of onset in the full sample is between 5 – 26 years old; with the average age of onset for the full sample being 14.25 years old. The average age of onset for males was higher (17.14 years old) than that of the female participants (12.69 years old). Of the 20 participants in the email interview sample, TTM has been experienced for an average of 20.05 years.

Table 5.1: Demographic Information of the 20 Asynchronous Email Interview Participants

Participant Number	Gender	Location	Age	Self-Identified Ethnicity or Nationality	Relationship Status	Years with TTM	Asynchronous Email Interview Schedule
P1	Female	Massachusetts, USA	49	White	Single	39	Completed
P2	Female	New Zealand	44	White	Married	32	Completed
P3	Male	Germany, EU	54	White	Single	30	Completed
P4	Male	India	29	Indian	Single	12	Completed
P5	Male	Canada	46	White	Married	41	Completed
P6	Male	Brazil	30	Brazilian	Single	18	Completed
P7	Female	China	22	Chinese	Single	12	Completed
P8	Female	Morocco	20	Moroccan	Single	13	Completed
P9	Male	Australia	26	White	Single	10	Completed
P10	Female	Mauritius	32	Mauritian	In a relationship	23	Completed
P11	Female	Abu Dhabi, UAE	24	Muslim	Single	15	Completed
P12	Male	Johannesburg, SA	35	White	In a relationship	15	Completed
P13	Female	Jamaica	18	Jamaican	Single	4	Completed
P14	Female	Ireland, UK	28	White	Single	23	Completed
P15	Female	Switzerland	55	White	Married	30	Completed
P16	Female	Illinois, USA	42	White	Married	18	Completed
P17	Male	Cape Town, SA	52	White	Married	26	Completed
P18	Female	England, UK	31	White British	In a relationship	18	Completed
P19	Female	Ohio, USA	27	White	Married	11	Completed – opted out of last set due to time constraints
P20	Female	Wales, UK	22	White Welsh	In a relationship	11	Completed

At the beginning of the interview schedule, participants were asked some introductory demographic questions and some descriptive questions based around their hair-pulling behaviours. Alongside asking participants to describe their full process of hair-pulling, other questions included their perceived causes and emotions that may trigger hair-pulling, how participants feel during and after hair-pulling, and the environments where it commonly takes place. Based around these descriptive questions, a central theme emerged involving a cyclical pattern in participants hair-pulling behaviours.

5.1 The Cycle of TTM

The full process of hair-pulling outlined by participants identified a clear cyclical pattern of TTM and highlighted the antecedents, motivations, environments and consequences associated with their TTM. The cyclical process appears to loop repetitively, as the short-term and long-term consequences and attempts to mediate hair-pulling behaviours both result in further hair-pulling. The descriptive details that emerged from participant responses revealed a cyclical pattern of TTM, this descriptive theme will be unpacked further with supporting extract quotes below.

Participants reported general feelings of upset (e.g. stress, frustration, anxiety, tension, depression), or neutral states (e.g. boredom or relaxation) before engaging in hair-pulling. Other antecedents included feeling an urge, being tired, automatic hair-pulling, or needing tactile stimulation. This highlights the wide array of potential hair-pulling drivers that one person may experience:

> *'Sometimes when I feel upset, or worried then it gives me the urge to pull out the hairs. Sometimes when I feel very tense, pulling the hairs makes me feel more relaxed. Sometimes when I'm bored, it gives me an extra stimulation which feels good'* (P4 – Male, 29)

> *'I believe in the stimulus theory for me. So before I pull I'm either bored and looking for something to interest my brain, or I feel overwhelmed with so much to do and the easiest option for me is to escape the situation and do none of the urgent things, and pull!' (P2 – Female, 44)*

Participants were asked about the feelings they experience when pulling their hair, they highlighted positive feelings such as: pleasurable sensation, escapism, satisfaction, and that it can feel addictive:

> *'Pulling my hair gives me a very pleasurable sensation, it feels great. It makes me relaxed and releases tension' (P9 – Male, 26)*

> *'Sometimes I do it automatically and then I only realise after I've pulled a few, but the feeling is addictive' (P3 – Male, 54)*

> *'The sensation of pulling the hairs out is the most amazing feeling, one of comfort and pleasure' (P7 – Female, 22)*

Participants revealed that their hair-pulling behaviours primarily take place when they are alone or in isolating situations, these may involve a variety of environments including; while watching television, if they're in bed, if they're alone / not in public or around people, on the computer or in the car:

> *'The pulling happens at night when I am by myself. It happens when I am watching tv or on the computer and lying in bed or reading a book or just relaxing' (P14 – Female, 28)*

Only two participants reported hair-pulling in public settings, with the remaining 18 participants reporting that their hair-pulling takes place largely when they are alone:

> *'Anywhere and everywhere! Home when I am watching the telly or in bed, in the bath, when I was in college/uni I would pull as I listened to my teacher, on the bus, in the car, outside spaces....basically unless I am using my hands I pull' (P18 – Female, 31)*

Participants were asked to describe their process of hair-pulling, this revealed that participants often engage in a ritualistic process when hair-pulling starts; participants either pull hairs at random or search for specific hairs (e.g. thick hairs, or curly hairs). Participants then describe pulling out the hairs and examining them. Some participants keep the hairs or rub them across their lips (tactile stimulation), the process typically ends by discarding the hairs:

> *'I feel a rough hair, a curly or wiry one. I keep lightly pulling it, wanting it to come out on its own, but if it doesn't, then I pull it out. I always look at it first, feeling the texture and examining it. If there's a bulb, I touch it, and on rare occasion have touched it to my lips. I'm fascinated with the really kinky ones. Then I pile them up in a spot, and throw them away afterwards' (P1 – Female, 49)*

There was a slight variation to the end process for several participants, who reported that their process typically does not end by discarding the hairs, as they sometimes engage in biting off the root or ingesting the hairs (trichophagia):

> *'I search through my head, or public region for a hair that feels shorter or longer than the rest, that may be course, or even pointy, just different in some way. And I pull it out with great force, then I usually look at it to see if it may have a root, or any type of difference than a plain hair. Sometimes I'll bite the end, sometimes I'll just chew on the root, sometimes I'll see if it will stick to my lip...' (P19 – Female, 27)*

> *'I sometimes eat the hairs, but I am afraid of the hairball problem' (P8 – Female, 20)*

Following on from the process of hair-pulling, participants reported the immediate consequences of their TTM very positively by saying they felt relaxed and happier. However, these immediate consequences were very short lived before the negative subsequent consequences took over, as participants reported feelings of guilt, sadness, shame, disgust, anger, self-loathing, insecurity, and jealousy of others.

> *'When I am under stress or feel very worried, I pull my hair, this makes me feel good and it relieves some tension. But shortly thereafter, the fact that I've pulled makes me stressed again and I feel worried and guilty all over again' (P4 – Male, 29)*

> *'After pulling there are feelings of relaxation, enjoyment, then followed by horrible feelings of guilt and disappointment at my actions' (P7 – Female, 22)*

Although participants did not expressly refer to short-term and long-term consequences, nor did they provide an explanation of the length of time each phase entails, the nature of their talk indicated this as they used phrases such as *'after pulling….'* and *'very short time only'* to indicate immediate consequences, and phrases such as *'but shortly thereafter*…' and '*followed by…'* to indicate the subsequent consequences of their TTM. This is succinctly described by participant 17 below:

'I find hair pulling very relaxing. Before I pull I often feel worried about something, and after I pull I feel more relaxed for a very short time only… then I get angry with myself that I've pulled again which increases the worry (which makes me want to pull again) it's a vicious cycle' (P17 – Male, 52)

This cyclical pattern of TTM outlined above is well described by participant 11:

'It's hard for people to understand that we destroy our bodies because it feels so nice, but then we have the most overwhelming feelings of shame and guilt, which causes more pulling to seek that pleasurable sensation again' (P11 – Female, 24)

Within this Cycle of TTM, participants discussed their hair-pulling by saying that it fluctuates, and they have *"no real control"* over TTM. They attempt to control their TTM by negotiating with themselves, with participants talking about an internal battle to control their hair-pulling. If the attempts of control (through negotiations or giving themselves permission to pull a small amount) fail, these attempts alongside the subsequent consequences lead to further hair-pulling:

'I used to give myself permission, but the constant cycle of failure was too much to handle. Giving myself permission to pull 5 hairs, but failing to stop and in reality pulling 50 – 100 hairs. I try not to impose too many tasks on myself where failure is inevitable' (P11 – Female, 24)

'I find hair pulling very relaxing. Before I pull I often feel worried about something, and after I pull I feel more relaxed for a very short time only… then I get angry with myself that I've pulled again which increases the worry (which makes me want to pull again) it's a vicious cycle' (P17 – Male, 52)

The negative emotions experienced in the 'subsequent consequences' phase seems to loop back around and interlink with the general feelings of upset (antecedents phase), this suggests that the process of TTM may loop repeatedly and exacerbate hair-pulling even further. The findings from this theme detailing the descriptive characteristics that may encompass the process of TTM is presented in figure 5.1.

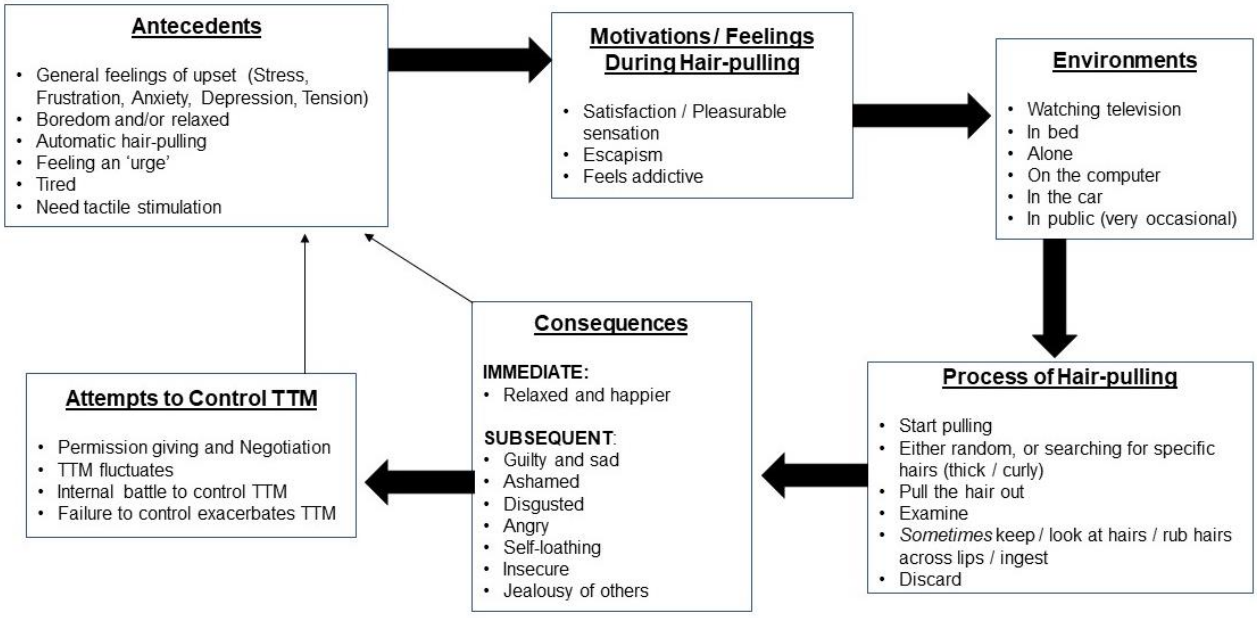


Figure 5.1: The Cycle of TTM

5.2 Themes and Subthemes from the Email Interview: Experiences, Opinions and Perceptions of Trichotillomania

This section links back to the primary aim of the project, to explore the experiences, opinions and perceptions of people with TTM alongside any overall effects relating to social, health and wellbeing implications. It is important to note that there are several aspects of the data where themes and sub-themes may interlink in places. Although some findings are fluid and overlap in many places, they will be presented separately. This section comprises four themes: a journey of uphill battles, the implications of fearing judgement, persistent and extensive effects, and coexisting health implications. The themes and sub-themes in this section are presented in figure 5.2 below

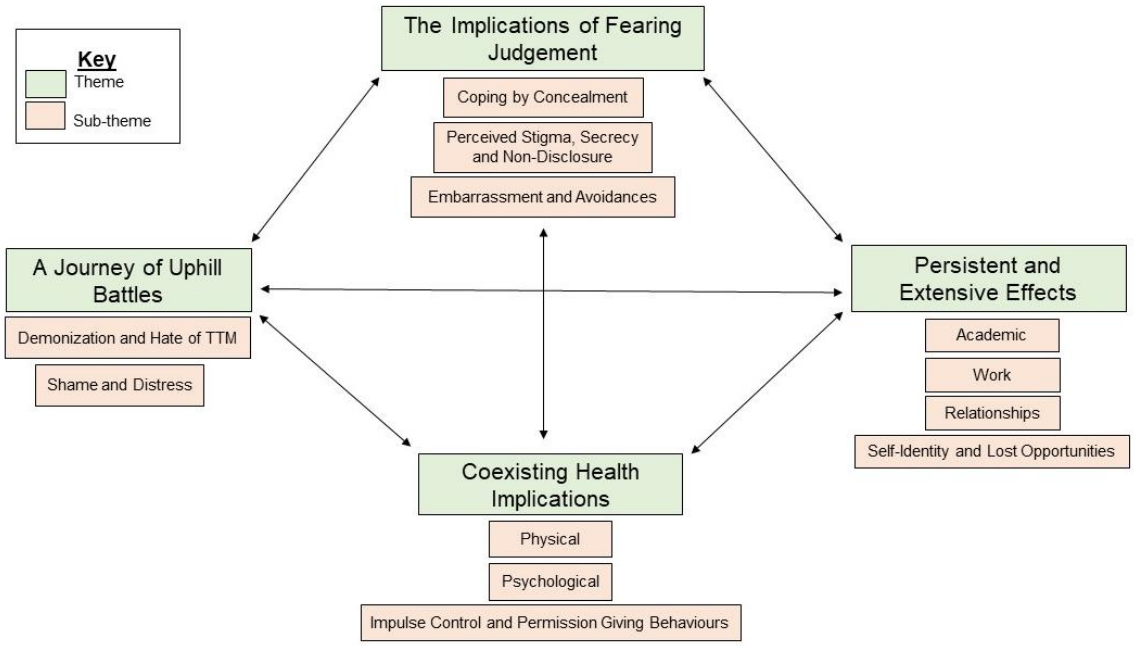


Figure 5.2: Diagram Illustrating the Themes and Sub-Themes from the Email Interview illustrating participant experiences, opinions and perceptions of TTM.

A Journey of Uphill Battles

The first theme, "a journey of uphill battles", describes the way participants feel about their relationship with TTM and consists primarily of hardships and negative connotations. This theme involves two sub-themes (demonization and hate of TTM, shame and distress) that will be discussed in turn. A worked example of theme development, including preliminary descriptive coding, extracts and interpretative coding of this theme and two subthemes is included in appendix ten (page 200).

Demonization and Hate of TTM

The email interviews suggested that participants primarily view their TTM in a negative light, with participants describing their TTM in ways that appear to vilify the disorder. Participants described their relationship with TTM in this regard by saying the following:

> *'Trichotillomania is an unwelcome evil in my life. I hate it, and I hate myself for having it' (P7 – Female, 22)*

'Trichotillomania must be some kind of demon and I really hate it.' (P6 – Male, 30)

'Trichotillomannia is like this very dark cloud hanging over my head, it brings despair and heartache. I hate it (P8 – Female, 20)

There were other participants who described their relationship with TTM as being an emotionally taxing and heart-breaking disorder, with it appearing to be the bane of their lives:

'I despise trich, it's the bane of my life' (P9 – Male, 26)

'It's just a terrible, heartbreaking, emotionally taxing, upsetting, and disgusting disorder. I think that my life would be completely different if I didn't have Trich…and when I think about how it would be different / what could have been, I feel so disappointed and unsatisfied with my current life' (P14 – Female, 28)

Shame and Distress

Participants frequently reported feelings of shame associated with their TTM, by detailing how they feel ashamed at having to hide the after-effects of hair-pulling and view their TTM as a shameful act.

'I do feel ashamed that I wear a wig because it feels like I am lying to people about my appearance' (P10 – Female, 32)

'I'm totally embarrassed, ashamed and disgusted in myself at the moment that EVERYTHING is so bad and that my kids and husband have to see a bald patchy haired ugly mum at home' (P2 – Female, 44)

'urgh! Why the hell do I do this to myself?! why cant i stop?! why do i feel so ashamed?! why me?' (P18 – Female, 31)

The feelings of shame may cause distress in participants' lives, and the feelings of shame and distress appear to be inextricably linked within the interviews. Participants detailed how significantly TTM impacts their lives, by suggesting that TTM causes frequent and long-term distress. This was expressed in a number of different ways, all of which involved talking about TTM in a negative manner:

'Trich is life impacting, and dominates my thoughts very often. It causes me distress in the sense that I worry if I'll ever live a normal life' (P12 – Male, 35)

'it's an awful, usually decades-long affliction. And I would say that we are all normal people with an unusual behavior; we are from all races and cultures, and we all just want to be accepted' (P1 – Female, 49)

Participants seemed to view their TTM as a long-term struggle and spoke about it in the context of being a 'burden' which may exacerbate feelings of distress:

'It's a terrible burden living with Trichotillomania, which not many people can fully understand' (P11 – Female, 24)

'I fear that trichotillomania will impact my whole life until my death. I fear that Trichotillomania will always control me, that I will never lead a normal life. Trichotillomania is a terrible and heavy burden to live with' (P8 – Female, 20)

Further highlighting the sub-theme of "shame and distress", participants suggested they were frustrated with having TTM by using the term *"why me?"* in relation to having TTM, implying they may view themselves as a victim of the disorder:

> *'urgh! Why the hell do I do this to myself?! why cant i stop?! why do i feel so ashamed?! why me?! all the hours i have wasted picking hairs!!' (P18 – Female, 31)*

> *'I feel like I'm stuck with having a bald head forever. I often wonder WHY ME. Why can't I just be a normal person who doesn't have to worry about such trivial things. Life is not fair' (P3 – Male, 54)*

The Implications of Fearing Judgement

The second theme, 'the implications of fearing judgement' encompasses the lengths participants will go to keep their TTM hidden, with wide-ranging motivations for keeping TTM hidden. The three sub-themes that feed into this main theme are: coping by concealment, perceived stigma, secrecy and non-disclosure, embarrassment and avoidances. These sub-themes are interlinked and overlap in various places, as participants reported that they engage in behaviours of secrecy and non-disclosure relating to their TTM due to the perceived stigma they may receive from other people. Participants reported feelings of embarrassment relating to their TTM and that they used concealment methods as a form of coping with their hair loss. Frequently avoiding certain situations which may make them feel vulnerable and reported feelings of paranoia that their TTM may be discovered. All three sub-themes represent the implications associated when participants fear being judged by others.

Coping by Concealment

While many participants expressed struggles about coping with TTM, some participants said they simply could not cope with their hair-pulling, while others said they had no choice but to cope with it.

> '*I cope because I have to cope. What other option to I have?' (P18 - Female, 31)*

> *'On the outside it looks like I cope very well but on the inside I cannot cope with Trichotillomania and it has broken my soul. Appearances are deceiving' (P8 - Female, 20)*

The topic of concealment was spoken about frequently in association with coping and it was evident that participants invested time, effort and money by using concealment as a coping strategy:

> *'I cope well by using clip in extensions or wigs, and fake eyelashes. If those didn't exist, I shudder to think what my reality would be' (P14 – Female, 28)*

> *'I do not cope, but I can use coping means to help – I wear a hat at work' (P6 – Male, 30)*

Alongside the comments about using concealment as a form of coping with TTM, other participants describe the difficulties of emotionally coping with their TTM:

> *'Physically coping by using hair products and makeup. Impossible to emotionally cope' (P7 – Female, 22)*

Further to this, there were other comments from non-western countries (Morocco and Abu-Dhabi) that highlighted how wearing traditional / conservative dress had become a means of concealing their hair loss:

> *'I am very lucky that my clothing hides my head and legs. If I didn't wear conservative dress, I imagine I would spend a lot of time and money trying to hide the effects of hair pulling' (P11 – Female, 24)*

> *'I spend money on eyebrow makeup to draw the eyebrows on. When I pull the arm, leg and pubic hairs with a tweezer, the skin becomes red with small bumps. I have to use lotion to calm the area. I dress conservatively and cover my body, none of the areas show except my eyebrow's (P8 – Female, 20)*

Participants reported feeling *'paranoid'*, worried and having to frequently check up on their methods of concealment. Although the medical meaning of paranoia has a different connotation, participants spoke about feeling paranoid in the sense that they would frequently worry that their concealment methods would be discovered:

> *'I go to the toilet at least 6 times per day to check that the makeup on my eyebrows still looks suitable' (P7 – Female, 22)*

It was also reported that levels of worry and paranoia were heightened if anyone observed a participant who started unconsciously / automatically pulling their hair:

> *'I also used to feel very worried and anxious if anyone every caught me pulling at work. Although I mainly pulled at home, I became paranoid that I'd start doing it unconsciously at work' (P3 – Male, 54)*

In a similar vein, other participants reported feelings of paranoia at having their TTM or hair loss exposed in some way:

> *'always terrified wig will fall off, don't ever let anyone touch my hair or face, paranoid about waking up first and getting makeup back on before partner wakes' (P2 – Female, 44)*

> *'I am very paranoid that my wig will come off or if the wig looks fake. This makes me very paranoid and worried and makes me feel very ugly. I would feel happyer [happier] and beautiful if my hair was real' (P10 – Female, 32)*

Perceived Stigma, Secrecy and Non-Disclosure

Secrecy and non-disclosure represent how participants largely keep their TTM a secret and aim to avoid telling other people about their hair-pulling:

> *'I do not tell anyone! It's a big secret. I can hide the areas well and I don't want people to pity me. I would rather live a secret life and lie to people than be embarassased [embarrassed] and pitied' (P6 – Male, 30)*

> *'Life is not good when you're living a secret life, we should all be free to live as we are – without judgement or scorn' (P4 – Male,29)*

> *'I don't tell anyone, I would prefer to live a secret life where people accept me than to tell people I wear a wig and be judged unfavourabley [unfavourably] for it. My hair should not matter. I do not want pity from people' (P10 – Female, 32)*

Some participants who had disclosed their TTM to close friends and family, expressed that it still appeared to be viewed as a taboo topic, where their hair-pulling was perceived to be ignored and not discussed:

> *'My family knows about it, no one ever speaks about it. It's like an elephant in the room. The topic is avoided entirely like it's a big secret' (P6 – Male, 30)*

> *'For the most part, no one talks about it and I think It's because no one understands it. It's like it's a voo-doo topic, people just avoid it at all costs. I think they see me as being abnormal, because they don't understand how I could do that to myself. Harm myself, and ruin my own appearance' (P12 – Male, 35)*

Within this main theme (the implications of fearing judgement), participants who may fear judgement have suggested they engage in various behaviours such as secrecy and non-disclosure in order to avoid the perceived stigma they may receive:

> *'There is a terrible judgement and stigma associated with Trichotillomania which is upsetting to us, and is probably the reason why we are so secretive about it' (P3 – Male, 54)*

> *'Mental health is so stigmatised that you are automatically seen as unwell/crazy/that you are attention seeking/ not capable or "normal" (P18, Female, 31)*

Interlinked into these sub-themes of participants keeping their TTM a secret due to perceived stigma and judgement from their peers, participants highlighted the importance of educating the wider community about TTM in a bid to minimise stigmatisation, so that this misunderstood mental health disorder could become more socially accepted:

> *'I think we should be educated from an early age so it isnt as stigmatised and understood better if there are young 'trichsters'. Therefore talks in schools would be an option (P18 – Female, 31)*

> *'I would like Trichotillomania to be more socially acceptable. There are other hidden illnesses, like IBS and Crohn's, and ME which are very widely accepted by people' (P3 – Male, 54)*

> *'Acceptance with no stigma is also very important' (P1 – Female, 49)*

Another participant touched on this by sharing the opinion that mental health conditions are not seen as equal to physical health conditions. This could imply that there may be a wider perception that mental health disorders may be seen as inferior in comparison to physical illnesses:

> *'I just wish more people knew about Trich, and that it was an accepted disorder (like MS) – and that people didn't feel disgusted by the idea of us pulling out our own hair. I wish more people took it seriously, but some people just see it as a silly mental health disorder… they view more physical illnesses as far superior' (P12 – Male, 35)*

The four supporting quotes used to illustrate perceived stigma represent two male and two female participants, all white in ethnicity, and represent the more mature side of the sample with an age range of between 31 – 54 years old. These sentiments were not widely noted among the younger

sample, only one participant referenced the need for education but did not discuss this in relation to stigmatisation:

> *'Education is very important, not enough people are educated on these issues' (P8 – Female, 20)*

Embarrassment and Avoidances

This sub-theme represents the situations that participants actively try to avoid due to the potential feelings of embarrassment that may result from their TTM or hair loss being discovered. Participants reported avoiding hairdressers and described various situations where a hairdresser had made them feel uncomfortable:

> *'I avoid the barber. I haven't been in at least ten years…. I avoid it completely because its embarassing. I would panic if I had to visit one, the idea makes me feel very uncomfortable. My cousin cuts my hair for me' (P6 – Male, 30)*

> *'The last time I visited the hairdresser was 8 or 9 years ago. She commented on the shorter parts, thinning areas, and I had a bald patch at the nape of my neck. She made me feel really guilty about it, the whole experience was a complete turnoff. I haven't been back since. She had no sensitivity at all, she spoke really loudly too so the whole salon could hear things like ''whats happened here then?'' (P14 – Female, 28)*

Participants also reported avoiding windy days or situations where their hair may become wet (swimming / rain), or other uncontrolled situations where a wig or hat may fall off:

> *'avoid the rain. Just because my hair looks thinner when it gets wet which can be a bit embarrassing' (P12 – Male, 35)*

> *'Both windy days and swimming obviously. Being upside down, roller coasters or anything fast. I wear a hat or wig so any situation they will fly off! Makeup nights or anyone touching my face or hair' (P2 – Female, 44)*

There was a small group of participants who stated that they try not to avoid situations and make efforts to live their lives despite their TTM and hair loss:

> *'I don't avoid situations really, I try and get on with my life' (P4 – Male, 29)*

> *'I try not to let trich control my life, or the activities which I do. I don't avoid any activities because of it' (P9 – Male, 26)*

Persistent and Extensive Effects

The theme of 'persistent and extensive effects' represents a part of the interview data about the impact participants experience as a result of their TTM. All 20 participants reported widespread and varying degrees as to the level of impact TTM has on their lives. This theme consists of four sub-themes (academic, work, relationships, self-identity and lost opportunities) which will be discussed in turn below:

Academic

Participants reported that TTM has had an impact on their academic lives, this commonly manifested itself as interrupted concentration which meant that academic tasks such as revision took longer:

> *'it definately interrupted my contentration [concentration] at school which made my grades a bit lower. I felt stressed for exams which made the hair pulling worse. Teachers were not understanding' (P6 – Male, 30)*

> *'It did have a negative effect on my concentration at school and university' (P11 – Female, 24)*

Participants also discussed how the impact of interrupted concentration meant that their overall grades could have been better:

> *'I think my grades in high school and university could have been better. My academic studying and revision has always been somewhat disjointed; my mind often travels to pulling instead of focussing on revising. A revision session lasting 1 hour would instead take 1 & a half hours, due to the problem of broken concentration' (P9 – Male, 26)*

> *'I'd say that my grades could have been 10% higher maybe, if I was spending more time doing my assigments, instead of worrying about pulling' (P12 – Male, 35)*

Work

Participants reported an impact on their work life due to TTM, by saying that they purposefully chose easier jobs with less stress regardless of their degree field /educational background, and would avoid certain types of roles (e.g. face to face customer service):

> *'I prefer jobs with little stress, where I'm in the background. I've had a very sporadic work life. I've done menial jobs even though I have a degree, and I've avoided customer service because I don't want anyone to notice my trich. When I am too physically close to people and I feel that they are looking at me, I go into "quiet panic" mode, where I can't think right or function at my job' (P1 – Female, 49)*

> *'I have an arts degree but never managed to make a career of it. So I currently work in an administration office job. It's very easy and the job doesn't cause me any stress' (F14 – Female, 28)*

Another participant stated that they experienced issues meeting deadlines which impacted their work:

> *I sometimes have problems meeting deadlines at work though, which I attribute to my trich struggles. (P9 – Male, 26)*

When asked if TTM had any impact on work life, another participant discussed how he attributed his slow career progression to his TTM:

> *'my professional life has been stunted. It took 10 years of being in an uhappy [unhappy] career path to now run my own company. Those 10 years were hell' (P3 – Male, 54)*

Relationships

The sub-theme involving impact on relationships revealed data where participants reported wide ranging impact on their relationships, including the fear of being rejected and the fear of living a solitary life.

> *'When I was 22 I told my girlfriend about my trich, and she broke up with me. She said it was weird, and she wasn't prepared to deal with issues like that. Ever since then, I've only been involved in short term casual relationships. I don't want to get too close to anyone, in fear of having the same reaction (…)I also worry if I will ever find a girlfriend who will accept me fully, or if I will be single forever.' (P9 – Male, 26)*

> *'It has affected both quality and quantity of romantic relations. I am 22 years old, and I am single. For many years now my grandparents have said I would never find a husband because of my problems with hair-pulling. It's always in my mind, the fear that I will be alone, because my problems mean that I have no self control and would not be good enough for a husband' (P7 – Female, 22)*

Other participants reported avoiding relationships altogether:

> *'Whenever I would get to a certain point of closeness to someone, I would panic and shut down. I've run away from several relationships. I no longer try, and have been single for 15 years' (P1 – Female, 49)*

> *'I have never been in a relationship. The idea of being in a relationship with a man or getting married fills me with dread, because I would have to bare my skin to the man and the effects of the Trichotillomannia would be visible' (P11 – Female, 24)*

There were other participants who touched upon their relationships with friends being impacted due to TTM, and having experienced ridicule by their peers:

> *'I had a friend in school and I told them about my hair pulling. They ridiculed me after that, and made me feel useless' (P4 – Male, 29)*

> *'In grade 9 when i first pulled every lash out, I was straight up told by my 'best friend' at the time that I was straight up ugly. I was embarrassed and hurt. She made me afraid to go around people. She made me feel as if I was a little ogre' (P13 – Female, 18)*

Self-Identity and Lost Opportunities

The sub-theme of 'self-identity and lost opportunities' are interlinked, as there were some participants who reported lowering their aspirations by not seizing opportunities as TTM had affected their confidence and self-esteem:

> *'Whenever opportunities arise for me, I let them slide by, because I don't think I could face the social interactions' (P1 – Female, 49)*

> *'awful condition that has destroyed my confidence, joy for life, robbed me of experiences and made need feel like (shxx) and a freak for 33 years' (P2 – Female, 44)*

The issue of low self-esteem and low self-confidence was noted among participants, which appeared to contribute towards feelings of unworthiness, thus impacting on their own self-identity:

'It has ruled my life and destroyed my self-esteem. Even after 30 yrs of therapy I still have very little. It has stunted my growth socially, and drained me of confidence and the feeling of belonging' (P1 – Female, 49)

'My own self has been impacted with negativity…. Self-doubt self-hate low esteem low confidence…. feeling abnormal and dirty' (P7 – Female, 22)

This is well summarised by participant 2 who makes a clear link between self-confidence and lost opportunities:

'It's debilitating and erodes confidence and opportunity (…) It's ruined my appearance forever and that's quite debilitating' (P2 – Female, 44)

These predominantly negative self-concepts may have implications as to general feelings of unworthiness:

'Having trichotillomania definitely effects my esteem and confidence. I feel like a lesser person because of this problem, and I feel like I am unworthy for a relationship or successful life' (P4 – Male, 29)

Some participants spoke about their issues with low self-esteem and low self-confidence by suggesting they try keep these feelings hidden by aiming to actively portray a façade of confidence around their peers:

'My self-esteem and self-confidence are very very low. I think if I didn't have trich my life would be better and I would be more confident and well.I can hide it very well. My friends think I am confident but it's all fake' (P10 – Female, 32)

'I do try and give off a confident vibe though, even though it's a façade. I've become incredibly skilled at the art of lying by omission' (P12 – Male, 35)

Further to the impact that TTM has on self-identity, a participant from a non-western country who wears conservative / traditional clothing said that revealing the extent of her struggles with TTM would make her feel unworthy:

'Showing my legs and head to someone where they can see the bumps and scars and bald patches would be worse than being naked. All my flaws would be visible. I would not feel beautiful and I would not feel like a worthy woman' (P11 – Female, 24)

Other participants reported that they deliberately chose easier career paths due to feelings of low self-worth, this negative view on themselves may lead to lowered aspirations and potentially result in delayed / lost opportunities for career progression:

'Although I had a university degree and was well educated, I accepted a very simple and menial job because I didn't think I was worthy of a better job. After many years of being in an unhappy job, I worked my way up the company and I now run it myself' (P3 – Male, 54)

'I wear the wig at work and I don't pull at work. My job is very easy. I chose an easy job to feel less life pressure, and sometimes I feel like I am only worth having an easy job because my problems make me less of a person' (P10 – Female, 32)

Coexisting Health Implications

This theme represents a significant part of the data set as all 20 participants reported experiencing varying degrees of co-occurring health issues in relation to their TTM. This theme consists of three sub-themes; physical, psychological, and impulse control and permission giving behaviours which will be discussed in turn below.

Physical implications

Participants reported physical problems associated with their TTM, these included musculoskeletal issues, muscle spasms, tension, headaches and pain:

> *'I'm ruining my body with the repetitive motions. I NEED to stop. I have many musculoskeletal problems, and am on pain meds every day (…) stress-related muscle spasms from tenseness and rigidity in my back and neck. I've had a lot of headaches. I have had panic attacks and social anxiety' (P1 – Female, 49)*

Dermatillomania (skin-picking disorder) seemed to be a common issue within the sample, as 10 participants reported issues with skin-picking behaviours:

> *'I pick my scalp, the skin sometimes. Maybe I have started doing this as an alternative to hair-pulling. It really hurts my scalp, it sometimes bleeds' (P7 – Female, 22)*

Psychological

Psychological implications were more commonly experienced by participants, with many reporting issues relating to anxiety and depression:

> *'I have a history of depression & anxiety - I'm sure that's linked to TTM. When my symptoms are raised, I pull more. 100% correlation' (P16 – Female, 42)*

> *'I suffer with really really terrible anxiety, like high functioning anxiety. I'm a perfectionist which makes it worse too. The trichotillomania worsens the anxiety, which worsens the trich. I think the anxiety developed a few years ago, as a result of dealing with trich for such a long time' (P14 – Female, 28)*

The psychological impact of TTM was discussed by participants alongside their perception of having a mental health disorder and their feelings of wellbeing. Participants indicated that they generally felt mentally well, despite having a mental health disorder:

> *Generally, I feel mentally well. Although Trich is a mental health disorder which impacts so many things, it would be easy to fall into the routine of feeling sorry for myself and feeling mentally unwell (…) Trich affects so much already, I don't want to give more power to it by having the mindset of being mentally unwell. (P9 – Male, 26)*

> *I think I'm mentally well, having a mental health disorder does not automatically mean you're mentally unwell. But I think it would depend on the person, some people have stronger minds than others, we can withstand more struggles! (P14 – Female, 28)*

While other participants suggested that they go through phases where they feel both mentally well and unwell:

'There are phases where I feel mentally well and mentally unwell, the trichotillomania has a lot to do with this. Sometimes when I'm struggling a lot with the hair pulling, I feel mentally unwell.' (P4 – Male, 29)

Impulse Control and Permission Giving Behaviours

Participants reported engaging in permission-giving behaviours in an attempt to exercise some form of control over their TTM. Many participants said they allowed themselves to pull out a few hairs (by pulling in a controlled manner), this was short lived as the permission-giving behaviours gave participants a false sense of control over their TTM, which appeared to exacerbate the hair-pulling.

'there is always a battle within me to control the hair-pulling. The sensation of pulling the hairs out is the most amazing feeling, one of comfort and pleasure. If I gave myself permission to pull twice per day instead of 2 solid hours, it gives my mind a false sense of control but In reality the Trichotillomaia controls me' (P7 – Female, 22)

'I negotiate with myself, If I pull 1 hair per day, I'll have it under control. Even when I negotiate with myself, allowing myself to pull 1 hair per day (as a form of control), the 1 hair turns into 5 which turns into 10 and then I've lost all control. The feelings of shame and guilt are tremendous' (P9 – Male, 26)

Linked into the idea of permission-giving behaviours is impulse control; participants reported that their TTM fluctuated and often became uncontrolled, some participants discussed this as the hair-pulling happening unconsciously (or automatically) by stating that their hand starts the behaviour independently of their will:

'I have never been in control of it. Trichotillomaniia controls me. Sometimes it feels like my hand has a mind of its own it just automatically goes up to my head to pull' (P4 – Male, 29)

'Sometimes my hand goes up to my beard or head automatically like a magnet. (P6 – Male, 30)

These feelings of permission-giving and lack of control over their TTM may result in wide ranging negative emotions and could lead to frustration. Participants reported that their attempts to reduce or control their hair-pulling mean that failure is an inevitability:

'I used to give myself permission, but the constant cycle of failure was too much to handle. Giving myself permission to pull 5 hairs, but failing to stop and in reality pulling 50 – 100 hairs. I try not to impose too many tasks on myself where failure is inevitable' (P11 – Female, 24)

'Giving myself permission would be giving myself a false sense of control and the bargaining would fail' (P17 – Male, 52)

There were other participants who reported issues with binge and overeating and risk-taking activities:

'I also binge eat, but I don't know if that's relatable' (P1 – Female, 49)

'I also eat! I was anorexic and buggered up my metabolism, so now I'm obese, Like trich, if i know I "shouldn't" have or do something, I think about it constantly! (P2 – Female, 44)

'I tend to say things and do things impulsively sometimes without a lot of thought. I have always been a big risk taker (adrenaline junkie)' (P5 – Male, 46)

5.3 Themes and Subthemes from the Email Interviews: Experiences of Previous Treatments alongside perceptions and opinions of participants' ideal treatment strategy

This section uses the interviews to look at previous successful and unsuccessful treatments, alongside participant perceptions and opinions of their ideal TTM treatment strategy. This section links back to two of the study objectives; to explore participant experiences, opinions and perceptions of TTM, and to identify participant treatment preferences. Four main themes were identified in this section alongside several sub-themes. The themes and sub-themes are illustrated in figure 5.3.

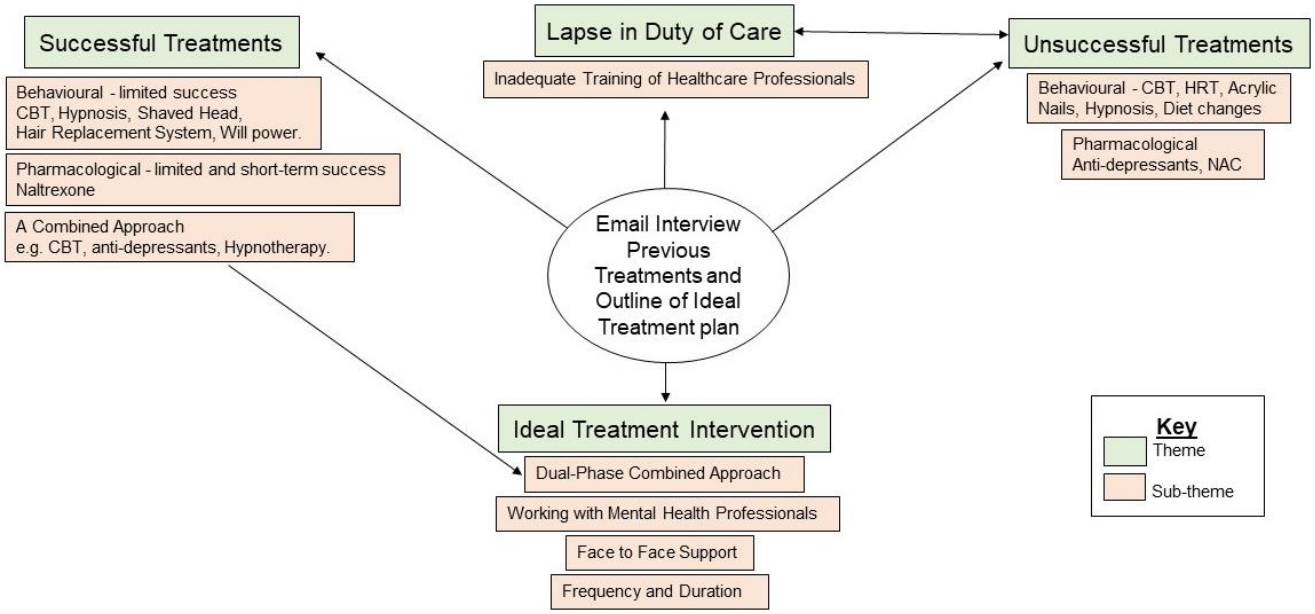


Figure 5.3: Diagram Illustrating the Themes and Sub-Themes of the Email Interview illustrating previous successful and unsuccessful treatments, alongside an outline of participants' ideal treatment plan

Successful Treatments

The first theme, 'Successful Treatments', describes the various treatments participants have tried that have had varying results in reducing hair-pulling behaviours. This theme involves three sub-themes (behavioural treatments, pharmacological treatments and a combined approach) that will each be discussed in turn below.

Behavioural Treatments

This sub-theme includes various forms of behaviour-based modifications that participants themselves have implemented, as well as behaviour-based treatments provided by healthcare providers. Participants described that they have experienced fairly limited success with behaviour-based treatments, with the behaviour-based methods primarily involving keeping their heads shaved, using will power, hypnosis and installing a hair replacement system. Some participants have reported that shaving their head has worked simply by removing hair so that pulling would not be possible:

'Now that I keep my head shaved, I can't pull anymore. I still get urges though even though the hair is gone' (P3 – Male, 54)

'shaving my head has kept it at bay off and on' (P1 – Female, 49)

There were mixed responses when it came to using will power with TTM, some participants reported that will power worked successfully, while others reported shaving their head and eliminating the hairs altogether as they did not have the will power to stop pulling on their own;

'I've now shaved my head and rub castor oil on. I'm trying to beat this by eliminating the possibility of me being able to pull. I don't have the self willpower to do it on my own' (P2 – Female, 44)

'Will power (the most success)' (P5 – Male, 46)

Other participants reported trying hypnosis which they described as working temporarily, with the success of this heavily influenced on the provider themselves:

'Hypnosis worked for 3 months straight, no pulling at all, but for some reason I started up again' (P1 – Female, 49)

'I did try try hypnosis with two different people. The man hypnosis doctor was THE BEST & helped! I was doing weekly sessions with him during nursing school for 3 months at $90 per session I paid out of pocket. I couldn't afford to pay for his sessions anymore, so I found a hypnosis women doctor who was covered through my insurance, I went to her for a few months she did not do as well as the male doctor. I never even felt like I was getting better, she called me for weeks after I quick [quit] making appointment and got very verbally angry that I quit making sessions, it made me has anxiety' (P19 – Female, 27)

One participant spoke extensively about having a hair replacement system installed, although this option is very expensive and requires maintenance and upkeep appointments, the hair replacement system is placed over the area (scalp) where the person pulls and is kept in place while the natural hair underneath has a chance to recover has been very successful in significantly reducing her TTM:

'I have not done anything treatment wise other than my [hair replacement system] which has helped me to be 97% pull free for the last year' (P19 – Female, 27)

Pharmacological Treatments

This sub-theme involves the various pharmacological treatments participants have found to be effective. Participants reported very limited pharmacologic success primarily with Naltrexone. Naltrexone is classed as an opioid antagonist and is commonly used to treat opioid addiction and alcohol use disorders by reducing the rewarding effects of opioids / alcohol. Naltrexone has been used as an off-label treatment for TTM and has gained research popularity in recent years (Grant et al, 2014), off-label refers to using a medication to treat a condition for which it does not yet have official approval. Participants reported positive but short-term success with naltrexone:

'I also tried Naltrexone which worked for 1 month before it wore off and it started again' (P4 - Male, 29)

'My gp then tried me on naltrexone which was amazing for the first 4 months I barely pulled at all and then it wore off and the pulling increased so we agreed to wean off of that. I am only taking a herbal supplement called NAC now, I take 1200 miilegrams [milligrams] per day. No results yet!' (P14 – Female, 28)

A Combined Approach

Participant 20 spoke about how a combination approach employing various techniques; by using cognitive behavioural therapy (CBT), hypnotherapy and anti-depressants which have had limited success in helping reduce the hair-pulling:

'CBT, hypnotherapy, anti-depressants. All have played a role to help but none have managed to stop it completely in the long run' (P20 – Female, 22)

Unsuccessful Treatments

Data from the interview revealed that participants frequently reported experiencing unsuccessful treatments, with the unsuccessful attempts at treating TTM far outweighing any limited success they had experienced. The 'unsuccessful treatments' theme consists of two sub-themes: behavioural treatments and pharmacological treatments.

Behavioural Treatments

Participants reported attempting both habit reversal therapy (HRT) and cognitive behavioural therapy (CBT). HRT is a behavioural treatment intended to reverse the positive reinforcement of hair-pulling behaviours, by using various self-monitoring and habit awareness techniques to avoid hair-pulling triggers. HRT often includes cognitive restructuring techniques aimed at modifying dysfunctional cognitions related to emotional regulation or hair-pulling behaviours (Morris et al, 2013). CBT is a psychological treatment where a patient and psychologist / CBT therapist work collaboratively to change thought and behaviour patterns. Participants mentioned that these treatment methods may have improved awareness of their hair-pulling behaviours, but failed to be a viable treatment for reducing their TTM:

'I also tried CBT, but this was a waste of time. It made me more aware, but the pulling and urges did not decrease' (P3 – Male, 54)

'I was transferred for CBT, I had 12 sessions it was very unsuccessful. The CBT therapist was rude in general' (P14 – Female, 28)

'CBT was also a waste of time. Habit Reversal Training also unsuccessful. 1 session of hypnosis also unsuccessful…… but I was sceptical of this to start' (P12 – Male, 35)

Some participants reported attending counselling sessions and sessions with a psychologist which they deemed to be unsuccessful:

'first was counseling, just frustrating because they would dig up every single negative situation I had in my life,through my childhood. Yet never get to my pulling. Just me talking about my horrible childhood. That was done for years, I literally mean from age 10-18.' (P19 – Female, 27)

'Psychologist (failed)' (P5 – Male, 46)

Participants also reported other unsuccessful behaviour-based changes involving diet changes, creating physical barriers to make pulling more difficult (wearing gloves or a hat / acrylic nails, etc), using topical products to discourage hair-pulling, and keeping track of hairs pulled to increase awareness:

> *'All unsuccessful - prozac [anti-depressant] no sugar, rubber bands on wrist, bandana, getting acrylic nails (helps not to break skin), scalpacin liquid, tea tree oil, cocnout oil, salysilic acid shampoo, tar shampoo, Beta methasone Dip 0.05% Lotn [lotion] (currently using - sooths the itch). Just ordered some special hair growing shampoo - let's see.' (P16 – Female, 42)*

> *'I've tried many antidepressants, anxiety meds, behavioral techniques (keeping track of hairs pulled and when, elastic on the wrist, gloves, etc..) . None of these worked (though the 'keeping track helped me become more aware). I've tried meditation, keeping a hat on, and playing with something to keep my fingers busy, but those didn't work. I've now been in therapy for almost 30 years' (P1 – Female, 49)*

> *'I've tried changing my diet, poor choice since I struggle with eating to begin with, I had instant disappointing results, lol' (P19 – Female, 27)*

Pharmacological Treatments

Participants reported attempting various pharmacological treatments which they suggest failed to help their trichotillomania. Anti-depressants seemed to be the most common form of pharmacological treatment:

> *'I tried both SSRI [selective serotonin reuptake inhibitor / anti-depressant] and Trycyclic anti depressents. Both were completely ineffective, in fact the SSRI anti depressant actually made me depressed, the irony!' (P3 – Male, 54)*

When discussing their experiences on anti-depressants, some participants reported significant side effects and that their hair-pulling worsened:

> *'the doctor offered me an anti-depressant. I didn't understand why because I was not depressed. First I was given a SSRI called Prozac (Fluozetine) which had terrible side effects and made the pulling worse! I was then given a trycyclic anti-depressant called Clomipramine which did not help either. I have now been told that nothing will work, and I should just try and stop on my own' (P11 – Female, 24)*

> *'My gp first gave me an ssri antidepressant (Prozac). I cant remember the dose. It reduced the pulling down to about half, but the side effects were very bad, and the pulling eventually increased again so I stopped taking it. My gp then tried me on a tricyclic antidepressant (clomipramine) which was just a disaster. It didn't reduce or stop the pulling and it made me gain weight and sleep all the time' (P14 – Female, 28)*

Participants felt frustrated at having tried a wide variety of treatment options for their TTM, with some suggesting that they have remained on the same treatment despite not experiencing any improvement in their TTM. This may suggest that there is a lack of progress in researching treatment strategies to help people with TTM:

'The Psychiatrists there put me on different drugs and despite requests and actual drug reviews (as fluoxitine isnt working) I have not moved off that drug for 20 years. clomipromine, fluoxetine and another one i can't remember but didn't work. That's it, for 33 years of "help" Ffs, toilet paper has evolved more in that time' (P2 – Female, 44)

The realities of trialling various pharmacologic treatments and experiencing the associated side effects can be very taxing for participants:

'I have tried several medicines including Fluoxetine [anti-depressant], Xanax [benzodiazepine], Clomipramine [anti-depressant], Citalopram [anti-depressant],. All have been unsuccessful. I would like to try more medicines, but it's quite taxing on the body. You need to allow for at least 6 months of a trial run to see if it works, and the side effects can be quite severe. Depression, weight gain, sleep disturbances, suicidal ideation, etc' (P9 – Male, 26)

A few participants reported trying a natural medicinal product called n-acetyl cysteine (NAC) to treat their TTM. NAC is a glutamate modulator which has shown promising therapeutic effects in treating obsessive compulsive and related disorders (Oliver et al, 2015). It is said that glutamate is an excitatory neurotransmitter in the central nervous system; researchers have hypothesised that NAC may alleviate TTM symptoms by lowering brain glutamate levels, and it has previously demonstrated a robust response in a placebo-controlled study of adults with TTM (Grant et al, 2009). However, the participants in the sample who spoke of NAC mentioned that they had not experienced success:

'I tried NAC but had no success but don't think I was taking enough' (P2 – Female, 44)

'NAC 1000mg per day was also unsuccessful' (P12 – Male, 35)

Lapse in Duty of Care

This theme represents how some participants were not offered any support or treatment options for their TTM and consists of one sub-theme (inadequate training of healthcare professionals). Alongside the findings presented above where participants reported their experiences of the various successful and unsuccessful treatments they have trialled for their TTM, some participants reported not being offered any support or referral from their primary healthcare professional. This suggests that some patient healthcare needs are being unmet:

'I have not tried anything, because I have never been offered treatment, although I have asked!' (P17 – Male, 52)

'My doctor cant even say the word 'trichotillomania' he offered no help and he is unwilling to even read about it' (P10 – Female, 32)

There were also reports that some healthcare professionals seemed to place the responsibility of stopping hair-pulling behaviours directly onto the participant:

'I have not tried any treatment because no treatments have been offered to me by doctors. They have just said I should control it myself' (P6 – Male, 30)

This finding seemed to resonate with other participants who suggested they were told to live with TTM as it's an incurable disorder, thus appearing to make participants feel alone in their diagnosis:

> *'I have tried no treatment, no treatment was offered! I was told it is incurable and I should just live with the problem. I am alone in this battle with Trichotillomania and there is no help' (P7 – Female, 22)*

> *'I was offered no treatment. I have been suffering alone. The doctor made me feel so stupid' (P8 – Female, 20)*

Inadequate Training of Healthcare Professionals

The sub-theme of 'inadequate training of healthcare professionals' links into the theme 'lapse in duty of care', as participants spoke extensively about their difficulties in dealing with doctors about TTM, with all 20 participants expressing that many healthcare providers had a lack of training around TTM:

> *'My mum took me to see 4 doctors (2 GP's, 1 Dermatologist, and 1 Psychiatrist). The first 3 knew nothing about Trich, would tell my mum I'd grow out of it and I should just stop (…) It was frustrating (…) 3 out of 4 were not educated enough to diagnose Trichotillomania…. That's 75%. Just ludicrous' (P9 – Male, 26)*

> *'I was only diagnosed 2 years ago, and have seen 6 doctors (none knew about it). The 7th doctor provided a diagnosis. (P11 – Female, 24)*

> *'I'd say, it took at least 5 years to be diagnosed as having Trichotillomania. There were times that I avoided talking about it to my GP, and avoided going to the GP altogether. (P12 – Male, 35)*

Coupled with the assertion that participants felt there was a lack of adequate training around TTM, participants also experienced a significant delay in receiving a formal diagnosis:

> *'I have been pulling for 12 years there about, but I was only diagnosed 2 years ago (…) doctors don't understand that it's a real problem. 3 GP's did not diagnose me, the diagnosis was made with psychiatrist' (P4 – Male, 29)*

> *'I have seen 6 doctors between the age of 18 – 22 now, 5 of them told me to stop this behaviour myself and increase my self control. No help was offered except threats (you will be bald. You will be alone)' (P7 – Female, 22)*

Participants also highlighted their frustration at the level of understanding healthcare professionals have about TTM by saying that some only know the "*bare essential information*" about TTM, while placing the responsibility of stopping hair-pulling onto the patient:

> *'I started at 24, it took 10 years to be properly diagnosed (…) In a total of 30 years trying to seek help, and only ONE person knew the bare essential information about Trichotillomania. (…) most times when I tell a healthcare ''professional'' I have Trichotillomania, they will say something such as 'you can just stop if you try hard enough' (P3 – Male, 54)*

This sub-theme (inadequate training of healthcare professionals) has also highlighted participant experiences which suggests there may be a lack of sensitivity training among healthcare professionals, with participants detailing how they felt doctors placed the onus on the patient:

'Some of them are so confused by the idea that I'm pulling out my own hair, they say things like ''well, just stop, surely you can control your own hands. It's infuriating' (P12 – Male, 35)

'they have no clue. I have yet to meet one that understands it. I've just been told to "quit it". That's the most frustrating part - it's like having a pain that you can't prove and nobody knows why' (P16 – Female, 42)

Another participant described how they felt their TTM was not properly understood, that the healthcare professional "*gave up*" too easily, and in some cases were repulsed by TTM:

'I don't feel they ever quite understood. They gave up on me too easily, or tried to push drugs at me. With some, I even got a sense that they were repulsed by it' (P1 – Female, 49)

In a similar vein, participants also expressed their frustration at attempting to seek help for their TTM but not being taken seriously:

'You finally open up about your darkest secret to a health professional whom you trust and they have no answers for you. So all you have done is admit your failures to no avail' (P2 – Female, 44)

'I have been pulling on & off for 26 years now and was only diagnosed about 8 years ago. My doctor has been very hesitant to try me on any medicine, he doesn't think the trichotillomania causes much of a distruption [disruption] in my life. I have asked for help, and he says it should be manageable without medicine…talk about frustrating! Sometimes doctors don't know best.' (P17 – Male, 52)

This issue whereby patients are not taken seriously in the difficulties they experience with their disorder is described succinctly by a participant who states her experiences of dealing with a doctor who did not make an effort to read up about TTM, alongside the assumption that they may not view TTM as a serious enough disorder:

'He didn't offer me help, and he has never made any effort to read up about treatments for me. That is the most frustrating thing… they are not willing to learn about it to try and help because in their view it's not an important or serious condition' (P10 – Female 32)

Ideal Treatment Intervention

The theme of 'ideal treatment intervention' represents an outline of what participants' ideal TTM treatment strategy would consist of. This theme consists of four sub-themes; dual-phase combined treatment approach, working with mental health professionals, face to face support, frequency and duration which will each be discussed in turn below.

Dual-Phase Combined Treatment Approach

Participants were clear in describing a dual-phase approach as their ideal treatment intervention, with participants discussing a combined approach of pharmacological and psychological-based support. Participants discussed how this would primarily consist of taking a medicine to help control / decrease TTM urges while attending therapy sessions to address any underlying or correlating issues:

'Perhaps for people with other emotional issues that go hand-in-hand with trichotillomania like depression and anxiety and low self-esteem, sessions with a therapist or psychologist can be used in conjunction with medicine' (P3 – Male, 54)

'psychologist sessions once per week, and medicine (even experimental medicine) to lessen the pulling and lessen the urges. In an ideal world, there would be 1 drug to take, 1 tablet per day to control Trichotillomania' (P12 – Male, 35)

Alongside the dual-phase combined approach, it was suggested that TTM patients may benefit from the use of a support animal:

'A combination of drug and support. A tablet to help the urges and stop pulling firstly, along with some counselling to improve the esteem and confidence problems. For very very bad hairpullers the use of a service animal can help' (P6 – Male, 30)

This dual-phase approach was emphasised by another participant who stated that a long-term commitment would be needed by a patient's primary healthcare provider in order to trial various treatment options to tailor a person-centred treatment approach:

'I think a long-term commitment needs to be made by your GP, to explore which medicine could work, and strategically try each one on a trial-run for 2 – 4 months per medicine…. Just to see which medicine works for you. Because everyone is different and an individualized treatment should be offered. If a person has a reall bad self image, then some therapy or life coaching lessons can help too. I always notice that I pull a lot less when I'm around my mum's dog. So for very bad cases of trich a service animal of some kind could be an option' (P14 – Female, 28)

One participant had success at using a hair replacement system to decrease her TTM while allowing her existing hair to recover. It was suggested that the hair replacement systems created a good 'barrier' and should be offered in combination with behaviour-based treatment:

'the [hair replacement system] has been amazing, just by helping keep my fingers out of my areas I enjoy pulling from. It has broken the habit of reaching up to my head. But I feel as if insurance companies should help pay for the [hair replacement system] if it is working. I also feel as if behavioral reversal therapy should be included with the [hair replacement system] (P19 – Female, 27)

Some participants expressed that they would prefer a pharmacological approach whereby they would rely solely on a medicine to help their TTM:

'I would like to see experimental trials, and in the end, one medicine that could cure TTM, or significantly reduce hair pulling. Medicine is the way forward and more trials are needed. I don't believe behavioural help is the way forward. I would like medicinal support in the form of taking 1 tablet per day to control pulling and urges' (P3 – Male, 54)

'Medicine, but we need to experiment which medicine may be effective enough to stop the pulling or make the pulling painful. When I pull my hair it feels so enjoyable and pleasurable, but if the feeling was painful then I would not pull.' (P7 – Female, 22)

Whilst another participant merely suggested that healthcare professionals are guided by a definitive treatment plan, suggesting that TTM does not have a definitive treatment protocol and varies depending on which doctor is seen:

> *'A definitive plan, similar to how doctors treat any other illness, would be helpful, note [not] just a stab in the dark guessing game'. (P2 – Female, 44)*

Working with Mental Health Professionals

Participants were asked who the ideal healthcare professional would be to deliver their treatment and seemed to agree that they would like to receive treatment from psychologists or psychiatrists:

> *'A psychiatrist for the medicine, and a psychologist for the emotional help. Once the treatment is working and stable then a GP visit once per month to follow up on progress would be fine.' (P7 – Female, 22)*

> *'a psychiatrist who is willing to experiment in finding the right medicine and the right dose.' (P17 – Male, 52)*

Some participants stated that they do not want to receive support from a GP, while other participants were open to receiving support from a GP who had some background or knowledge of TTM:

> *'Definitely not a therapist or counsellor or dermatologist, and most GP's are not qualified enough' (P3 - Male, 54)*

> *'GP ideally but they may not have enough qualifications, but can refer you to a psych with training in trich' (P2 – Female, 44)*

> *'GP/psych [psychologist] as long as they have a back ground in the understanding of Trich' (P5 – Male, 46)*

Face to Face Support

Participants were asked how they would like to access their ideal TTM treatment, with all 20 participants suggesting they would prefer face-to-face support. Many participants suggested other means of access alongside in-person appointments, such as online methods (e.g. email or skype) and telephone support:

> *'Face to face support is ideal, and telephone or online support (email and skype) too' (P3 - Male, 54)*

> *'face to face is best but on-line might be a great starting point' (P5 – Male, 46)*

> *'Face to face. If there are issues with making appointments then telephone session (20 minutes) would be fine.' (P7 – Female, 22)*

Some participants spoke of the potential issues arising from in-person appointments being time and transport issues, while mentioning that online / telephone methods can be convenient:

> *'I would prefer face to face support. Although time and transport could be a potential problem' (P4 – Male, 29)*

'Face to face is preferred. If time is short then a telephone consultation or video chat is also convenient.' (P11 – Female, 24)

'Prefer face to face support, but online support could also be helpful and convenient such as telephone calls, or emails, or face time skype' (P12 – Male, 35)

The most illuminating reason for the preference of face-to-face support was described as personal connection, being that it would be easier for the healthcare provider to connect with the patient at an in-person appointment:

'I would prefer a face to face support, because when dealing with persons with trich, it would be easier to connect with the person' (P13 – Female, 18)

Frequency and Duration

Participants were asked to provide details about how often they would like to receive support and treatment for their TTM, some participants indicated they would like to receive support once per month:

'Once per month for both therapy and drug treatment follow up'. (P11 – Female, 24)

'Once per month for both (pharmacological and behavioural)' (P14 – Female, 28)

Other participants stated they would prefer to receive pharmacological support once per month and psychological support twice per month:

'Once per month to check up on medicinal effectiveness, and twice per month for emotional support' (P3 – Male, 54)

'Once per month for drug, and twice per month for the counselling'. (P6 – Male, 30)

Two participants suggested they would like to receive support on an ad-hoc basis as TTM may fluctuate. They suggested receiving support as and when needed, frequently at first, then tapering off:

'when ever im in a low spot and bingeing' (P5 – Male, 46)

'Initially weekly, but then monthly, to bimonthly etc weaning off with the support and ability to come back at a moment's notice if and when needed' (P2 – Female, 44)

In terms of their ideal treatment duration, participants highlighted they would like to receive support for 8 – 12 months, with follow-up appointments once per year for 3 – 5 years:

'12 months. Then follow up every 12 months for 5 years, 5 checks total' (P7 – Female, 22)

'8 – 12 months. With a follow up once per year for 3 years.' (P9 – Male, 26)

There were some participants who suggested they would like to receive on-going support over their lifetime, this interlinks with previous extract quotes which highlight how TTM can be a lifelong disorder that may cause intermittent and / or long-term distress.

'Lifetime. It's a lifetime condition and when you go through different scenarios in life it will rear it's ugly head more, so sorry and availability needs to be there for life.' (P2 – Female, 44)

'1 year. With a check in appointment each year for lifetime' (P8 – Female, 20)

Participants also stated that the duration of treatment would depend on the severity the person is experiencing, and treatment should be tailored according to the individual:

'12 months or so, unless I started up again and needed support again' (P1 – Female, 49)

'1 year. It's possible that shorter (6 months) or longer (18 months) may be needed, depending on how severe the trich case is.' (P12 – Male, 35)

'I think this depends on the person and severity of their TTM' (P18 – Female, 31)

In summary, participants ideal treatment intervention reveals that a dual-phase targeted treatment intervention consisting of both behavioural and pharmacological treatment is perceived as an ideal strategy, where participants receive pharmacological support once per month and psychological support twice per month for one year. Face-to-face treatment is preferred, but other methods would also be beneficial (i.e. telephone calls or skype). Following this, treatment tapers off with a follow-up visit every 6 months for 3 – 5 years. Participants suggested they would like this treatment plan to be delivered by a psychiatrist or psychologist, or another healthcare professional who has training in TTM. In terms of receiving support from a healthcare professional; an illuminating finding relating to face-to-face support was described as personal connection; it can be suggested that people with TTM want to feel a sense of connection and alliance with the person delivering their support.

5.4 Acceptability and Feasibility of the Email Interview Method

This section provides a discussion of the asynchronous email interview study method and is informed by supplementary quotations. Within the email interview, participants were asked a series of acceptability and feasibility-based questions about the study method and their experience of participating in the interview, followed by their opinions on the strengths and weaknesses of participating and any suggested improvements they could volunteer about the process. Overall, most participants reported enjoying participating in the email interview, with 14 participants reporting positively about the process:

'nice to voice a personal opinion on the subject and mostly to be involved with something that has been a long and lonely trip' (P5 – Male, 46)

'It was nice to know someone is taking this issue seriously. I've never had anyone ask these questions before. It's validating that this is not all in my head and I'm not the only one' (P16 – Female, 42)

Many participants spoke about the importance of being understood by their healthcare provider and forming a therapeutic alliance (see 'face to face support' on page 108). This thread was also noted when participants provided feedback about participating in the email interview. Some participants commented on interacting with a researcher who understood them, understood their TTM and did not

judge their responses. This highlights that people with TTM want to feel a connection to someone who may understand their TTM:

> *'Great! It was nice to talk about living with trich, and It was also nice to talk to someone who can sympathise with us. It makes a world of difference knowing you are not judging us' (P17 – Male, 52)*
>
> *'Very enjoyable. I mostly enjoyed interacting with a researcher who understands people with Trichotillomania and does not judge us' (P3 – Male, 54)*
>
> *'You were nice to talk to on email and I felt like you didn't judge me or my answers, probably because you also have Trich, you are the right person to do this research!'(P14 – Female, 28)*

Four participants suggested the email interview schedule questions were thought provoking, while two participants stated that participation felt cathartic:

> *'brought up a lot of emotions that I thought were behind me, such as the rage and depressive pain. I also found it healing in a way' (P1 – Female, 49)*
>
> *'Thought provoking and difficult at times. It has also been therapeutic to write it down. I could also be completely honest as I know it is confidential and I know I am not being judged by you' (P18 – Female, 31)*

When asked about participating in the email interview, ten participants volunteered no suggested improvements and stated that the interview had a good variety of questions and was thorough:

> *'No. It had a good variaty [variety] of questions on different topics' (P4 – Male, 29)*
>
> *'I also think you executed the interviews well and I see no need for improvement' (P13 – Female, 18)*

Two participants suggested asking for photos as a visual representation of hair loss. This was taken into consideration and a revised ethics application was submitted which included photo consent:

> *'You could have asked us for photos, but I'm not sure if that is important to include in your final project' (P3 – Male, 54)*
>
> *'Perhaps asked for photos so you can clearly see how our trich looks as with mine being on my hands it is hard to describe and I guess for you to picture' (P18 – Female, 31)*

After the revised ethics application (see appendix two, page 175) to include photo consent was approved, participants were contacted about voluntarily providing a photo, as a visual representation of their hair loss. Four participants emailed their photos, which were anonymised of any identifying features. The four photos submitted by participants (see appendix eight, page 198) aim to demonstrate a range of different hair-pulling sites (eyebrows, scalp and fingers), with significant hair loss in places, further demonstrating the impact of TTM.

There were six participants who suggested other questions to ask, which included topics of severity, if TTM is curable, if TTM is hereditary and/or genetic, and TTM's relation to any social disorders:

> *'Do you feel TTM is something that should be or can be cured or is it something that really isnt as bad a habit as other tich's' (P5 – Male, 46)*
>
> *'Do we have relatives with this problem' (P10 – Female, 32)*

'I'm sure there could be a million other things you could ask. I guess the severity at which I pull, but some questions circled around that' (P19 – Female, 27)

'I think for ne [me] TTM has to do something with the ability to be social, friendship, Asperger... I think this should be considered too... '(P15 – Female, 55)

When participants were asked their opinion on the strengths of the email interview, five people said that the email schedule was thorough:

'I think you have covered everything very thoroughly' (P2 – Female, 44)

In line with 'netiquette' (see page 75) which suggests that within online communication guidelines (Mann and Stewart, 2000), email communications should be viewed on a single screen, eliminating the unnecessary need to scroll up and down the page (Roodt, 2014), this was echoed by seven participants who volunteered that the number of questions per email was manageable:

'The number of questions per email was good and very manageable' (P3 – Male, 54)

'Good questions. Good amount to anwer in every email. Good to be given time to answer, when we can have some free time' (P10 – Female, 32)

Many participants suggested that the interview was convenient and could be fitted in to their daily life:

'I liked that you only asked a few questions per email, and that you gave us 2 weeks to answer… so I could fit this into my daily schedule which was very convenient. Because this interview took place over several emails, I feel like we're basically friends now' (P12 – Male, 35)

'The questions were enough to answer per email. You were very nice and helpful. I can answer the questions when I like within 2 weeks that is very convenient. And I can email you if I had any questions' (P6 – Male, 30)

Some participants mentioned they could answer questions honestly and review their answers before emailing them back, saying the process was not pressured and felt confidential:

'The strengths are that you can be completely honest in how you answer as there is no reaction to what you say unlike in a face to face interview. you also have time to think about your answers and have time to make sure you have included everything you want. There is no pressure and it feels more confidential.' (P18 – Female, 31)

There were a few comments relating to rapport during the 8 – 10 email exchanges, with some participants suggesting that the emails had a personal touch and did not feel clinical:

'Your emails were very nice and polite, you didn't pressure us and I had the choice of not answering a question if I didn't want to. You explained things well, and I thought the emails had a personal touch, it didn't feel clinical or rigid.' (P11 – Female, 24)

'you were kind, and patient with me and continued to keep in touch which was nice.' (P19 – Female, 27)

When asked about the suggested weaknesses of participating in the interview, 11 participants stated that they found no weaknesses within the email interview:

'No weaknesses' (P3 – Male, 54)

'I saw no weaknesses, it was well administered.' (P12 – Male, 35)

One participant said there were a lot of questions, this was contrasted by another participant who suggested that the number of email exchanges was forewarned:

'didn't expect there to be quite so many questions but am happy to help out' (P20-Female, 22)

'Sure there were a few different email exchanges, but that was forewarned. The questions covered lots of topics, and it was very interesting.' (P9 – Male, 26)

Another participant said there could be potential weaknesses in that the researcher cannot see the participants' body language or hear their voice intonation during an online interview:

'weaknesses are you can write anything you want so how does the interviewer know you are lying giving false results for research? as they can not see your body language, voice intonation ect that could show deception as with face to face interviews' (P18 – Female, 31)

By including questions associated with acceptability and feasibility aspects, participants were able to provide feedback and critique about the study method. Participants responses were taken into consideration, which resulted in a revised ethics application to include separate photo consent.

5.5 Themes and Subthemes from the Blog Posts: Experiences, Opinions and Perceptions of Trichotillomania.

This section uses the ten blog posts to look at participant experiences, opinions and perceptions of TTM. This section links back to one of the study objectives; to explore experiences, opinions and perceptions of TTM and aims to provide an insightful and supplementary perspective into TTM alongside the interview data. Three main themes were identified in this section: acceptance, societal view of beauty and an endless cycle that causes distress. Blog post data is presented unedited, some blog posts were originally presented in uppercase font and have not been altered within this thesis. The blog post extracts have been presented as B1 to B10, as mentioned in the methodology and methods chapters, demographic information was not widely available. Any spelling or unclear wording will be clarified with the use of square brackets, in line with the previous extracts from interview participants.

Acceptance

Some blog posts spoke about acceptance of the TTM and acceptance of themselves as having TTM. There were extracts which represented how blog users took a significant amount of time to talk about TTM openly:

'*IF I ALREADY HAD A WELL-ESTABLISHED SELF-CONCEPT AT THE TIME OF ONSET, PERHAPS IT WOULDN'T HAVE TAKEN ME 20+ YEARS TO COME TO TERMS WITH IT AND TALK ABOUT IT OPENLY' (B7)*

Another blog user spoke about her acceptance of TTM and accepting herself as having TTM in the context of not "*trying to fix it*":

'Instead of trying to fix it right now, though, I'm trying to be okay with it...to be okay with me...disorder and all.' *(B9)*

This has also been highlighted by other blog users who suggested that accepting the TTM and disclosing it has made a positive impact on their lives:

'*There's something powerful about just allowing myself to be vulnerable and not having to worry about hiding my disorder' (B5)*

'*about two weeks ago I decided I was sick of keeping it to myself so I 'came out' as a trichster online (…) I no longer feel like a freak, I feel like part of a community' (B6)*

This was echoed by another blog user who suggested that admitting you have TTM to other people is a difficult task:

'*admiting you have trich [TTM] & pull your hair is the hardest thing a puller has to do' (B1)*

Societal View of Beauty

The theme 'societal view of beauty' involves how blog users feel shame about their TTM and subsequently are secretive about the disorder and actively conceal their issues with hair-pulling. Blog users speak about feeling ashamed and secretive and discuss this alongside the images they see around them. This theme includes two sub-themes; secrecy and shame, and stigma which will each be discussed in turn below:

Secrecy and Shame

Blog users spoke about how they experienced feelings of shame associated with their TTM, these feelings of shame often lead to being secretive about their disorder:

'SHAME IS A HUGE PART OF BEING A TRICHOTILLOMANIAC. WELL, IT IS A HUGE PART OF OF MY EXPERIENCE, ANYWAY' (B7)

'I'm so used to hiding and concealing it, rather than sharing it.' (B10)

Another blog user spoke about the impact of hair loss and never feeling "*truly beautiful"* alongside seeing other people with beautiful hair, this may suggest that the images in the media (including social media) may possibly put too much emphasis on physical appearance and could contribute towards feelings of shame:

'I was hopeless and never felt truly beautiful. I hated the bald spots I was developing and was so envious of girls with beautiful hair.' (B2)

Secrecy was also touched upon with another blog user suggesting they considered their TTM to be a *'horrible secret'*:

'*for years I didn't know what this problem was. I thought I was a freak with a horrible secret' (B6)*

Other blog users describe their shame and embarrassment at the effects of TTM and hair loss;

'I have no words for how embarrassed I was by my own appearance. I can't accurately articulate how much I hated myself. I can't describe the flush (…) from embarrassment when anyone would stare at my head or ask me questions' (B7)

Stigma

This sub-theme represents how blog users spoke of experiencing stigma associated with their TTM, and how some cultures may place high levels of importance on physical appearance while stigmatising hair loss and/or baldness:

'WHILE I HESITATE TO MAKE GENERALIZATIONS, I THINK IT IS SAFE TO SAY THAT EVEN THE MOST WELL-SUPPORTED OF US HAS EXPERIENCED THE STIGMA' (B7)

This was echoed again, when it was suggested that the hair loss associated with TTM is self-inflicted which may be stigmatised by other people who don't fully understand TTM:

'In a culture that places a ridiculous amount of emphasis on appearances and stigmatizes baldness (…) You might think that people with trichotillomania don't have "legitimate" reasons for their hair loss (…) since they do it to themselves, they're not worthy of your compassion' (B7)

Another blog user described their long-term struggle with TTM and their hopes of spreading awareness and helping destigmatise the disorder:

'It's quite possible (…) that I will struggle with this forever so instead of self-pity and/or hiding, I want share my story and try to (…) spreading awareness, and helping to destigmatize trich (B5)

An Endless Cycle that causes Distress

The theme 'an endless cycle that causes distress' involves how blog users describe their TTM as being an '*endless*' and '*constant*' cycle which can lead to distress in their lives.

'The stress from how bad I've let my situation get causes me to pull more, so the cycle is endless' (B5)

'It just a constant, painful cycle (…) And my worst fear, what if one day my hair doesn't grow back because I have damaged it beyond repair?' (B3)

Some blog users suggested that their TTM can make them feel like a burden, with some blog posts describing situations where blog users did not have support or compassion even during incidences of bullying:

'it makes me feel like I'm a burden to have around. And it makes it REALLY hard to talk about my trich' (B6)

'I was teased mercilessly (…) and received no support, compassion, or understanding from my parents. It was rough' (B7)

Other blog users discussed distress in various forms, by suggesting that a single hair-pull may '*later corrupt me'*, and described feelings in the aftermath of a bad TTM episode as '*destruction*':

'Nothing in my life had prepared me for the feeling it gave me; the shocking and comforting feeling. Little did I know at the time, that single pluck would later corrupt me' (B8)

'the next day you just feel awful, after you see the destruction you've done to your head' (B3)

The themes and sub-themes illustrating the blog user's data is found in figure 5.4 below:

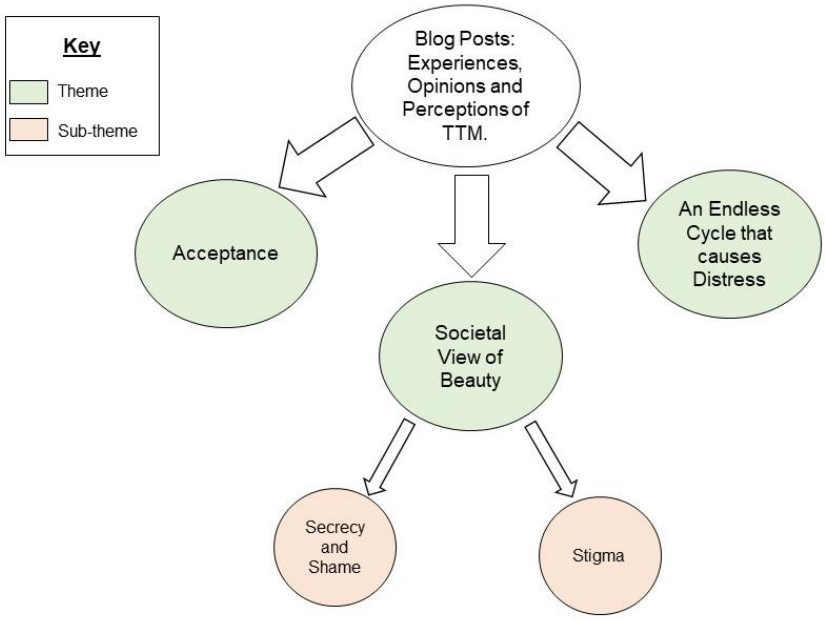


Figure 5.4: Diagram Illustrating the Themes and Sub-Themes of from Blog Posts, illustrating blog user's experiences, opinions and perceptions of TTM.

5.6 Summary of Findings

Data from the email interviews and blog posts do interlink and overlap in some instances. Email interview participants often experience primarily negative thoughts and emotions about their TTM; participants discussed how they experience shame and distress which may lead to certain behaviours and/or consequences (e.g. secrecy and non-disclosure, embarrassment and avoidances). Participants also spoke about their TTM in a largely negative manner, suggesting that they hated the disorder and attributed demonizing characteristics toward their TTM. These emotions could lead to further physical and/or psychological consequences (e.g. anxiety / depression). Many participants revealed that they fear being judged by others, with this often leading to further secrecy, non-disclosure, other coexisting health implications, embarrassment and avoidances. Many of the subsequent behaviours (e.g. secrecy and non-disclosure, and permission giving behaviours) and subsequent consequences (e.g. coexisting physical and/or psychological health implications, embarrassment and avoidances) may often lead to persistent and extensive effects within academic and work life. These persistent and extensive effects also involve an impact on relationships, self-identity and lost opportunities. The thoughts and emotions described by participants often lead to various behaviours and/or consequences alongside persistent and extensive effects of TTM, whereby participants used various forms of concealment as an attempt to cope with their TTM.

Email interview participants highlighted the variety of different treatment options they have tried, alongside an overview of what their ideal treatment intervention would consist of. Participants were clear in describing how they thought healthcare professionals were inadequately trained in TTM, with several describing a lapse in duty of care whereby they were not offered any TTM treatment by their primary healthcare provider.

Blog post data revealed the societal view of beauty as a key theme, with many blog users discussing secrecy, shame and stigma alongside the images portrayed in the media and how hair loss is perceived within wider society. Blog users also spoke about TTM as being an 'endless cycle that causes distress', which interlinks with the 'secrecy and shame' sub-theme discussed within the blog posts. An illuminating facet of the blog post data were several discussions around 'acceptance', with some blog users describing how they have accepted their TTM and felt comfortable enough to be vulnerable in disclosing their disorder in an attempt to be "*okay with it."*

The findings within the email interview and blog post data illustrate that TTM can be a difficult long-term disorder causing wide ranging and varying degrees of impairment in all areas of life, with the coexisting health implications further exacerbating hair-pulling. These findings have indicated that the current training of healthcare providers may not be adequate enough to support people with TTM, as many participants highlighted a lack of treatment or referral alongside a lack of sensitivity from their primary healthcare professional. This often makes participants feel unsupported and alone in their diagnosis. Participants also highlighted how the treatments they have been offered have been largely ineffective in helping the severity of their TTM symptoms. Email interviews and blog post findings supported each other in aspects relating to distress, secrecy, shame and stigma. Blog posts revealed themes (acceptance and societal view of beauty) that were not noted in the interviews, this provided a unique insight into TTM by accessing data from a different sample.

As previously mentioned, this project has adopted a constructivist position which asserts that humans construct knowledge through meaningful interactions with the world (Morcol, 2001). Given the sample size, it was not a specific aim to produce generalisable findings. However, many participants described similar experiences when speaking extensively about their experiences, perceptions and opinions of TTM. Creswell has stated that constructivists aim to "generate or inductively develop a theory or pattern of meaning" (Creswell 2014, p8) throughout the research process. Due to the length of the findings chapter, the conceptual map (figure 5.5, page 119) is intended to provide a visual representation of the relationships between some of the themes, sub-themes and patterns of meaning that were derived from the thematic analysis. The use of both single and double headed arrows indicates how the links between some themes and sub-themes may not always move in a linear or one directional manner.

To contribute towards transparency, an example from the conceptual map will be provided in order to illustrate movement between some key concepts. Participants from the email interview outlined

feeling shame and distress (an internal process, linked to their emotional states), in many cases this led to external behaviours and/or consequences; participants became secretive about their TTM and engaged in non-disclosure behaviours, the feelings of shame and distress often resulted in embarrassment and avoiding certain situations. It is important to note that these behaviours and/or consequences do not move in a linear way and can revert back to internal processes (thoughts and emotions), this is demonstrated by the use of double headed arrows. The behaviours and/or consequences often led to external impact, with effects on social and/or personal relationships and self-identity. For example, many people who described shame and distress and the subsequent engagement of secrecy and non-disclosure behaviours spoke about an impact on career or academic life and highlighted issues with low self-esteem and low self-confidence. This commonly led to coping behaviours, with the most common being the use of concealment methods. Participants who spoke about using concealment as an attempt to cope with TTM also described the perceived stigma (revert back to internal processes) that they anticipated if their TTM was discovered. Due to the length of the findings chapter, the conceptual map is intended to provide a succinct visual summary of the relationship and links between some key themes and sub-themes.

A summary table of all themes and subthemes discussed in this chapter can be viewed in appendix nine, page 199. The severe and far-reaching impairments in all areas of life (i.e. personal life, relationships, career paths, academic life) coupled with the coexisting health implications (i.e. physical / psychological impairment) further signifies that TTM can be a severe and life impacting disorder for which there is no cure or effective treatment protocol. These findings will now be discussed alongside relevant literature and theory in chapter six.

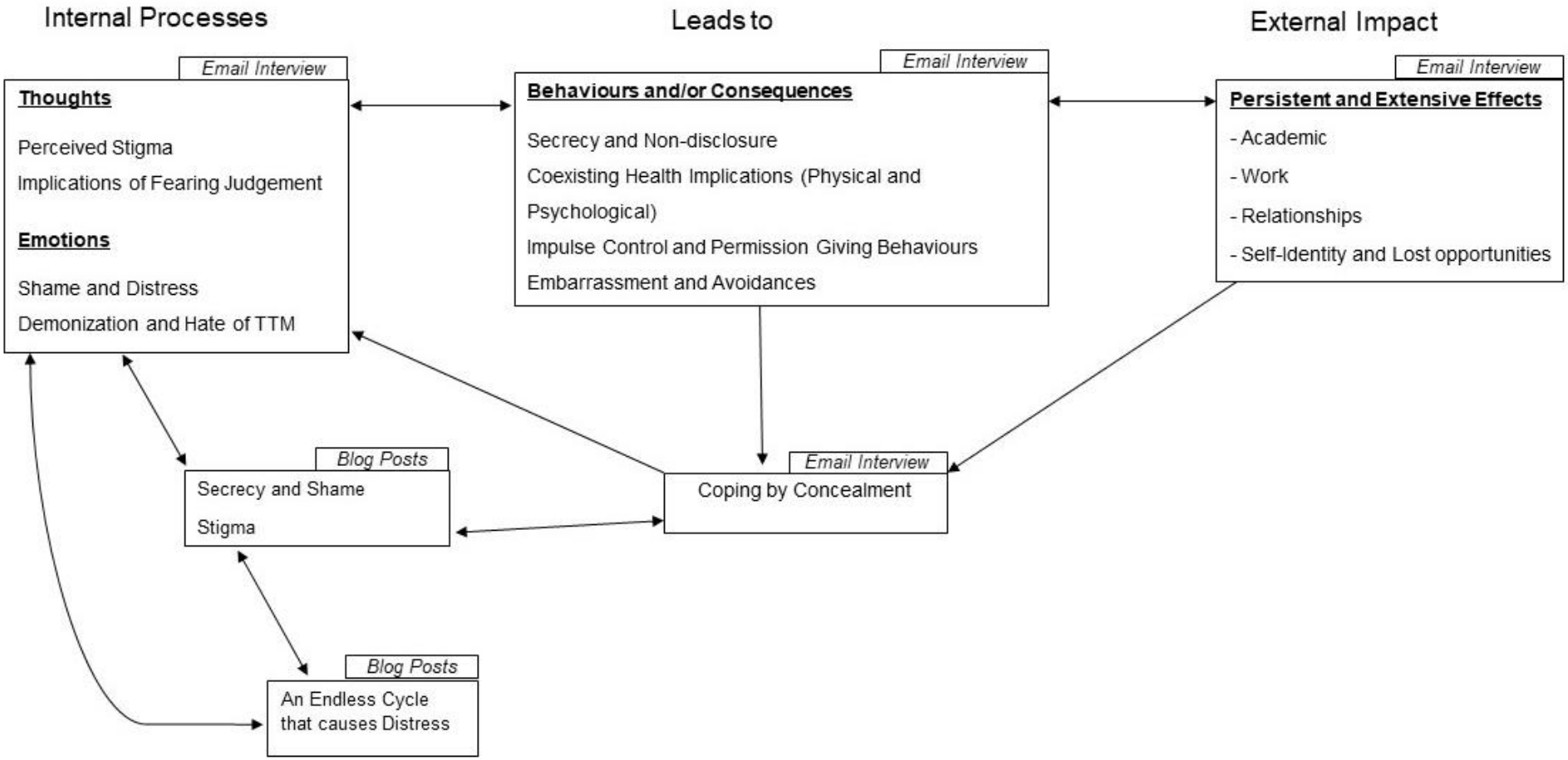


Figure 5.5: Conceptual Map highlighting relationships between TTM themes and sub-themes

Chapter Six: Discussion

This chapter will present an overview of the project and the extent to which it addressed the primary aim and three objectives. A general 'look back' at the key themes and sub-themes from the findings chapter will be presented. The findings will be applied to previous literature and relevant theory. Strengths and limitations will be considered, alongside implications for clinical practice, support for people with TTM, and suggestions for future research.

6.1 Critique of Project in relation to Aim and Objectives

This primary aim of this project intended to explore the experiences, opinions and perceptions of people with TTM, this involved looking at their direct experiences alongside any effects relating to social, health and wellbeing implications. Alongside this primary aim, there were three objectives of the project:

- Explore participant experiences, opinions and perceptions of TTM via asynchronous email interviews and blog post data.
- Identify participant treatment preferences, to potentially inform or develop an intervention
- Consider implications for future development and delivery of support / services for people with TTM.

The aims and objectives were unpacked via the use of a semi-structured email interview with additional supplementary questions, and blog post data. The consent form left an opportunity to revert back to participants at a later date, for clarification on their responses, additional questions or other research opportunities. This project has successfully addressed the primary aim and three objectives; a summary of the findings will now be presented as a general 'look back' at the thesis, in relation to the aim and objectives.

The primary aim of the project (to explore the experiences, opinions and perceptions of people with TTM, including any effects relating to social, health and wellbeing implications) highlighted four main themes, each with various sub-themes from the email interview data, illustrated in the figure below.

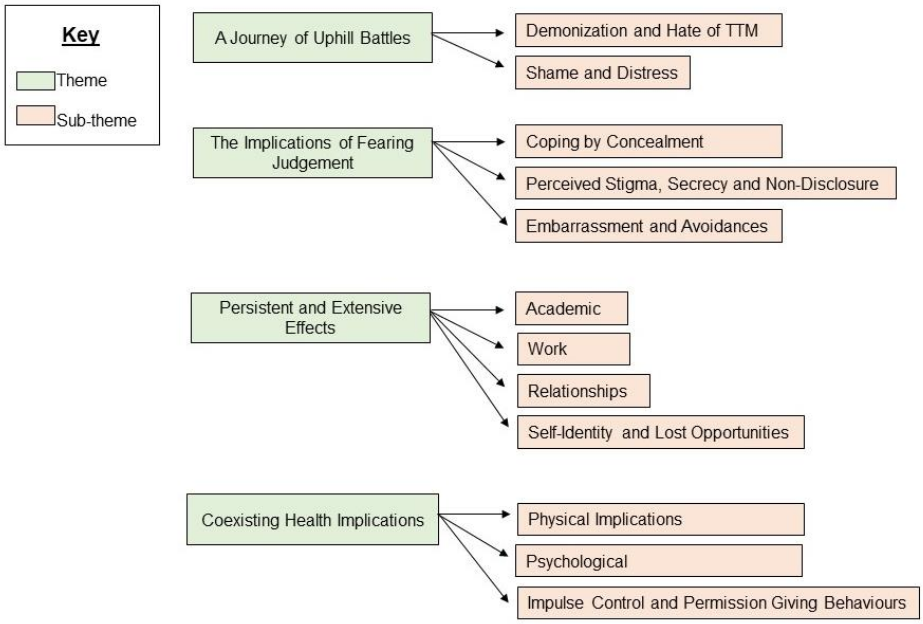


Figure 6.1 – Summary of Themes and Sub-themes from the Email Interview relating to the primary aim.

Many of the themes and sub-themes from the diagram (above) interlink and overlap in some instances. Email interview participants clearly highlighted the negative thoughts and emotions they felt about their TTM (such as shame and distress) which often led to other behaviours and/or consequences (e.g. secrecy, non-disclosure, embarrassment and avoidances). These feelings can often feel repetitive; if a participant felt ashamed about their TTM, these feelings of shame are likely to cause distress which leads to the participant keeping their TTM a secret and not disclosing their disorder to their peers. Participants often reported feelings of embarrassment at the physical characteristics of their hair loss and subsequently avoided certain activities for fear their TTM may be discovered. This often resulted in further shame and distress. Participants spoke about their TTM in a largely negative manner, suggesting that they hated the disorder and attributed demonizing characteristics toward their TTM. The thoughts and emotions described by participants often led to various behaviours and/or consequences alongside persistent and extensive effects of TTM, whereby participants used various forms of concealment as an attempt to cope with their TTM.

Many participants revealed a significant fear of judgement, this is spoken about in connection with other sub-themes and participants highlighted how this often leads to further secrecy, non-disclosure and other coexisting health implications, embarrassment and avoidances. Many of these subsequent behaviours (e.g. secrecy and non-disclosure, and permission giving behaviours) and subsequent consequences (e.g. coexisting physical and/or psychological health implications, embarrassment and avoidances) may often lead to persistent and extensive effects within academic and work life. These persistent and extensive effects then impact onto relationships, self-identity and lost opportunities.

In relation to one of the study objectives, to highlight people's opinions, perceptions and experiences of TTM from blog post data. This revealed three themes and two sub-themes. Some of these interlink;

blog users spoke about experiencing and perceiving shame and stigma about their TTM and subsequent hair loss and spoke about this in association with secrecy. Many blog users referred to shame, secrecy and stigma while talking about the images shown through the media and social media. Many blog users spoke about how they have grown to accept their TTM, in contrast, this was not widely noted within the email interviews.

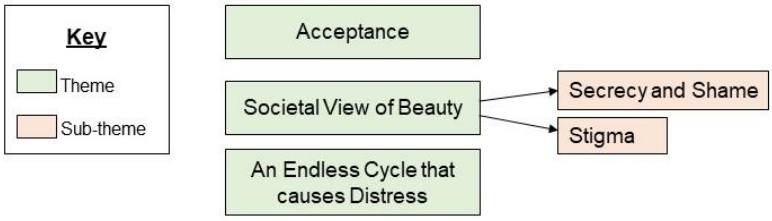


Figure 6.2 – Summary of Themes and Sub-themes from the Blog Data relating to a study objective

Another project objective (to identify participant treatment preferences) was explored when email interview participants were asked a series of questions about what they envisaged their ideal TTM treatment / intervention would consist of. As there is no consensus over the aetiology of TTM (Duke et al, 2010), nor is there a definitive 'cause' of TTM or 'cure' for TTM, treatment options can vary according to what healthcare professional is seen. As far as the researcher is aware, a participant sample has not previously been asked to explicitly detail the contents of their preferred TTM treatment strategy. Participants were very clear about what their ideal treatment intervention would consist of: outlining a dual-phase targeted treatment intervention consisting of both behavioural and pharmacological treatment is perceived as an ideal strategy, where participants receive pharmacological support from a healthcare professional once per month and psychological support twice per month for one year, this implies that participants acknowledge the importance of a mind and body therapeutic alliance. Face-to-face treatment is preferred, but other methods would also be beneficial (i.e. telephone calls or skype), participants have highlighted that they are open to novel ways of intervention delivery, this may be useful in setting up support services that could be delivered via online methods by a small expert team, as it can be difficult to develop expert support services across all countries. Following this, treatment tapers off with a follow-up visit every 6 months for 3 – 5 years. Participants suggested they would like this treatment plan to be delivered by a psychiatrist or psychologist, or another healthcare professional who has training in TTM; but indicated that a connection and therapeutic alliance with someone who understood TTM would be beneficial.

This is linked to a further project objective (to consider implications for future development and delivery of support / services for people with TTM), as the outlined ideal intervention can be used in further research to construct a treatment intervention for people with TTM. Alongside additional training for healthcare professionals, as it seems that many healthcare professionals are not suitably trained or equipped to deal with TTM patients. Many participants described how their healthcare

support needs are being unmet; in many cases support is not provided, and diagnosis often takes a significant length of time. These findings reveal that there appears to be a lapse in duty of care for many people with TTM. All 20 email participants suggested that there was inadequate training of healthcare professionals about TTM, with many suggesting that there was no sensitivity training in dealing with this as a sensitive topic. This will be further discussed (below) under 'professional relevance and implications' (see section 6.4).

6.2 Critical Discussion of Themes and Sub-Themes

This section will provide a discussion of some key findings, alongside previous literature and other theory. The 'cycle of TTM' highlighted in the findings will be discussed in conjunction with the DSM-5 criteria and Mansueto's comprehensive model for behavioural treatment (ComB).

Cycle of TTM

The 'cycle of TTM' descriptive characteristics of TTM detailed several descriptive points that participants often engage in during their process of hair-pulling. This consisted of antecedents, behaviours, environments and consequences. This is largely in line with previous findings; Stemberger et al (2003) previously suggested that the antecedents linked to common TTM behaviours are often identified as environmental, motoric, sensory, affective and cognitive. This was echoed at a later date by Kell and Kress (2006) who stated that clinicians often establish age of onset, frequency, quantity, emotional states, environmental, motoric, sensory, affective and cognitive factors when dealing with people with TTM. However, participants in the current sample still detail feeling the short-term / immediate effects of pulling out their hair as enjoyment, tension relief and gratification. This criterion was previously removed from the DSM-5, but participants in the current email interview sample clearly spoke about these feelings as part of their hair-pulling process. Participants spoke about their attempts at decreasing their TTM by trying to assert control over it, by negotiating with themselves / giving themselves permission to pull a small amount, these control tactics often fail resulting in further negative emotional consequences. The 'cycle of TTM' illustrates the descriptive characteristics of the process of hair-pulling, the negative emotions associated with the consequences of TTM appear to loop back around and interlink with general feelings of upset (antecedents phase); thus suggesting that the process of TTM may loop repeatedly and exacerbate TTM even further. Within the 'cycle of TTM', it is argued that the reported antecedents and motivations outlined by participants seem to align with the four-function model of nonsuicidal self-injury. Although TTM is not classed as a form of self-injury, some of the model's functions share minor similarities with the current findings. Nonsuicidal self-injury is described as the deliberate harming of one's own body, with an absence of suicidal intent. The four-function model suggests that nonsuicidal self-injury is maintained by four reinforcement processes (Bentley et al, 2014). People who engage in these self-injuring behaviours often refer to short-term and long-term consequences, negative emotions (e.g. shame and anger), academic difficulties and a lower overall functioning (Bentley et al, 2014). Participants in the current sample reported immediate and subsequent consequences of TTM (enjoyment and tension relief, followed by negative emotions such as shame and guilt), participants also reported an impact on daily functioning and various impairments (including an impact on work life and academic life).

As detailed in the diagram 'cycle of TTM' (see page 88), the descriptive characteristics of TTM detailed several points that participants often engage in during their process of hair-pulling. This consisted of antecedents, behaviours, environments and consequences. This is largely in line with the comprehensive model for behavioural treatment (ComB) outlined by Mansueto (1999), a CBT based approach to treating various disorders, it aims to identify a target behaviour and create a targeted replacement. This model is endorsed by one of the largest TTM organisations, the TLC foundation for body focussed repetitive behaviours (previously called 'TLC' or Trichotillomania Learning Centre, but recently renamed to include the umbrella term 'BFRB'). Mansueto's (1999) ComB has five modalities that act as cues and feedback that maintain pulling:

Cognitive	(individuals' thoughts and beliefs, e.g. I'll pull a few hairs, and then I'll stop)
Affective	(emotional states, e.g. emotional triggers, and subsequent consequences)
Motoric	(physical actions, e.g. wandering hands, and creating a block to help awareness)
Sensory	(sight, touch, etc)
Place	(external / environmental)

Many of the descriptive findings within this project align with Mansueto's ComB, although Mansueto did not illustrate this in diagram form. The findings in the current project identify a cyclical pattern of TTM that appears to loop repetitively, with the immediate and subsequent consequences and attempts to mediate hair-pulling behaviours often resulting in further hair-pulling. The most significant variation between the current findings and Mansueto's ComB is the participants in the current sample speak about the immediate (feeling happier and more relaxed) and subsequent (feelings of guilt, shame, anger, self-loathing, etc) consequences of TTM. Participants also speak about the ritualistic nature of their TTM, which is not overtly discussed in the ComB. The ComB outlines a step by step treatment of TTM, which involves identifying antecedents, behaviours and consequences in order to address the behavioural changes required; this treatment strategy appears to be influenced by the A-B-C (antecedents-behaviours-consequences) model for cognitive behavioural therapy.

Shame and Distress

The feelings of shame that participants feel often causes distress in their lives. Participants clearly described how significantly TTM impacts their lives by stating that TTM causes frequent and long-term distress. Within the sub-theme 'shame and distress', there appear to be gender differences within the email data, as the supporting quotes provided in the presentation of findings are all from female participants, male interviewees did not report such strong feelings of shame. This may be attributed to the idea that it is often considered socially acceptable for men to have short, bald or thinning hair as commonly found in male pattern hair loss. Feelings of shame have been reported in previous literature (Townsley-Stemberger et al, 2000), with 75% of the sample experiencing shame associated with TTM. Therefore, the current study findings confirm previous literature that shame is experienced by many people with TTM.

Many participants view TTM in a negative light, with participants expressing how TTM is a burden in their lives. The negative and intrusive thoughts associated with TTM can be applied to ego-syntonic

and ego-dystonic literature commonly found in eating disorder research. Ego-syntonic is consistent with values, feelings and a desired self-view, whereas ego-dystonic is a trait that defines obsessions and intrusive thoughts. As described by Clark (2004) and Langlois et al (2000), ego-dystonicity is considered as one of the traits that define obsessions, and it has been suggested as a main criterion to differentiate obsessions from other modalities of negative and intrusive thoughts (i.e. intrusive memories or thoughts related to PTSD). Langlois et al (2000) suggested that an inconsistency with a person's belief system can form the basis for an ego-dystonic nature of obsessions. With this in mind, the thought's content should be taken into consideration when attempting to understand how and why an obsessional intrusive thought is negatively appraised, as this can escalate into a clinical issue must be considered when aiming to understand how and why a specific obsessional intrusive thought (Clark et al, 2000, cited in Belloch et al, 2012). Ego-syntonic disorders are known to be more difficult to treat because they are largely aligned with the self-concept, as a person's disordered thinking may be aligned with their ego state, this means that the person is unable to identify the need for change and may be hostile towards change. In contrast, ego-dystonic disorders cause distress, and as such they are considered easier to treat. CBT is often recommended in the treatment of ego-dystonic disorders, where a healthcare professional aims to challenge unhelpful thoughts and behaviours to encourage the development of a more rational self-concept (Comer, 2010). OCD is a commonly used example of an ego-dystonic disorder, and TTM is classified as an obsessive compulsive and related disorder.

Purdon et al (2007) described how behaviours can have both ego-syntonic and ego-dystonic qualities, by stating that a given obsession (e.g. the need to avoid possible contamination) can be syntonic with some valued aspects of the self (e.g. protection from disease), and also simultaneously dystonic with others (e.g. excessiveness of the concern in question). It can be argued that TTM has both ego-syntonic and ego-dystonic qualities; people with TTM often try and enhance their self-control and have increased motivation for trying to change a behaviour (ego-syntonic), by actively trying to control and reduce their hair-pulling behaviours, typically by imposing a restriction on the number of hairs pulled which can arguably signal an increased motivation to change, although these attempts of control usually result in failure. Additionally, people with TTM often experience lower mood, and the effects of TTM commonly interfere with activities and daily life (ego-dystonic), with many participants describing how they avoid certain situations which may uncover their hair loss, and general emotional and psychological impairments in daily life (e.g. shame, embarrassment, perceived judgement and stigma by others). The idea that TTM encompasses both ego-syntonic and ego-dystonic qualities implies that it is more difficult to treat, and that relapse rates may be high. This "dualism" may require consideration during treatment of TTM; participants in the Higbed and Fox (2010) study described anorexia nervosa as both a separate entity and as part of their identity. This "dualism" may suggest the blurring of self and mental illness (Kinderman et al, 2006). The idea that TTM is a difficult disorder to treat is very strongly reported by participants in the current study, participants reported many unsuccessful treatment experiences and high relapse rates.

Coping by Concealment

Many participants spoke about the implications of fearing judgement from other people and their use of concealment as a coping strategy. Some participants suggested they did not cope with TTM, others stated they had no choice but to cope, while most spoke about using concealment as a form of coping. Participants discussed their investment of time, effort and money at concealing their hair loss. This sub-theme interlinks with many other facets of the data set, as many participants conceal their hair loss to minimise the shame they may feel, to minimise the perceived judgement they may receive from others, in an attempt to lessen the perceived stigma they may feel and to minimise the embarrassment they may feel. Franklin et al (2011) stated that many adolescent TTM sufferers express fear that their classmates or peers will discover their bald patches and evaluate them negatively. The current findings echo this, as some participants in the study commented on having experienced ridicule by their peers, which ultimately impacts their self-esteem and self-confidence.

Concealment is a key feature of previous literature, both Diefenbach, Tolin, Crocetto et al (2005) and Diefenbach, Tolin, Hannan et al (2005) have indicated people with TTM will often use various methods to conceal and disguise the hair loss, such as wigs, makeup, and hats. The financial investment aspect of this has also been noted in previous literature, people with TTM often spend a lot of money on methods of concealment (Wetterneck et al, 2006). Within the sub-theme 'coping by concealment', there appear to be gender differences within the email data, as supporting quotes revealed that there were several female participants who commented on the physical aspects of coping by using methods to conceal their hair loss, but spoke about the difficulties of emotionally coping with TTM, but this was not noted in data from male participants. Most of the male participants did not speak about the difficulties of emotionally coping with TTM, but largely highlighted more practical ways that they use to cope via the use of various forms of concealment (e.g. shaving the head, wearing a hat, covering any affected areas).

Persistent and Extensive Effects

The theme of 'persistent and extensive effects' represents a part of the interview data about the impact participants experience as a result of their TTM. All 20 participants reported widespread and varying degrees as to the level of impact TTM has on their lives. As mentioned in the email interviews, participants spoke about the impact TTM has on their academic lives and referenced interrupted concentration which subsequently affects the ability to complete academic tasks. Some participants stated that the interrupted concentration resulted in academic tasks taking longer to complete, with an impact on overall grades. Participants also noted that stressful academic periods (e.g. exams) resulted in increased hair-pulling severity, with some stating that teachers were not understanding. It has been largely accepted that the average age of onset is between 9 – 13 years old (Sah, Koo and Price, 2008), this time period within academic life is often full of exams. Given this average age of onset and the outlined impact on academic life, teaching staff should be made aware of trichotillomania and other mental health disorders which may have a significant impact on academic life. The personal and psychological impact of TTM has also been highlighted within the data,

including low self-esteem, low self-confidence, perceived stigma, shame, isolation, perceived judgement from peers. Teaching staff may be vigilant about visible issues (e.g. self-harm), but due to the average age of onset and far reaching implications, teaching staff should be encouraged to be aware of mental health disorders and less visible issues.

Franklin et al (2008) found that TTM impairs the social and academic world of children. The current findings confirm this, as many participants stated they experienced interrupted concentration in education settings which impacted their overall grades. Furthermore, many participants in the current sample highlighted an impact on friendships and relationships with other people and spoke extensively about keeping their TTM a secret and actively engaging in non-disclosure behaviours. Wetterneck et al (2006) previously found that people with TTM have difficulty focusing on tasks, which may subsequently impact academic or occupational work and career advancement. The current findings confirm this as participants suggested TTM had an impact on their career and professional life: some mentioned that they deliberately chose easier jobs which would cause less stress, this may have been done as a protective factor against excess stress which may exacerbate TTM symptoms and hair-pulling behaviour. The sub-theme involving impact on relationships revealed data where participants reported wide ranging impact on their relationships, including the fear of being rejected and the fear of living a solitary life. Other participants touched upon their relationships with friends by saying they had experienced ridicule from peers as a result of the TTM.

The effects of TTM have been widely noted in previous literature and is a common thread throughout TTM research. The issues surrounding self-esteem and feelings of unattractiveness seem to be ongoing in relation to TTM; Townsley-Stemberger et al (2000) used a clinical sample of 67 patients, results revealed negative affective states evident in the sample which included feeling unattractive (87%), low self-esteem (77%), secretiveness (83%), shame (75%), and increased numbers of arguments with loved ones (49%). Diefenbach, Tolin, Hannan et al (2005) explored the impact of hair-pulling on psychosocial functioning, with a sample of 28 TTM patients and 28 non-psychiatric control participants. Results indicated that TTM participants reported higher levels of distress, associated impairments (including depression) and lower life satisfaction compared with control participants, thus highlighting the emotional toll associated with TTM. The current study supports these earlier findings on the impact of TTM and provides additional depth by highlighting the impact of TTM from a qualitative perspective.

Self-Identity and Lost Opportunities

The sub-theme of 'self-identity and lost opportunities' are interlinked in the sense that there were some participants who reported lowering their aspirations by not seizing opportunities because TTM had affected their self-confidence and self-esteem. Self-efficacy is said to play a key role in stress reactions and has an impact on how individuals cope in adverse situations (Bandura, 1997). In turn, self-efficacy beliefs regulate functioning through various cognitive, motivational, affective, and decisional processes (Benight and Bandura, 2004). This affects whether a person thinks in a self-enhancing or self-debilitating way, this also affects how well a person motivates themselves, how

effectively a person perseveres in difficult circumstances, the quality of their emotional life, their vulnerability to adverse situations (e.g. stress and depression), their resiliency in adverse situations, and other important choices which influence and set life courses. Umubyeyi et al (2016) investigated help-seeking behaviours, barriers to care and self-efficacy for young adults with depression and/or suicidality in low income settings who were seeking mental health care. Results indicated that, only 6 of 247 participants received help from a mental health professional, with the most common barrier to care being accessibility and acceptability of health services. This was noted by the current sample, as participants indicated a lack of support from healthcare professionals and barriers to seeking care. Additionally, people with low self-efficacy are more likely to experience barriers to care (Schmutte et al, 2009). Therefore, by addressing low self-efficacy in TTM patients, they may feel better equipped to seek care for their TTM, to better cope both emotionally and physically from the wide range of effects of the disorder.

These reports of low self-esteem and low self-confidence, coupled with many reports of negative self-concepts appeared to contribute towards feelings of unworthiness, thus impacting on participant's self-identity. Some participants described how they tried to keep their issues with low self-confidence and self-esteem hidden by portraying a façade of confidence around their peers. In relation to how these concepts impact self-identity, a participant from a non-western country who wears conservative / traditional clothing revealed how her clothing hides the effects of TTM, saying if she did not have traditional clothing, she would feel unworthy. Other participants reported how they deliberately chose easier career paths due to low self-worth, this negative self-view could arguably lead to lowered aspirations and may result in delayed / lost opportunities for career progression. It could be argued that less onerous jobs lead to lower income, and lower income may then be associated with poorer health outcomes, creating a negative cycle.

This is largely in line with previous literature which has highlighted how TTM has numerous functional outcomes, adults have reported impairment in school, work, social functioning, lowered career aspirations (Diefenbach, Tolin, Hannan et al, 2005; and Woods et al, 2006). The issue of interrupted concentration was noted in the email interview within both work and academic life, which also links to previous literature (Wetterneck et al, 2006) who stated that people with TTM may have difficulty focusing or concentrating on tasks which may affect academic work and career advancement. However, the cultural aspect of traditional dress highlighted in the email interviews is not noted within previous literature.

Impulse Control and Permission Giving Behaviours

Within the sub-theme 'impulse control and permission giving behaviours', more male participants spoke about these ideas than female participants, thus suggesting gender differences within this sub-theme. Four male participants spoke about these topics even though male participants were in the minority within the interview sample (7 of 20 participants). The issues surrounding impulse control provide a valuable insight into the lives of people with TTM and contributes towards a discussion around impulsivity and compulsivity; TTM was previously categorised as an impulse control disorder

before being re-classified as an obsessive compulsive and related disorder. The idea that participants spoke openly about struggling to control their hair-pulling and giving themselves permission to pull a small number of hairs at an attempt to gain control, as well as highlighting their difficulties with impulse control (e.g. binge eating, shopping) and various other issues with compulsive behaviours seems to 'blur' the lines between the classification of the disorder.

TTM has been recategorised several times, both as an impulse control disorder and an obsessive compulsive and related disorder. The central theme to these recategorisations are the two concepts of impulsivity and compulsivity. Chamberlain et al (2009) has stated that compulsions can be viewed as a failure to subdue repetitive behaviours that may reduce negative affective states (e.g. anxiety). Compulsive behaviours can therefore be linked to high harm avoidance, high risk aversion and low sensation seeking (Stein and Lochner, 2006). In contrast to this, impulsivity can be viewed as a failure to prevent behaviours that are motivated by reward, and therefore may be associated with high sensation seeking and reduced harm avoidance. Impulsivity is thought to be a failure to control one's actions, which results in uninhibited behaviours. Whereas, compulsivity is seen as a form of excessive control which leads to the inhibition of behaviour. Furthermore, Ferrao et al (2006) has stated that the primary purpose of a compulsion is to reduce anxiety, whereas impulsivity is largely linked to pleasure acquisition. Ferrao et al (2006) compared impulsivity and compulsivity by comparing 20 patients with OCD, and 20 patients with skin picking and/or TTM, in a case control study. Results revealed six significant differences between both groups, these differences involved the ability or inability to delay an impulse, feelings of pleasure or guilt during or after the act, ritualisation, and whether a person believes there will be losses or benefits if prevented from acting on their impulses or compulsions. Although TTM does indeed demonstrate compulsive aspects, further research would be advantageous to further investigate phenomenological and neurobiological aspects of TTM in order to determine if it can definitively be categorised as an obsessive-compulsive and related disorder.

Perceived Stigma, Secrecy and Non-Disclosure

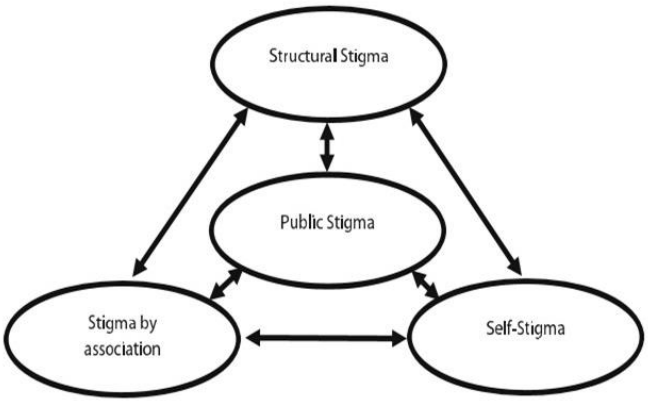
Within the sub-theme 'perceived stigma, secrecy and non-disclosure' the supporting quotes used in the presentation of findings are from both male and female participants, all white in ethnicity and represent the more mature side of the sample with an age range between 31-54 years old. These sentiments were not widely noted among the younger sample; with only 1 younger participant referencing the need for education but did not expressly discuss this in relation to stigmatisation.

Phelan et al (2008) has stated that prejudice is more concerned with the processes driven by inter-group domination and exploitation (e.g. ethnicity), whereas stigma research focuses primarily on the processes that are driven by norm enforcement and disease avoidance (e.g. disabilities or illnesses). Corrigan (2004) suggested that negative reactions of stigmatised individuals (i.e. people who have a mental illness) can represent a form of prejudice. Although there are significant overlaps between stigma and prejudice, stigma can be differentiated as it necessarily involves reactions to perceived negative deviance. Stigmatisation can arise on societal, interpersonal and individual levels (Bos et al, 2013).

Previous literature has pointed to people with TTM experiencing stigma; Franklin et al (2011) stated that adolescent TTM sufferers expressed fear of being evaluated negatively by their classmates. This fear may be well founded; Boudjouk et al (2000) found that developmentally normal teenagers assessed the social acceptability of people with TTM and chronic tic disorders (CTDs) as significantly lower than people without TTM or CTDs. The findings in this study have highlighted the perceived stigma participants may receive from others, subsequently resulting in secrecy and non-disclosure of their TTM, brings to mind a model of stigma.

Pryor and Reeder (2011) outlined a conceptual model which aimed to provide clarity in the diverse literature surrounding stigma. The conceptual model built on previous theories (Herek, 2007) identified four interrelated manifestations of stigma. Firstly, “public stigma” is at the core of this model and is associated with people’s social and/or psychological reactions to a person they perceive as having a stigmatising condition. This form of public stigma is often triggered by a label, these labels can emerge in historical and cultural contexts; participants often highlighted how TTM made them feel ‘abnormal’ and like a ‘freak’. Self-stigma represents the social and psychological impact of possessing a stigma; this generally involves the anticipation of stigma or the internalisation of stigmatising responses. Corrigan and Watson (2002) has stated that self-stigma is a private shame that negatively impacts self-esteem and causes self-doubt regarding in many areas of life (e.g. the ability to hold a job or the ability to find a life partner). Many participants in the current study detailed how TTM impacts their self-esteem, self-confidence and negatively affects the quality and quantity of their interpersonal relationships. “Stigma by association” is similar to Goffman’s (1963) courtesy stigma and involves social and psychological reactions to people who are associated with a stigmatised person, this aspect of stigma was not widely noted in the study findings, but can be explored in future research. Lastly, “structural stigma” is defined by Hatzenbuehler and Link (2014, p2) as the “societal-level conditions, cultural norms, and institutional practices that constrain the opportunities, resources, and wellbeing for stigmatised populations”. Structural stigma can be applied to the blog post data findings in relation to the theme ‘societal view of beauty’ and the often unrealistic forms of beauty promoted by the media.

Bos et al (2013) states that more empirical research on the inter-relatedness of the four manifestations of stigma is required. Three aspects of Pryor and Reeder’s conceptual model of stigma can be applied to the current findings, as detailed in the figure below.



Public Stigma
Participants described how TTM made them feel like 'abnormal' and like a 'freak'

Self-Stigma
Participants described how they kept their TTM a secret and did not disclose the condition due to the perceived stigma and judgement they may receive. Participants also reported an impact on self-esteem, self-confidence, career progression and interpersonal relationships.

Structural Stigma
Can potentially be applied to the idea that many healthcare professionals do not take TTM seriously or provide adequate support, with many healthcare professionals placing the burden of controlling and/or stopping TTM directly onto the patient, this may appear to perpetuate a stigmatized status.

Structural Stigma can also be applied to theme 'Societal View of Beauty' where some participants referenced never feeling 'truly beautiful', being 'envious of girls with beautiful hair', and living in a culture that places 'emphasis on appearances'

Figure 6.3: Four Types of Stigma Model (based on Pryor and Reeder, 2011), applied to TTM

Embarrassment and Avoidances

Participants within this sub-theme spoke about feeling embarrassment about their TTM and its subsequent hair loss, while suggesting that they avoided various activities because of their TTM. Avoiding social activities is also evident in previous literature, with Winchel et al (1992) stating that people with TTM exhibit avoidance behaviours due to embarrassment about their hair loss. This is echoed in later literature (Townsley-Stemberger et al, 2000), who highlights avoiding common activities such as haircuts and physical activities. Stemming from the idea of embarrassment, comes the concept of avoidance behaviours, with O'Sullivan et al (1996) asserting that this may contribute toward barriers to care and limit the patients desire to seek help.

Acceptance

In relation to this theme from the blog data, some blog users spoke about how they have grown to accept their TTM, this was not widely noted within the email interviews. It could be said that blog users who place their blog entries onto the internet do so voluntarily and are more open to writing about topics they want to virtually share their experiences about. In contrast, the email interview participants supplied their experiences and perceptions in a largely confidential / anonymous way, which could explain why this resulted in different findings between the sample. The two samples were distinctly separate, none of the 20 interviewees overtly stated that they engaged in blogging or were active blog users.

6.3 Discussion around the DSM-5 criteria in relation to the current findings

There has been some contention over the classification of TTM over the years, with the disorder being reclassified several times. The element of '*tension*' had originally placed TTM in the classification of an impulse control disorder. However, "many consider the disorder to be in the spectrum of obsessive-compulsive disorders (OCD) due to its similar phenotypical, neurobiological,

and clinical features" (Corso and McGeary, 2008, p1136). Similarly, TTM has previously been discussed alongside Tourette's syndrome, as it consists of repetitive motor tics and/or repetitive compulsive rituals in certain OCD conditions (Chamberlain et al, 2009).

The DSM-IV-TR (American Psychiatric Association, 2000) previously classed TTM as an impulse control disorder not elsewhere classified, this has since been re-classified as an obsessive-compulsive and related disorder in the DSM-5 (American Psychiatric Association, 2013). Under Section 63 of the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10, World Health Organisation, 2016), TTM is classified as a habit and impulse control disorder, under the same category as other disorders such as pathological gambling, pyromania, kleptomania, and intermittent explosive disorder. The table below highlights the different TTM criteria between the latest version of the ICD clinical modification (ICD-10-CM) and the DSM-5.

Table 6.1: Summary of ICD-10-CM and DSM-5 Definitions of Trichotillomania

ICD-10-CM classification (2020)	**DSM-5 criteria (APA, 2013)**
Section F63.3 - impulse disorders A disorder characterised by repetitive pulling out of one's hair resulting in noticeable hair loss; the individual experiences a rising subjective sense of tension before pulling out the hair and a sense of gratification or relief when pulling out the hair. Compulsion to pull out one's hair. Excessive pulling of one's own hair. Excludes: other stereotyped movement disorder (F98.4)	**Section 312.39: Obsessive Compulsive and related disorders.** Recurrent pulling out of one's hair, resulting in hair loss. Repeated attempts to decrease or stop hair pulling. The hair pulling causes clinically significant distress or impairment in social, occupational, or other important areas of functioning. The hair pulling or hair loss is not attributable to another medical condition (e.g., a dermatological condition). The hair pulling is not better explained by the symptoms of another mental disorder (e.g., attempts to improve a perceived defect or flaw in appearance in body dysmorphic disorder).

As this project has used DSM-5 (American Psychiatric Association, 2013) criteria from the outset, particularly in screening individuals via the participant consent form to ensure they met DSM criteria for a TTM diagnosis, the current findings have been discussed in relation to the DSM-5 criteria. The accounts from the email interview participants on their described 'cycle of TTM' do not appear to fully align with the current DSM-5 criteria for diagnosing TTM. There has previously been contention over the DSM criteria; the DSM-IV-TR (APA, 2000, p677) outlined five criteria for TTM diagnosis:

(a) recurrent pulling out of one's own hair that results in noticeable hair loss
(b) increasing sense of tension immediately before pulling out the hair or when attempting to resist the behaviour
(c) pleasure gratification or relief when pulling out the hair
(d) the diagnosis is not given if the hair-pulling is better accounted for by another mental disorder
(e) the disturbance must cause significant distress or impairment in social, occupational, or other important areas of functioning

The contention was regarding two aspects of the diagnostic criteria; point (b) and (c). Therefore, the criteria were revised for the DSM-5 which proposed the exclusion of these two points. The new DSM-5 criteria for TTM, which is arguably more lenient, will certainly have an effect on participant recruitment in future research studies. Additionally, as highlighted in the participant interviews, many participants still report feeling tension before hairpulling, and relief / satisfaction directly after hairpulling episodes. Therefore, the current findings are in direct contrast to the new DSM-5 criteria, so participants may feel that their symptoms are not fully recognised by the new diagnostic criteria.

Regarding the classification and reclassifications of TTM over the years due to the complex nature of the disorder, there still appears to be confusion over the category it should belong to. At present, TTM is listed under section 312.39 (obsessive compulsive and related disorders) of the DSM-5. However, there is a very large and internationally recognised TTM organisation that refer to TTM as a BFRB (body-focussed repetitive behaviour). Upon contacting the TTM organisation in question for further clarification, it was confirmed that TTM is indeed classified as an 'OCD related disorder' (as per the DSM-5), although "their scientific advisory board" refers to BFRB's as an "umbrella category" for TTM, cheek / lip biting and skin picking altogether. Importantly, trichotillomania is listed under its own sub-section, while BFRB's are listed in a separate sub-section titled "*unspecified* obsessive-compulsive and related disorders". Stein et al (2007) had previously proposed that TTM be classed as a BFRB, alongside other disorders such as skin picking and nail biting. These BFRB behaviours are often viewed along a spectrum ranging from minor routine grooming for cosmetic purposes to more severe / extreme pathologic behaviours. There is a working group that have made recommendations for the upcoming ICD-11 classification; the working group (Grant and Stein, 2014) suggested that both TTM and skin picking be placed in the ICD-11 obsessive compulsive and related disorder section, under the rubric of body focused repetitive behaviours which is in-line with the DSM-5, although they offer that this is not a perfect 'fit'. Grouping all these disorders together under an "umbrella category" may be convenient for large organisations, but it may make people with TTM feel like their disorder does not stand alone and may not be valid without other diagnoses. Furthermore, these re-classifications of TTM over the years only establishes that TTM remains a misunderstood disorder, and the re-classifications have not helped in the pursuit of effective interventions.

6.4 Professional Relevance and Implications

Participants in the study described having limited success with behaviour-based treatments and described the behaviour-based methods most commonly used as: head shaving, will power, and installing a hair-replacement system. Other behaviour-based activities which were described as unsuccessful consisted of dietary changes, wearing gloves / acrylic nails, and using topical products. Participants also described attempting HRT and CBT, and counselling sessions which they also deemed unsuccessful. Participants described attempting various pharmacological treatments which they deemed unsuccessful, including anti-depressants and n-acetyl cysteine (NAC). In summary, the reported unsuccessful treatments far outweighed the limited success participants had experienced in treating their TTM. Participants in the current study largely did not find CBT to be efficacious, this

finding is in contrast with Flessner et al (2010) who explored consensus among experts in current TTM treatment practices; clinicians and clinical researchers (n = 67) responded to an internet survey, CBT was ranked (n = 49) as the treatment of choice for both children and adults with TTM. Respondents in the Flessner et al (2010) study indicated that, if CBT was not effective, referral onto medication is the next treatment step, with SSRI's being the most commonly used form of pharmacological treatment, followed by antipsychotics, SNRI's and opiate blockers. Although it is important to ask how experts treat TTM (as in the Flessner et al study), the current study has provided further depth to this area by asking participants to describe the treatments they have tried and detail their ideal treatment intervention, as these are the people who live with and directly experience TTM.

Participant responses seem to provide an insight into the level of care they have received when seeking help for their TTM and their responses can be used to highlight where healthcare needs are being unmet due to a variety of factors. It was clear that participants felt there was a lack of adequate training among healthcare professionals in the understanding, diagnosing and treatment of TTM. Many participants described how it had taken a considerable length of time to be diagnosed, with participants detailing how there was a lack of sensitivity when dealing with healthcare professionals. Stanley et al (2017) online survey involving mental health providers in the National Veterans Health Administration (VHA) also indicated insufficient training with respondents suggesting that VHA mental health providers lack sufficient knowledge and expertise to adequately diagnose and treat people with obsessive compulsive and related disorders. 19% of mental health providers reported that additional specialised training would be "extremely valuable", while 35% reported that extra specialised training would be "very valuable". Although this survey used the accepted umbrella term 'obsessive-compulsive and related disorders', it failed to separate the disorders (e.g. trichotillomania / excoriation disorder / OCD / hoarding / body dysmorphic disorder) within this category, making it difficult to decipher which disorders mental health providers were referring to. In the current study, there were very clear feelings of frustration as interview participants noted how they were not taken seriously when seeking help, with a key finding and contribution to knowledge being that many healthcare professionals fail to offer any support whatsoever.

Another key finding is that participants provided clear points on what their ideal TTM treatment and/or interventions would entail. To my knowledge, there is no other study that directly asks participants their opinions on how their TTM should be addressed, as TTM still remains a misunderstood disorder, the level of insight that has been provided directly from people with TTM could provide an invaluable direction into the content of a TTM treatment / intervention plan. Participants very clearly offered details about the content, duration, and frequency of the support they want to receive, which certainly contributes to the area and can be used to develop or inform future support for service users. It can be argued that, based on the findings, a person-centred approach in dealing with an individual's TTM would be the best way forward.

The current project has also outlined a 'cycle of TTM' diagram which stemmed from the descriptive details provided by the 20 interviewees. Many of these facets have been discussed in previous

literature: Stemberger et al (2003) suggested that the antecedents linked to engaging in common TTM behaviours involve environmental, motoric, sensory, affective and cognitive aspects. This was echoed at a later date by Kell and Kress (2006) who state that clinicians often establish age of onset, frequency, quantity, emotional states, environmental, motoric, sensory, affective and cognitive factors when dealing with people with TTM. Mansueto's ComB (1999) also uses these aspects when discussing how to treat TTM. The ComB is a widely used treatment outline for TTM and other disorders and remains popular today. However, it can be argued that this approach requires updating. Mansueto has stated that TTM is a complicated problem with many inputs and triggers, that people with TTM have many individual differences and that no one model truly explains TTM. Furthermore, Mansueto has stated that the ComB model does not address hypothesised, distal determinants of TTM (e.g. biological vulnerability / family dysfunction), nor does it address comorbid conditions (e.g. depression or anxiety) or dysfunctional characteristics (e.g. perfectionism or low self-esteem) which may co-exist with TTM. Several years later, Odlaug et al (2010) stated that TTM sufferers experience a lower quality of life compared with control participants, this lower quality of life is regardless of the severity of TTM symptoms. Thus, suggesting that all symptoms of trichotillomania should be addressed, which in turn should improve patient wellbeing.

Based on the responses from participants, a person-centred approach may be the best way forward as a treatment plan for TTM. However, based on the current interview findings, it remains clear that healthcare professionals are not adequately trained to deal with TTM, and patients' needs are being unmet. All 20 interviewees reported a lack of training (in health professionals) around TTM, some stated their diagnosis took a significant length of time, while others stated they received no treatment whatsoever. This key finding (receiving no treatment for TTM) was highlighted alongside a lack of empathy and sensitivity from healthcare providers. The current findings highlight a full range of impairment and comorbid disorders (e.g. anxiety) associated with TTM, these should all be incorporated into a person-centred treatment approach for people seeking treatment. There is previous literature which highlights the significant impairment and comorbid disorders associated with TTM, yet the treatment protocols simply do not reflect this.

Participants in the email interview have highlighted their ideal treatment intervention which incorporates help for the associated impairments; thus, implying that TTM service users hope their TTM is treated as a whole, by healthcare professionals who don't selectively choose ('cherry pick') which symptoms to treat. Although selectively choosing which symptoms to treat may not be a deliberate choice by healthcare professionals; it may signal a lack of knowledge on the topic, inexperience in treating TTM and a lack of treatment guidance. For example: within the UK, the National Institute for Heath and Care Excellence (NICE), a key organisation for providing essential information to key groups such as GP's and other health professionals currently has no clinical advice or guidance listed on their website. This lack of information for healthcare providers in the UK signals a lack of resources on how people with TTM should be treated or supported. Although this is a key organisation within the UK, it is acknowledged that the current study involves an internationally

inclusive sample. In providing a suggestion for a potential treatment strategy, based on the current findings, an outline of a potential TTM treatment could be as follows:

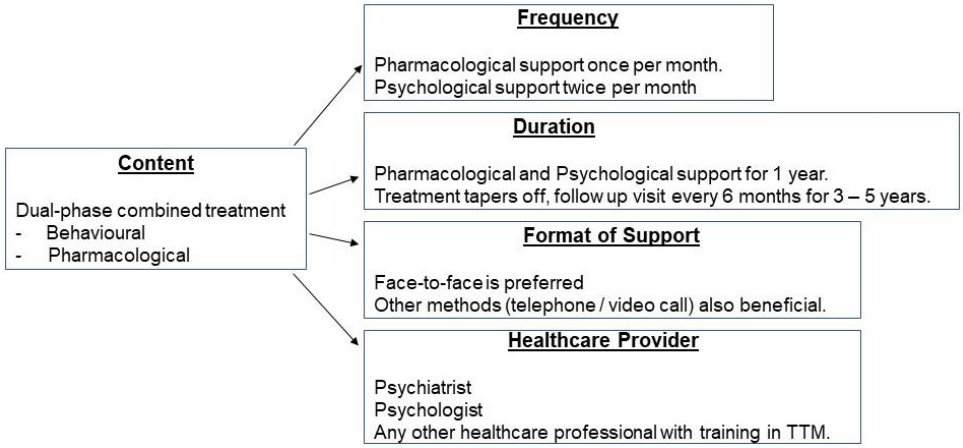


Figure 6.4 – Outline of potential TTM treatment strategy, based on email interview responses

Medically Unexplained Conditions and the need for Individualised Treatment Plans

It could be argued that TTM may be considered a medically unexplained disorder, as the aetiology of TTM still remains unknown. Medically unexplained symptoms (MUS) are often referred to as an umbrella term for disorders of no known or understood pathological cause (McCrae et al, 2015). It can be argued that people who experience debilitating symptoms or impairments without a definitive explanation, prognosis or treatment are likely to experience significant levels of embodied doubt and uncertainty (Nettleton, 2006). Nettleton (2006) conducted qualitative interviews with 18 outpatients with MUS from a neurology clinic, themes from the Nettleton study broadly concurred with existing literature on MUS, with themes around difficulties living with uncertainty, dealing with illness legitimacy, and a resistance to psychological explanations of suffering. This was echoed in later research where Chew-Graham et al (2011) suggested that people with MUS commonly avoid psychological framing of their issues.

Lidén et al (2015) has stated that the dearth of a medical explanation and cure often leaves both patients and their doctors unsatisfied. However, adequately treating people with MUS is of great importance, as living with medically unexplained conditions has been described as a struggle, with feelings of being in chaos and being a medical orphan (Nettleton et al, 2005). Lidén et al (2015) performed narrative interviews on 10 patients with MUS, findings revealed how people with MUS often have feelings that their symptoms overwhelm life, that they lose their sense of self, and experience a restricted and dependent daily life. These negative feelings slowly evolve into gaining insight and moving on (in the search for explanations, accepting the illness and becoming mindful).

Often the first point of contact for many patients, GP's face a formidable challenge when dealing with patients who have complex symptoms for which there is no explanation (Eriksen et al, 2013). It has previously been suggested that health services have unsuccessfully addressed the healthcare needs

of people with MUS, as there is often a failure to account for the complex nature of a persons' issues (Fink and Rosendal, 2008). Emphasis has been placed on the need for a personalised approach when helping people with medically unexplained conditions (Aamland et al, 2014). In terms of assisting people with medically unexplained conditions, healthcare providers should aim to be attentive to a patients' emotions and interpretations of their health (Gask et al, 2011). Additionally, healthcare providers should consider the personal narratives of their patients as trustworthy (Werner and Malterud, 2003) in order to take the health concerns of their patients seriously.

Improving access to psychological therapies should be a key aim on a global scale, especially for people with chronic conditions and medically unexplained symptoms, as people with MUS and associated comorbidity often make heavy demand on multiple healthcare services, with generally unsatisfactory outcomes (McCrae et al, 2015). It could be argued that TTM may be considered a medically unexplained disorder, as the aetiology of TTM still remains unknown and TTM is often associated with significant impairment and comorbidity, with depression and anxiety being very common. As an example, an individual with TTM may have both depression and anxiety, and request referrals to a psychologist for CBT in an attempt to treat anxiety, while a psychiatrist simultaneously treats depression via pharmacotherapy. However, if the severity of hair-pulling and TTM symptoms are not treated, there may be no significant improvements in depression and anxiety, resulting in a largely unsatisfactory outcome. In line with people who have MUS, participants in the current study described frustration and echo a lack of knowledge in how healthcare professionals deal with TTM.

Trichotillomania applied to Briddon's ABC-E model of Emotion

As a suggestion towards a potential TTM treatment strategy informed by participant responses, it is suggested that a full and detailed case history of a patient is taken to identify urges, triggers and behaviours associated with TTM, alongside any comorbidity and impairment. Ideally, treatment would be administered as a dual-phase targeted treatment whereby one healthcare professional (e.g. psychiatrist) aims to address any comorbid issues (e.g. anxiety / depression) by pharmacological methods, while another healthcare professional (e.g. psychologist) aims to deal with the behavioural and impairment aspects of TTM. Many participants indicated they would like to find a pharmacologic treatment that works best for them, which may take time in finding the right medication and dosage. Participants also described the significant impairments and comorbid issues that are linked to / consequences of and/or further exacerbate TTM (e.g. low self-esteem, low self-confidence, anxiety, depression). The treatment phase which addresses impairments and comorbidity may involve a behaviour-based treatment such as CBT or HRT, perhaps alongside coping strategies to improve levels of self-esteem and self-confidence. This two-person treatment team offering a person-centred approach in treating the many complex concepts that feed into TTM may help improve the severity and consequences of hair-pulling which may make living with TTM more manageable. This suggestion is based on the current findings and signals the beginning of a process to develop and deliver an accessible and acceptable intervention. However, additional work is needed to consult with both participants and professionals on the development of an intervention.

In line with the previously discussed idea that TTM has ego-dystonic qualities which may respond well to CBT, within the person-centred treatment approach, it brings to mind the potential use of Briddon's ABC-E model that can be utilised on a case by case basis for people with TTM. The ABC-E model of emotion is a biopsychosocial model which highlights the cycle of common mental health issues and provides an outlined framework for the development of interventions (Briddon et al, 2008). Briddon's model is underpinned by cognitive and behavioural models of emotional disorder (see Beck, 1979), and aims to deconstruct a person's mental health issue into four components:

A Autonomic (the physical effects of distress)
B Behaviour (changes in behaviour due to distress)
C Cognition (changes in patterns of thinking)
E Environment (environmental triggers, maintaining factors and social impact)

Within Briddon's model, patient centred interviewing is a vital component and interventions are informed by the problem the patient outlines. It is likely that a person's understanding of their mental health issue will most likely be broader than the narrow definition outlined by a diagnostic category. This is crucial when considering the development of appropriate and achievable goals for an intervention and journey toward recovery. After a patient answers a series of questions, a summarised version is given in a verbal statement to check for accuracy. The model can then be developed in collaboration with the patient, this may help the patient feel empowered in their own healthcare journey. The final map will guide shared decision-making and inform various interventions which will influence changes on physical, behavioural, cognitive or environmental factors in an attempt to break the cycle (Briddon et al, 2008).

As an *example*, the diagram below illustrates how some of the current findings map onto the ABC-E model, the intervention phase contains a cognitive restructuring aspect which can be addressed with CBT (as discussed above, as the behaviour-based part of treatment that participants highlighted). Healthcare providers can offer a person-centred approach by applying their patient's symptoms and identifying manageable goals for intervention by working in a collaborative manner. This example diagram (below) may not account for the treatment of associated impairment or comorbidity in people with TTM, which would need to be addressed with appropriate psychiatric referral.

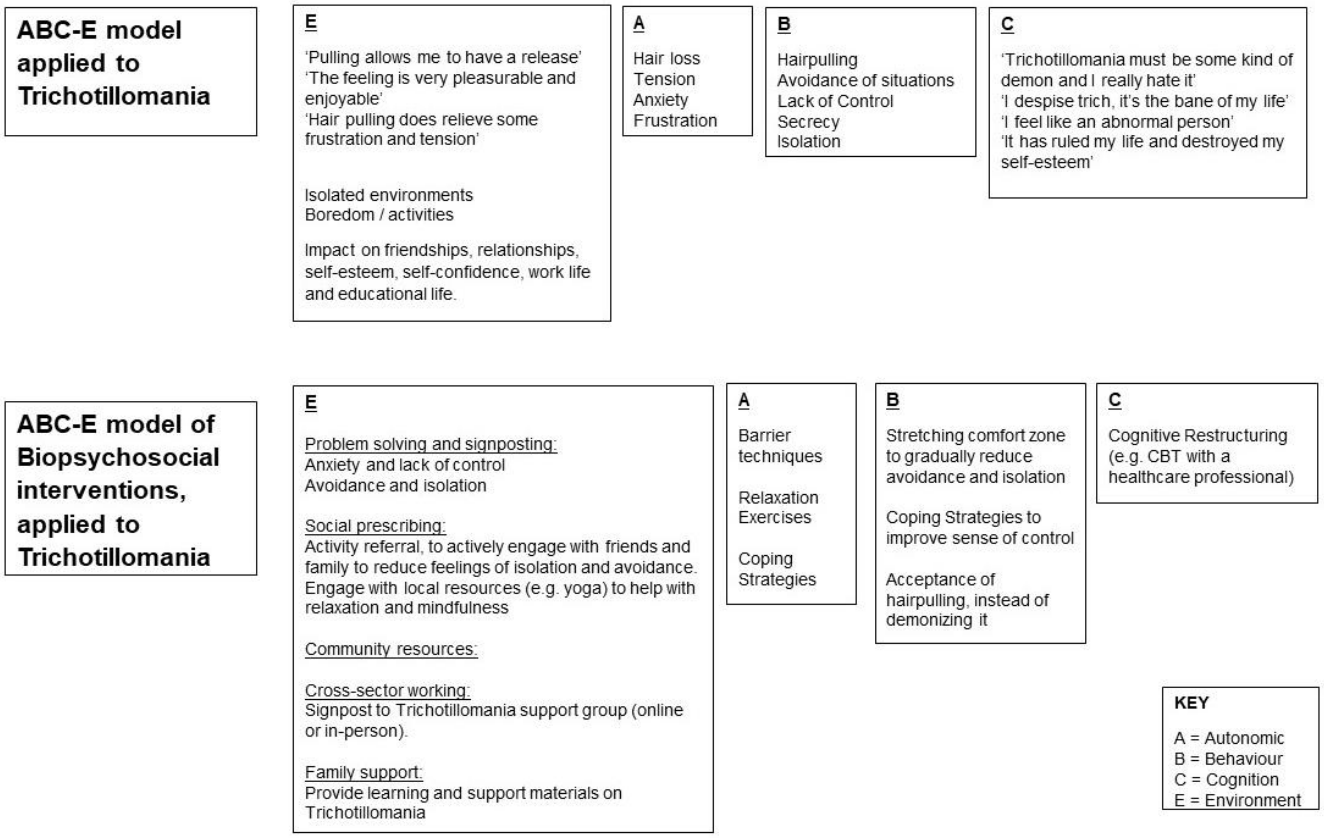


Figure 6.5: Trichotillomania applied to the ABC-E model.

6.5 Discussion around Acceptability and Feasibility of the Email Interview Method

By including questions associated with acceptability and feasibility aspects, participants were able to provide feedback and critique about the study method. Participants responses were taken into consideration, which resulted in a revised ethics application to include separate photo consent.

The acceptability and feasibility-based questions contributed toward an improved understanding of participant experiences of the email interview procedure by providing insight into their perceptions on the suitability of the method and data collection procedure. Participants were asked to identify the strengths, weaknesses and suggested improvements of the interview. The thematic analysis largely revealed that this was a highly suitable and convenient method to access data from hard to reach populations, this further solidified that the initial rationale of using an email interview method in recruiting an international sample was the correct way forward. Participants reported that the prolonged interview was not too burdensome, did not take too much time, and could be completed at their convenience. Participants felt the interview was thoroughly administered, with clear instructions and flexible response times. Asking participants about the method of data collection and their experiences of participation is important in contributing towards rigour. As previously mentioned, this study has used reflexivity, prolonged engagement and an audit trail to establish rigour (see page 57), including aspects of acceptability and feasibility of the asynchronous email interview method has

contributed towards rigour by asking participants to detail their feedback about the study method and full process of participation.

6.6 Reflexive Account of the Research Process

As someone who feels passionate about representing the voices of people with mental health disorders as well as having intermittent phases of TTM throughout my life, I was aware that my own views may influence my interpretation of the data. As mentioned, this project was underpinned using a constructivist epistemological approach, therefore I acknowledged that my own interpretations may be linked to the way I construct and make sense of the data set. Although there were a number of different ways in which I attempted to mitigate these factors, I made regular reflexive notes during the data collection and analysis process which helped inform the various reflexive pauses throughout the chapters. At the beginning of the data analysis process, several participant interview transcripts that I had coded were discussed at length during supervision meetings, sometimes coding labels were questioned and revised where necessary. During the thematic analysis steps were taken to check whether the findings remained data driven, or if my own views had taken the interpretation beyond the data itself. It was an aim to keep the study findings data driven in order to contribute towards trustworthiness, in line with Lincoln and Guba's (1985) assertion that rigour is achieved when the study findings reflect participant data as closely as possible. Furthermore, there was a point where participants expressed an interest in submitting photographs to visually depict their hair loss. This resulted in a revised ethics application including a separate photo consent form. I was so grateful that participants trusted in the research process and wanted to visually show images which may have made them feel vulnerable, and I had envisaged including one photo showing my own effects of TTM in solidarity with the sample, but upon further consideration decided against this as the data and findings should remain driven by the sample only.

Reflections on the Methodology and Methods

In thinking about method of data collection, it can be argued that recruiting email interview participants on facebook and conducting online interviews is indeed an innovative method, especially considering one of the aims was recruitment of an international sample. An equally geographically diverse sample would not have been recruited using more traditional methods such as focus groups or in-person interviews without significant time and financial implications. To my knowledge, no other TTM studies have utilised the asynchronous email interview method or blog posts using qualitative methods. Therefore, these two data collection methods coupled with recruitment of an international and geographically diverse sample is the first research of its kind.

Using a generic qualitative approach for the current project has provided a flexible approach to assess the data, without viewing or analysing the data set through the confines of a single established methodology. Using a more traditional approach would have likely highlighted different findings; a study underpinned with grounded theory would have aimed to generate a theory of TTM grounded in the resultant data. Whereas, a study using a phenomenological methodological approach would be primarily concerned with lived experience. As previously mentioned, over immersion in the

epistemological and ontological perspectives that underpin a chosen methodology can often result in theoretical perspectives becoming a dominant focus in research, rather than the research questions / aims or objectives (Sandelowski, 2000). Therefore, the theoretical freedom of the generic qualitative approach has provided a multi-faceted perspective into TTM in the current study, by highlighting participant experiences, perceptions and opinions on a variety of different topics associated with TTM.

Reflections on the Sample and Recruitment

In reflecting on the diversity of the sample, of the 20 email interview participants, 7 were male and 13 were female. These 20 participants reflect an international sample from 15 different countries, with an age range between 18 – 55 years old. 13 of the 20 participants identified as being from a white ethnic background. I strongly believe that this project has recruited a diverse email sample and the 13 female participants are in line with the literature that suggests TTM affects more females than males. The sample was geographically diverse and allowed for any cultural differences to be highlighted. If I had the opportunity to recruit the sample again, I would focus on recruiting a sample where more ethnicities are represented.

In reflecting on the process of participant recruitment and data collection, recruiting participants took much less time than originally anticipated. There was a rush of interest at the beginning which felt incredibly overwhelming at first. This rapid participant recruitment meant that the interviews began fairly quickly and were completed in less time than was originally envisaged which allowed more time for immersion in the data during the data analysis phase. However, working a full-time job whilst completing the PhD has meant that there has been very limited time to further disseminate my research findings through various journal articles and presentations. If I had the opportunity to recruit in this manner for a different study, I would stagger the recruitment process to allow more time to seek demographic details and be more selective of the sample based on age, gender, location and ethnicity to further encourage a more diverse sample.

Blogs provided a different insight into the topic and relied on blog users voluntarily writing posts and uploading them publicly onto the internet. There are other more modern forms of data collection that could have been used (e.g. different forms of social media such as twitter or instagram). Using these other forms of social media may have recruited a wider range of participants.

The 'Insider Perspective'

Although I aimed to keep my own preconceived experiences and ideas separate to allow participant voices to speak for themselves, it is important to acknowledge an 'insider perspective' within the current study. I had disclosed my own TTM at the beginning of the recruitment process which certainly impacted the level of recruitment. Participants very generously contributed their time over a prolonged period which was enabled by their trust of me, this impacted on the rapport that quickly developed during the email interviews. Although I did not share details of my own personal TTM story with individual participants, I aimed to make participants feel understood, respected and accepted as people.

An Online Connection for people with Shared Conditions

There are large online communities, particularly on facebook, where people with TTM can join together to talk about their experiences and struggles. These online communities provide a powerful 'virtual' connection to people throughout the world who have a shared diagnosis (Murray, 2016). The mediating effect that social media and online support has offered in the current research has provided an insight into participants' experiences of TTM which has the power to provide a platform to further consider virtual negotiations of TTM and the experience of chronic disorders. Utilising the internet to engage with people who have TTM, recruiting participants and collecting data via the internet has been an illuminating method. It is overwhelmingly clear that the internet has provided a medium of community for people with TTM who may feel alone or isolated. This is evident as participant recruitment began on a private facebook group with over 10,000 people with TTM around the world, with hundreds of active users commenting on posts about sharing experiences throughout the day. In this vein, Bradley and Poppen (2003) have asserted that the internet can provide a forum for like-minded people which may reduce feelings of isolation.

6.7 Strengths

I was not able to identify any previous literature that utilises blog posts in TTM research, thus including this aspect in the current project has contributed towards viewing TTM from a different perspective. Using blog posts as a method of data collection was also a strength as there are limited ethical considerations associated with this if the 'fair-game public domain' argument is presented in line with using the data for academic purposes. Although email interviews are not a new form of data collection, participant recruitment using facebook and blog posts has been a novel way of gathering data from a wide range of geographic locations. Previous literature has pointed to a lack of qualitative studies using an international sample, which this project has accounted for, by recruitment of an international and geographically diverse sample and fully exploring participant perceptions, opinions and experiences using an in-depth qualitative approach. The study findings have also provided a definitive outline in relation to content, frequency and treatment duration which has the potential to inform the development of a treatment intervention for people with TTM.

Due to the long-term participant engagement, with 8 – 10 email exchanges in total, it was possible to develop a rapport with participants. Coupled with my own disclosure of TTM at the beginning of the recruitment process, many participants commented on this aspect by indicating that they viewed the email interactions very positively. Participants responded well to the use of asynchronous email interviews, with many saying the method was convenient and allowed them to answer questions in their own time and at their own pace. Furthermore, this method saves significant time on transcription, recording equipment and travel expenses. This method was highly appropriate to use with the international sample as it would not have been financially viable to travel abroad to conduct in-person interviews. The asynchronous aspect of this method is highly relevant as it allows for participants to respond in their own time regardless of the time zone a participant lives in.

6.8 Limitations

There are several limitations regarding the asynchronous email interview method. During the acceptability and feasibility phase of data collection and analysis, several participants nominated their perceived weaknesses of this method by stating that the researcher was not able to view body language or listen to voice intonation. A further limitation of this interview method, being a long-term email exchange was that some participants may lose interest and drop out. There were a few participants who stopped responding or voluntarily dropped out by citing various reasons such as change of mind and time constraints. Although this is a limitation which can be difficult to overcome when methodological design is dependent on active participation, dropouts in the current study were replaced with additional participants until a good sample size and information power was achieved.

Although email participants were recruited on a TTM social media group and interested participants were required to complete a consent form which included confirming their diagnosis and TTM symptoms prior to participation, it was not possible to formally verify participant diagnoses. There was an attempt to mitigate this factor by asking questions on the consent from that specifically related to DSM-5 (American Psychiatric Association, 2013) criteria for TTM. Recruiting participants via the internet could arguably be a limitation, however, internet sampling procedures have been said to provide results consistent with traditional methods (Gosling et al, 2004).

This study has included a wide range of questions involving what participants would like their ideal TTM treatment intervention to entail alongside their thoughts on how TTM is dealt with by their healthcare professionals. Although the sample size was fairly small, the findings revealed powerful data which may be used to suggest a potential framework or key ideas for future healthcare training and TTM interventions. The study did not explicitly aim to generate generalisable findings, however, findings from this study can help with the design of a larger scale study that may be more generalisable to the wider population.

6.9 Recommendations for Policy and Practice

Treatment seeking behaviours appear to be low within the TTM population; of the 1697 participants in the Woods et al (2006) survey, only 1048 reported seeking treatment for their TTM symptoms. It's no surprise that only approximately 14.8% of the people who accessed treatment reported a moderate to large reduction in TTM symptoms (Woods et al, 2006); while 20.8% reported "minimally improved", 37.7% reported "unchanged", 7.4% reported "minimally worse", and 5.4% reported "much worse". In conjunction with the current findings which indicate that participants feel unsupported by their healthcare professionals, a key theme emerged (lapse in duty of care) whereby some participants were offered no support or TTM treatment whatsoever. A subtheme (inadequate training of healthcare professionals) also emerged from the data, suggesting that patient healthcare needs are being unmet.

Participants were very clear in asserting that there was a lack of adequate TTM training and significant delays in receiving a formal diagnosis. Participants described frustration at dealing with healthcare professionals who do not have adequate levels of understanding around TTM, with many

placing the responsibility of stopping hair-pulling onto the patient. A lack of sensitivity training was also noted, and participants described how their issues with TTM were not taken seriously when attempting to seek help. Moving forward, this key finding can be used to inform how clinicians support people with TTM, as guidance for practitioners on this subject is generally sparse. It is recommended that provision of education for clinicians is needed to understand TTM. Additionally, the findings from the current study infers that accessibility to effective intervention is minimal for people with TTM and the next phase of research should be to develop (in conjunction with people with TTM) an acceptable, accessible and effective intervention.

Mental health disorders which are largely hidden such as TTM are often underdiagnosed or not diagnosed at all. Winning et al (2015) has stated “dysregulation that emerges in early life may become more difficult to mitigate in adolescence or adulthood” therefore, the burden of mental health issues may be marginally lessened with early diagnosis and treatment. However, 75% - 80% of youth do not receive the mental health services they require (Stagman and Cooper, 2010). TTM impairment appears to worsen over time, with mild to moderate social and interpersonal impairment noted during childhood (Franklin et al, 2008), which progresses to moderate to severe impairment during middle to late adulthood (Woods et al, 2006). Many participants in the current sample reported significant impairment and unmet healthcare needs. This signals the need for early intervention that may prevent moderate to severe impairment and impact positively on health and social outcomes.

The onset of TTM commonly occurs between 9 – 13 years (Woods et al, 2006) and during school years. As established in the current findings, participants reported interrupted concentration in educational environments, which often leads to achieving lower grades. Furthermore, the secrecy, non-disclosure and concealment of TTM may mean that it is not overtly noticed by teaching staff in order to offer support. People with TTM are notoriously secretive about the disorder, as many fear judgements from their peers. All these aspects can contribute towards poor mental health which may be associated with increased health risk behaviours and lower educational achievement (Breslau et al, 2009). Given the average age of onset, it is vital that schools have an open-door policy when it comes to mental health disorders, whereby students may approach a staff member for help, with the staff member subsequently addressing these needs by making appropriate referrals to mental health services. Schools should also have dedicated emotional and mental health wellbeing policies in place which include aspects of awareness, mental health education, acceptance, non-judgement, stigma, and anti-bullying. Schools should also place emphasis on the importance of mental health and wellbeing alongside physical health.

There may be barriers to accessing mental health services, these may be socioeconomic status, cultural beliefs, and family beliefs. Overcoming obstacles in seeking treatment can depend on support from friends / family, work-place leadership, and other factors such as convenience and affordability (Wright et al, 2009). Although, people with mental health disorders are more likely to perceive stigma and barriers to care which may result in a failure to seek treatment (Visco, 2009). This emphasises the importance of developing an accessible service that people with TTM can access.

People with TTM often experience comorbidity, it is important that the person is treated as a whole, and various departments work in collaboration to ensure the most comprehensive support is provided. For example, participants in the current study indicated their ideal treatment intervention would be a dual-phase targeted treatment consisting of both behavioural and pharmacological treatment. This would imply that behaviour-based treatment may be delivered by a psychologist, while pharmacological treatment may be overseen by a psychiatrist. Furthermore, many participants noted comorbid issues with anxiety and depression, with TTM symptoms often exacerbating the comorbid disorders and vice versa. Baldacchino (2007) has stated that there is a tendency within specialist services to keep things separated, with the idea that disorders may belong to different services. This can directly result in people with comorbidity that may span several departments falling through the cracks. This points to the need for partnership across healthcare departments so that people feel adequately supported. Alternatively, funding more novel ways of intervention delivery (i.e. telephone, skype) may be beneficial if delivered by a highly skilled team with good clinical skills that can be accessed internationally via online methods.

Duke et al (2010) has previously stated that there is an inadequate supply of counselors who are trained or specialise in the treatment of TTM, this subsequently means that people with TTM are likely underserved. Similarly, Franklin et al (2011) previously stated that, in the next 5 years, it is critical for TTM researchers to aim to meet the demand for information and training by developing optimised models, in an attempt to address the major shortage of therapist expertise in TTM that is evident globally. Unfortunately, based on the current findings and from the perspective of a person with TTM, no significant improvements have been made to improve expertise in supporting patients with TTM. All 20 email participants identified a lack of adequate TTM training, suggesting that there is still a shortage of TTM therapist expertise on a global scale. Although this only represents one perspective, it is evident that those working within healthcare service should receive training on TTM, as well as the associated comorbidities in order to adequately provide support to people with TTM and their families who may not understand or know how to support their loved one. General practitioners should be made aware of TTM, as they are often the first point of contact for patients. Therefore, the introduction of an educational component at undergraduate levels in relevant fields (e.g. medicine, teaching, psychology, social work, nursing, social care and other health professions) would be advantageous. As comorbidity is a common occurrence with TTM, clinical services should aim to utilise an inclusive approach to support people in distress, whereby provisions should be needs-led rather than service-led (Baldacchino, 2007).

Findings from this project can be used to provide information to people with TTM so they may be better able to understand the disorder and recognize the many different antecedents and ways their disorder is maintained. An informative leaflet may be useful in disseminating key findings using accessible language so that friends or family members can better understand and support a person with TTM. Key findings from this study can be used as a starting point for therapists with limited or no experience of TTM before they access further training. An educational booklet or short training

workshop could be formulated to deliver key findings from this study to contribute towards TTM specific training, for example: the Cycle of TTM (see page 88) can be used as a baseline guide and applied to each individual case of TTM. This may enable a therapist to understand TTM's antecedents, motivations, environments and consequences associated with the individual person they are treating. This individualized level of understanding TTM may prove to be beneficial before undertaking person-centred behavioural therapy.

Participants very clearly outlined their ideal treatment intervention and this key finding can be used to inform the development of an intervention. In thinking about developing an intervention, strict standardisation of a treatment intervention may be inappropriate and potentially problematic.
It would be advantageous to utilise a fairly adaptable person-centred approach that takes the individuals' case history and personal goals into consideration. For example: a standardised intervention may not be suitable, as TTM has many different facets to consider. If an intervention focuses solely on preventing relapse, this may not be in line with a persons most valued goal. A more flexible intervention approach that meets the needs of an individual's TTM goals may be useful, this may be to focus on coping strategies, addressing comorbidity and focusing on a move toward management and recovery. It is also evident from the literature review chapter that online support can be useful in conjunction with in-person behavioural therapy. Similarly, the method chapter has established that contacting people from hard to reach populations using online methods works well. Therefore, the internet can be used as an 'open door' for support and a TTM intervention may include the option for additional support via online means in conjunction with in-person support.

In summary, key findings from this study can be used to inform policy and practitioner guidance, and the ideal treatment findings can be used as baseline information in the development of a TTM intervention. It is recommended that there is collaboration between healthcare professionals in treating and supporting people with TTM. Furthermore, professional education should include a module on TTM and other mental health disorders at undergraduate level or additional training in healthcare fields, specifically to understand TTM and be empathetic towards patients. People with mental health disorders should feel supported by their primary healthcare provider, participant responses in this study indicate that changes to policy and practice are certainly warranted. Extra focus should also be given to advocacy, including raising awareness of TTM by educating peers and the wider community. This has the potential to reduce stigma (and perceived stigma) which may empower people with TTM to avoid engaging in secrecy and non-disclosure behaviours, while also encouraging treatment seeking behaviours.

6.10 Recommendations for Future Research

A larger sample may allow for a claim to be made that the findings and knowledge could be attributable to a wider population. Bearing this in mind, the methodological approach and research design may have to change to support the management of a larger data set. Therefore, a suggestion for future research could be to use a mixed methods approach. Within a mixed methods study, key

ideas stemming from the quantitative section of the literature could be further explored in the qualitative section. Social media and the internet are both everchanging mediums that can be used for recruitment and data collection and future research could further explore the use of online methods by using other websites (e.g. instagram) which may provide a wider range of participants and data.

There were cultural differences relating to TTM and 'coping by concealment', as participants from non-western countries (Morocco and Abu-Dhabi) discussed how they used traditional dress to conceal hair loss. Additionally, the findings about 'self-identity and lost opportunities' and the cultural aspect of participants using traditional dress to hide the effects of TTM to avoid feeling unworthy is not noted in previous literature. Future research involving a more culturally diverse sample could explore these two aspects further. In terms of the 'persistent and extensive effects' related to TTM in the email interviews, four of the five supporting quotes used to represent the impact TTM has on relationships came from female participants. This would tentatively point to gender differences within the email interview sample and it may be beneficial for future research to explore if females perceive TTM to have a more significant impact on relationships compared to males.

As noted in the section 1.6 (page 22), early research on TTM has involved a lot of small scale and underpowered studies. This has improved in more recent research which has involved larger samples. However, our understanding of TTM and interventions for TTM still require further exploration. The biological basis for TTM still remains elusive, it would be advantageous for future research to explore biological or neurological models alongside participants' individual motivations and process of hair-pulling, as this may provide a more complete explanation for the development and maintenance of TTM which may impact the delivery of a treatment intervention. This study has clearly outlined what participants envisage their ideal TTM treatment intervention would consist of, this may be used in the future when outlining a treatment strategy, which can be explored within a case study series involving the treatment applied to real life cases.

The next step forward would be to develop and pilot an innovative and accessible intervention, co-produced with people with TTM. The findings from this study detailing TTM participants' ideal treatment intervention can be used to inform this next phase. It would be appropriate to test the acceptability, feasibility and fidelity of an intervention in a pilot study. The use of technology to facilitate delivery of the intervention may help to reach a wider population in a field where clinical expertise is sparse.

6.11 Contribution to Knowledge

The original rationale (see section 2.3, page 45) of this project was to explore experiences, perceptions and opinions of TTM using a qualitative approach. The reasoning behind this was because the majority of TTM research appears to use quantitative approaches to focus primarily on pharmacological and behavioural treatments and issues associated with TTM (Franklin et al 2011, and Slikboer et al 2015). This project has addressed this gap by providing an in depth contextual

qualitative account. Furthermore, there has been limited research exploring the effects of TTM; Woods et al (2006) conducted a survey of 1697 participants, results indicated mild to moderate life impairment (including social, occupational, academic and psychological areas). Qualitative research which fully explores these impairments from the perspective of the TTM patient is lacking. TTM is generally considered to be a misunderstood disorder requiring further research. Therefore, this project has also addressed this gap by providing an in-depth qualitative account of the impact of TTM across various areas of life, including personal life, impact on friendships and relationships, impact on social, occupational and educational areas, as well as impact on psychological areas.

Duke et al (2009) has stated that using large, geographically diverse samples would be a factor in advancing the understanding of hair-pulling behaviours. Adding to this, Walther et al (2010) stated that there is little research on the cross-cultural impact of TTM. Franklin et al (2011) reported that much previous research surrounding TTM has been conducted through open and uncontrolled trials. There is a large amount of quantitative research on TTM, which focuses on biomedical and behavioural topics, while this does indeed provide vital information on TTM, it fails to provide an in-depth and well-rounded insight into the topic. Most of the qualitative studies found are unpublished or still being conducted and focus on one group of participants (i.e. solely an Australian sample). Thus, a broad cross-cultural qualitative study is absent in this area. Therefore, this project has contributed to the area through recruitment of an international and geographically diverse sample as TTM occurs across the world and incorporating an international approach has aimed to generate new and relevant insights.

To the researcher's knowledge, previous studies have not asked participants to clearly describe their ideal TTM treatment / intervention strategy. Although most literature reiterates how TTM remains a poorly understood disorder where treatment is varied with no clear treatment protocol, participants who live with TTM have not been asked what their ideal TTM treatment would consist of. Participants were very clear in describing the lack of availability and quality of support from healthcare professionals, detailing their largely unmet healthcare needs. A key finding is that many participants have not been offered or received any TTM treatment whatsoever by their primary healthcare provider, this can be used to inform potential syllabus changes for key health fields at undergraduate level. Another key finding is that participants very clearly outlined their ideal treatment intervention, with details about the content, duration, and frequency of the support they want to receive. Some participants highlighted the importance of therapeutic alliance and connection with their healthcare provider, indicating that they want to be empathised and understood by the person delivering their treatment. This further emphasises the need for additional TTM training among healthcare providers and can be used to inform practitioner guidance. This project has contributed to the area by asking people with TTM to clearly outline their ideal treatment, this information can be used to inform a potential TTM intervention / inform future support for service users which may subsequently have a positive impact on treating people with TTM in the future.

This project has attempted to inform the overall understanding of TTM by exploring the experiences, perceptions and opinions of people who have TTM, alongside the social implications and health and wellbeing issues they have experienced. The researcher had identified no TTM research utilising the asynchronous email interview method or blog post data using qualitative methods in the area. Therefore, these two data collection methods coupled with recruitment of an international and geographically diverse sample is the first research its kind.

The findings have highlighted that there appears to be a number of intertwined core facets that influence the wide-ranging consequences of TTM. It is overwhelmingly clear that participants experience wide ranging and persistent impairment in both their personal and professional lives. These impairments seem to exist on a continuum, whereby the more severe the TTM, often participants report more significant impairment and consequences associated with TTM.

Chapter Seven: Conclusion

The people who participated in this research allowed insightful glimpses into their journey with TTM and shared their experiences, opinions and perceptions of TTM. This project has provided an illuminating perspective into many different facets of TTM and provided a deep insight into the complex nature of TTM. The contextual and detailed perspectives of people's experiences of TTM has provided clear evidence that it is vital the voices of people with TTM need to be heard and understood on a global scale.

Qualitative research is known to be a contextual method with a wide range of benefits, the key benefit being to provide a data set rich in detail and personal experience (Willig, 2008). The use of qualitative methods in this study provided a unique and multi-faceted understanding on the experiences, opinions and perceptions of TTM. This project has solidified that TTM remains a misunderstood disorder with poor prognosis and that TTM is associated with significant impairments across all areas of life. Although the asynchronous email interview method was fairly time consuming, it provided contextual data from an international and geographically diverse sample while eliminating transcription times and the financial burden of travelling to conduct in-person interviews. Similarly, as Acaster and Wild (2009) have suggested, blogs have been used as an abundant source of qualitative data. The broad themes derived from both data sources (email interviews and blog posts) were fairly comparable, with blogs highlighting a small number of new themes. The interactive and long-term nature of the asynchronous email interviews produced richer and more reliable data than that contained within the blog posts. However, as data had originated from two separate populations, analysis occurred separately and resulted in some different findings among phase one and phase two. Two themes (acceptance and societal view of beauty) from the blog posts were not noted in the email interviews.

Duke et al (2010) has stated that people with TTM are often secretive about having the disorder and engage in concealment and non-disclosure behaviours, implying that it may be a difficult disorder to research. Duke et al further suggested that due to the secrecy associated with TTM, multi-site or internet-based studies are key in the area; this project has involved an internet-based study involving significant aspects of computer mediated communication. Based on the email interview findings, it was overwhelmingly clear that participants experience primarily negative thoughts and emotions about their TTM: shame and distress often lead to a wide range of behaviours and consequences such as secrecy, non-disclosure, embarrassment and avoidances. Participants viewed TTM in a largely negative manner, expressing hate and demonizing characteristics toward the disorder, with the negative emotions potentially leading to further physical and/or psychological consequences (e.g. anxiety / depression). Many participants reported a fear of being judged by others, alongside impact on academic and work life and an impact on relationships, self-identity and lost opportunities. Participants also spoke extensively about using concealment as a form of coping, alongside engaging in permission giving behaviours in an attempt to control the amount of hair-pulling. Blog post data revealed two themes which were not noted within the interviews; the 'societal view of beauty' involving

how images are portrayed in the media and how hair loss is perceived within wider society and 'acceptance' of TTM.

Treatment seeking behaviours appear to be low within the TTM population, with limited numbers of people who access treatment reporting any improvement in symptoms (Woods et al, 2006). Participants in the current study described a small number of treatments with very limited success, and a large number of unsuccessful treatments. Email interview participants were clear when describing a lack of adequate TTM training among healthcare professionals and a lack of sensitivity, with some participants detailing a lapse in duty of care where no treatment whatsoever was offered which may make a person feel alone in their diagnosis. The current findings emphasise the need for an increased understanding about TTM. Participants clearly described experiencing frequent distress and associated impairments in all aspects of life, while describing a lack of support and unmet needs from healthcare providers. The findings from this study have revealed a significant mismatch between the distress experienced by participants, and the lack of recognition by healthcare professionals.

Interestingly, participants commented on the importance of therapeutic alliance and connection, implying that they want to be understood by the person delivering treatment. It is evident that changes need to be made within the healthcare field in both healthcare professional training and levels of support being provided to service users. The current findings can be used to inform policy and practitioner guidance, and it is suggested that additional training is required among healthcare providers to widen their understanding of TTM and increase sensitivity in dealing with TTM. This could also be implemented as a module at undergraduate level in the relevant fields. Furthermore, due to the typical age of onset, there should be a compulsory component in education staff training whereby teaching staff are made aware of TTM and other largely non-visible mental health disorders.

Participants provided a clear outline of their ideal treatment intervention; a dual-phase targeted treatment intervention consisting of both behavioural and pharmacological treatment, where participants receive pharmacological support once per month and psychological support twice per month for one year. Face-to-face treatment is preferred, but other methods would also be beneficial (i.e. telephone calls or skype). Following this, treatment tapers off with a follow-up visit every 6 months for 3 – 5 years. Participants suggested they would like this treatment plan to be delivered by a psychiatrist or psychologist, or another healthcare professional who has training in TTM. Given the lack of clinical guidance that is evident globally, these key findings can be used as a step towards development of a treatment intervention.

There are still key issues about TTM that remain unknown, meaning that there are many different pathways that may be taken for future research. The aetiology of TTM still remains unclear, but it is likely that it manifests through multiple pathways (Duke et al, 2010). Chamberlain et al (2007) has stated that the lack of clarity on the aetiology and brain basis of TTM hinders improvements in diagnostic classification and treatment. Therefore, Chamberlain et al has suggested that additional

research from the neuroscientific perspective could be beneficial to explore neurochemistry, structural and functional neuroimaging and genetics.

The findings within the email interview and blog post data illustrate that TTM can be a difficult long-term disorder. The severe and far-reaching impairments in all areas of life (i.e. personal life, relationships, career paths, academic life) coupled with the coexisting health implications (i.e. physical / psychological impairment) further signifies that TTM can be a severe and life impacting disorder for which there is no cure or effective treatment protocol. The evidently clear wide-ranging impairments and consequences associated with TTM imply high societal costs that justify the importance for researchers and clinicians to acknowledge and understand TTM.

It has been said that “people suffering from mental illness and other mental health problems are among the most stigmatized, discriminated against, marginalised, disadvantaged and vulnerable members of society” (Johnstone, 2001, p. 201). The overarching findings have indicated intermittent and severe, often lifelong impairment, frequent experiences of comorbid disorders, with the effects of TTM often feeling debilitating. It is of utmost importance that people with TTM (and other less visible mental health disorders) need to be supported, accepted and understood by their healthcare providers and society as a whole. Creating awareness through educational means may lessen stigma and encourage more acceptance and self-disclosure, which may lessen the burden that people with TTM often experience.

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Appendices

Appendix One - Successful Ethical Approval Application

THE UNIVERSITY OF HUDDERSFIELD
School of Human and Health Sciences – School Research Ethics Panel

OUTLINE OF PROPOSAL

Please complete and return via email to:

Kirsty Thomson SREP Administrator

Name of applicant: Miss Chané Roodt

Title of study: A qualitative study investigating the health, wellbeing and social implications of individuals with Trichotillomania (provisional title).

Department: School of Human and Health Sciences **Date sent**: December 2015

Issue	Please provide sufficient detail for SREP to assess strategies used to address ethical issues in the research proposal
Researcher(s) details	Chané Roodt
Supervisor details	Prof. Philip Keeley
Aim / objectives	The purpose of the proposed research would be to examine the experiences, attitudes and perceptions of people living with Trichotillomania (TTM) Primary Aims and Objectives: - Investigating the overall struggles of people who have Trichotillomania. - Investigating the social implications of people who have Trichotillomania (such as; identity, exclusion, peer rejection, stigma). - Investigating the health and wellbeing implications of people who have Trichotillomania (such as; depression, anxiety). - If any previous treatment has been successful at reducing hair-pulling, and the effects of any/all treatments they have tried. - To fully explore any impairments from the perspective of the individual with TTM. - Explore the acceptability and feasibility of the study. Secondary Aims and Objectives: - Identify participant preferences, to possibly inform and develop interventions. It is an aim to evaluate the processes of recruiting participants and conducting research in this way; participants will be asked several supplementary questions and to give their thoughts and opinions about the email interview approach, and their experiences of participating in the research. - To consider implications for future development and delivery of support / services to service users.
Brief overview of research methodology	Qualitative. See attached pages 4 - 6. Phenomenology. Asynchronous email interviews, and Blog posts. International sample. Thematic Analysis.
Study Start & End Date	Start Date: 01 April 2015 End Date: 31 March 2021
Permissions for study	Appropriate permissions will be received through SREP.
Access to participants	Access to participants will be primarily through online methods (e.g. Emails).

	Part 1: Asynchronous email interviews Interviewing people with TTM in person, or arranging a TTM focus group would not be an appropriate method of data collection, as most people with TTM are secretive and have feelings of shame / embarrassment at having Trichotillomania. Therefore, an email interview method is proposed. Access to the sample population would be through the use of online methods. I am already a member of several TTM support groups, which I will contact with the intention of sending a generic email to all members on the mailing list. I will also be contacting international TTM support groups, with the hopes of gathering an international sample. I will also be placing posts on several TTM Facebook pages, in an attempt to notify people with TTM about the study. If the privacy settings of these TTM Facebook pages are set to 'private', I will send a private inbox message to the page administrator requesting their help in publishing a post on their page about the study. Part 2: Blog posts The second phase of this study will be to qualitatively analyse blog posts. It is hoped that the contents of these blog posts will correlate with the overall themes of the interview data, and aim to provide a very deep insight into the struggles of living with TTM. Some of the blog *examples* are listed See attached page 4 Further discussion on page 6.
Confidentiality	For the asynchronous email interviews, participants will be informed of their rights in a detailed Information Sheet and Consent Form. Data will be stored on a Password Protected Computer, and locked in a safe place when not in use. Emails will take place on a secure server only (https present in the web bar) and may also be encrypted. Participant data will only be discussed between researcher and supervisors, and all participants will be allocated a code / pseudonym at the earliest available opportunity.
Anonymity	Participants taking part in the email interview will be fully anonymous. An information sheet and consent form will confirm this. See attached forms, See attached pages 9 - 11. Blog post data will also be anonymised (example: if a blogger makes reference to a specific peer / frequently visited shopping centre – this will be anonymised).
Data Storage	Participants will be made aware that their anonymised data may be kept in secure conditions at the University of Huddersfield, and destroyed at the earliest convenience.
Psychological support for participants	Support will be made available for all email interview participants, and details of available support will be clearly stated on the Debrief Form (See attached page 12).
Researcher safety / support (attach complete University Risk Analysis and Management form)	See attached Risk Assessment – See attached page 8
Identify any potential conflicts of interest	There are no potential conflicts of interest. The researcher has not been funded by an external agency and the potential participants will not include people the researcher works with.
Please supply copies of all relevant supporting documentation electronically. If this is not available electronically, please provide explanation and supply hard copy	
Information sheet	See attached pages 9 – 10
Consent form	See attached page 11
Letters	Reference to a draft email / introductory message, which may be sent to potential participants during initial contact (See attached page 13)
Questionnaire	

Interview guide	See attached (pages 14 - 15) Online asynchronous email interviews will take place electronically, between 6 - 10 email exchanges at the convenience of the participants (depending on if any supplementary questions are asked). It is anticipated that 8 email exchanges will involve the information sheet, consent, interview schedule and debrief, with a further 1 - 2 email exchanges where participants will be asked supplementary questions relating to their thoughts on participating in the research and their opinions on this particular approach (email interviews). Participants can answer the questions in their own time, but it is requested that the participants take no longer than 2 weeks to answer each set of questions. Email responses from participants confirms their ongoing consent, as detailed in the consent form.
Dissemination of results	The proposed research is part of a programme of study (PhD) and will be presented in a Thesis for evaluation. The research may also be prepared for publication in an academic journal or presentation – both methodological papers and dissemination of findings. Conference presentations – academic / professional journals.
Other issues	n/a
Where application is to be made to NHS Research Ethics	n/a
All documentation has been read by supervisor (where applicable)	This proposal will not be considered unless the supervisor has submitted a report confirming that (s)he has read all documents and supports their submission to SREP Confirmed. Supervisor Form attached.

All documentation must be submitted to the SREP administrator. All proposals will be reviewed by two members of SREP.
If you have any queries relating to the completion of this form or any other queries relating to SREP's consideration of this proposal, please contact the SREP administrator in the first instance.

Appendix Two – Resubmitted Ethical Approval Application with Photo Consent

THE UNIVERSITY OF HUDDERSFIELD
School of Human and Health Sciences – School Research Ethics Panel

PROPOSED REVISIONS TO PREVIOUSLY APPROVED APPLICATION

(Attach separate sheets as necessary)

Applicant Name: Miss Chané Roodt

Title of previously approved study: A qualitative study investigating the health, wellbeing and social implications of individuals with Trichotillomania (provisional title).

Ref: SREP/2015_118_Rev1_200616

Date approved: 15 February 2016

Issue	**Please clearly identify below revisions made to previously approved SREP application.**
Researcher(s) details	Chané Roodt
Supervisor details	Prof. Philip Keeley
Aim / objectives	*(Same as previous application)* The purpose of the proposed research would be to examine the experiences, attitudes and perceptions of people living with Trichotillomania (TTM) Primary Aims and Objectives: - Investigating the overall struggles of people who have Trichotillomania. - Investigating the social implications of people who have Trichotillomania (such as; identity, exclusion, peer rejection, stigma). - Investigating the health and wellbeing implications of people who have Trichotillomania (such as; depression, anxiety). - If any previous treatment has been successful at reducing hair-pulling, and the effects of any/all treatments they have tried. - To fully explore any impairments from the perspective of the individual with TTM. - Explore the acceptability and feasibility of the study. Secondary Aims and Objectives: - Identify participant preferences, to possibly inform and develop interventions. It is an aim to evaluate the processes of recruiting participants and conducting research in this way; participants will be asked several supplementary questions and to give their thoughts and opinions about the email interview approach, and their experiences of participating in the research. - To consider implications for future development and delivery of support / services to service users.
Methodology	*(Same as previous application)* Qualitative. Asynchronous email interviews, and Blog posts. International sample. Thematic Analysis.

Permissions for study	*(Same as previous application)* Appropriate permissions received through SREP on 15 February 2016. **This Revised Application is just to include 1 x extra Consent Form, for the use of photographs.** **This was not originally a priority – however, several participants have willingly emailed their photo's to use in the study.** **The original SREP application and original Consent Form did not specifically have permission to use participant photo's. Therefore, the inclusion of a supplementary Consent Form with specific reference to photo's has been included.**
Access to participants	*(Same as previous application)* Access to participants will be primarily through online methods (e.g. Emails). Part 1: Asynchronous email interviews Interviewing people with TTM in person, or arranging a TTM focus group would not be an appropriate method of data collection, as most people with TTM are secretive and have feelings of shame / embarrassment at having Trichotillomania. Therefore, an email interview method is proposed. Access to the sample population would be through the use of online methods. I am already a member of several TTM support groups, which I will contact with the intention of sending a generic email to all members on the mailing list. I will also be contacting international TTM support groups, with the hopes of gathering an international sample. I will also be placing posts on several TTM Facebook pages, in an attempt to notify people with TTM about the study. If the privacy settings of these TTM Facebook pages are set to 'private', I will send a private inbox message to the page administrator requesting their help in publishing a post on their page about the study. Part 2: Blog posts The second phase of this study will be to qualitatively analyse blog posts. It is hoped that the contents of these blog posts will correlate with the overall themes of the interview data, and aim to provide a very deep insight into the struggles of living with TTM.
Confidentiality	*(Same as previous application)* For the asynchronous email interviews, participants will be informed of their rights in a detailed Information Sheet and Consent Form. Data will be stored on a Password Protected Computer, and locked in a safe place when not in use. Emails will take place on a secure server only (https present in the web bar) and may also be encrypted. Participant data will only be discussed between researcher and supervisors, and all participants will be allocated a code / pseudonym at the earliest available opportunity
Anonymity	*(Same as previous application)* Participants taking part in the email interview will be fully anonymous. An information sheet and consent form will confirm this. Blog post data will also be anonymised (example: if a blogger makes reference **Additionally, if participants would like their photo's to be used in the study, photo's will be edited (e.g. cropped / blurred) to remove any identifying features.**

Psychological support for participants	*(Same as previous application)* Support will be made available for all email interview participants, and details of available support will be clearly stated on the Debrief Form
Researcher safety / support (attach complete University Risk Analysis and Management form)	*(Same as previous application)*
Information sheet	*(Same as previous application)*
Consent form	*(Original Consent Form is the same as previous application).* **Consent From II (see attached) will be introduced to participants, and refers to the use of photographic evidence in providing a visual representation of Trichotillomania.** All of the current participants have already completed and returned the original Consent Form (approved by SREP in February 2016) Therefore, it would be necessary to introduce a separate Consent Form, specifically for the use of photographs. Photos will likely be used in an appendix of the thesis, and possibly other academic documents.
Letters	*(Same as previous application)*
Questionnaire	
Interview schedule	*(Same as previous application)*
Dissemination of results	*(Same as previous application)*
Other issues	
Where application is to be made to NHS Research Ethics Committee	n/a
All documentation has been read by supervisor (where applicable)	Yes.

Signed: Miss. C. Roodt
(SREP Applicant – electronic signature acceptable)

Date: 20 June 2016

Appendix Three – Participant Information Sheet and Consent Form

A qualitative study investigating the health, wellbeing, and social implications of individuals with Trichotillomania.

PARTICIPANT - INFORMATION SHEET

You are being invited to take part in this research study. Before you decide to take part it is important that you understand why the research is being done and what it will involve.
Please take time to read this information sheet carefully.

If you have any questions / concerns / or need more information, please don't hesitate to contact me directly using the contact details at the bottom of this sheet.

What is the study about?

The overall research aim is to investigate people's experiences of living with Trichotillomania.
This will be investigated through various avenues such as; health, wellbeing and social implications.

I am interested in your experiences, perceptions and opinions on having Trichotillomania and living with this disorder, so please give as much detail as possible when answering questions.
You will also be asked a few questions about your opinions / thoughts about participating in this research.
You may be contacted for future Trichotillomania studies, but you don't have to participate in any future studies if you don't want to.

Why I have been approached?

You have been asked to participate because you have on-going struggles with Trichotillomania, and your experiences could provide invaluable input in the current study.

Do I have to take part?

Your participation is voluntary – you don't have to take part, but your participation will be appreciated.
If you want to participate, please sign the Consent Form.

You can withdraw at any time (by emailing Chane.Roodt@hud.ac.uk), your initial data will be kept and used in the study. If you withdraw from the study, your data can be destroyed, at your request.

What will I need to do?

If you agree to take part, you will be asked to complete an email interview, by answering a series of questions.
In some cases, you may be contacted again if further detail is needed on your original responses. As mentioned, please try and give as much detail as possible when responding to the email interview questions.

Up to 6 – 10 email exchanges may be necessary to gain enough data.
You can answer these emails in your own time, but it is requested that you take no longer than 2 weeks to answer each set of questions. It is understood that your email responses confirm your ongoing consent.

Will my identity be disclosed?

Your data will be kept securely and confidentiality will be maintained.
Your name, email address, and country will only be known to 3 people (the researcher, and 2 supervisors) for a *very* short time.
Your data will then be anonymised, and you will be given a code/pseudonym to protect your identity.
Your identity will not be disclosed to anyone else at any time.

What will happen to the information?

All information collected from you during this research will be kept secure and any identifying material (e.g. names / location names) will be removed at the earliest available opportunity in order to ensure identity protection and anonymity. Your electronic data will be stored in a secure password protected server, and be destroyed at the earliest available opportunity.

It is anticipated that the research may, at some point, be published in a journal or report. However, should this happen, your privacy and anonymity will be ensured.
It may be necessary to use your words in the presentation of the findings and your permission for this is included in the consent form, and your identity will be protected at all times.

Summary of Important Information:

- Participation is voluntary
- All participants will need to sign a consent form
- You are free to withdraw at any time, by emailing me: Chane.Roodt@hud.ac.uk
  Data cannot be withdrawn after 01 February 2017.

- All data will be kept on a secure, password protected server.
- All data will be stored separately from other personally identifying data.
- Data will be anonymised at the *earliest* possible point, participants will be assigned a unique code / pseudonym. Participants should quote this code / pseudonym if they wish to withdraw their data.

- Personal Details (name, country, email address) will remain private at all times.
- You do not need to answer any questions which you are uncomfortable with.
- Data will be destroyed at the earliest possible opportunity.

Who can I contact for further information?

If you require any further information about the research, please contact me (at your convenience) on:

Researcher: Chané Roodt	Email: Chane.Roodt@hud.ac.uk
Main Supervisor: Prof. Keeley	Email: P.N.Keeley@hud.ac.uk

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PARTICIPANT - CONSENT FORM

A qualitative study investigating the health, wellbeing, and social implications of individuals with Trichotillomania.

It is important that you read, understand and sign the consent form. Your contribution to this research is entirely voluntary and you are not obliged in any way to participate, if you require any further details please contact the researcher. **Please place an ''X'' in / next to the boxes, to indicate agreement.**

I confirm that I am over the age of 18 ☐

I have been fully informed of the nature and aims of this research, and consent to taking part in it ☐

I understand that I have the right to withdraw from the research at any time, without giving any reason. ☐

I give permission for my words to be quoted (by use of a code / pseudonym) ☐

I understand that the information collected will be encoded, and kept in secure conditions at the University of Huddersfield, and destroyed at the earliest convenience ☐

I confirm that I have on-going struggles with TTM (or a diagnosis of TTM from a professional) ☐

I have / or have previously had reoccurring pulling of my hair, resulting in hair loss ☐

I have / or have previously had repeated attempts to decrease / stop my hair pulling ☐

When I pull my hair, it causes me distress ☐

My hair pulling is not due to another medical condition ☐

I disclose that I do not consider myself to be a vulnerable adult ☐

I understand and accept all the Information detailed in the ''Information Sheet'' ☐

Would you be happy to be contacted again - for future Trichotillomania studies? ☐

If you are satisfied that you understand the information and are happy to take part in this project please put a tick in the boxes above (or type an 'x' next to the box), then sign / type your name and date below.

Researcher Print / Type C. ROODT Date: 12 July 2016	Participant Print / Type Date:

(one copy to be retained by Participant / one copy to be retained by Researcher)

Appendix Four – Photo Consent Form

PARTICIPANT - CONSENT FORM II

A qualitative study investigating the health, wellbeing, and social implications of individuals with Trichotillomania.

Consent form II refers to the use of photographic evidence, in providing a visual representation of Trichotillomania.

Photos may be used to highlight the severity of Trichotillomania, and will be used to compliment the current email interview data.

Your contribution to this research in the form of providing a photo's of your Trichotillomania is entirely voluntary and you are not obliged to email photo's if you do not wish to.

If you require any further details, please contact the researcher.

Please read the following points carefully, and place an ''x'' in / next to the boxes to indicate agreement.

I confirm that I have willingly sent photos of my Trichotillomania for use in the current study ☐

I understand that photos will be anonymised and my identity will remain confidential ☐

After photos are anonymised (blurred / cropped) the original photo will be destroyed ☐

Any personally identifying features (e.g. tattoos) will be edited / cropped / blurred out ☐

I understand and give permission for my photo(s) to be used in the project, most likely in an Appendix ☐

If you are sending a photo of your Trichotillomania, please aim to provide a photo which does not show any identifying features (e.g. full face / jewellery / tattoos, etc).

If you are satisfied that you understand the information and give permission for your photo(s) to be used to visually illustrate Trichotillomania in the current study, please type your name and the date below.

Researcher Print / Type C. ROODT Date: 1 August 2016	Participant Print / Type Date:

(one copy to be retained by Participant / one copy to be retained by Researcher)

Appendix Five – Participant Debrief Sheet

PARTICIPANT – DEBRIEF SHEET

A qualitative study investigating the health, wellbeing, and social implications of individuals with Trichotillomania.

Thank you for taking part in this research study, your valued participation has been appreciated. If you decide that you would like to withdraw your data from the study, please email me on Chane.Roodt@hud.ac.uk. **The deadline to withdraw data is: 01 February 2017.**

Below is a list of helpful numbers / web links, should you feel you would like to discuss any feelings which may have arisen from completing the interview.

UK participants	**Helpline Number**: Samaritans – 0845 7909090 **SANE's Mental Health Support**: 0300 304 7000 (6pm - 11pm) **Referral**: to your designated Health Care Professional
USA participants	**Helpline Number:** Crisis Support Services - (800) 309-2131 **Online Support**: www.childhelp.org/pages/help-for-professionals1 **Referral:** to your designated Health Care Professional
Canadian participants	**Helpline Number:** Telehealth Ontario at 1-866-797-0000 **Online Support** http://livechat.connexontario.ca/ECCChat/MHHchat.html
South African participants	**Helpline Number:** National Counselling Line 0861-322-322 **Online Support**: www.lifeline.org.za **Referral:** to your designated Health Care Professional
Australian participants	**Helpline Number**: Lifeline Crisis Support – 13 11 14 **Online Support:** https://www.lifeline.org.au/Get-Help/Online-Services/crisis-chat
New Zealand participants	**Helpline Number:** Mental Health Foundation 09 623 4812 **Online Support:** https://www.mentalhealth.org.nz/get-help
EU participants	**Helpline Numbers**: http://suicideprevention.wikia.com/wiki/Europe **Online Support:** https://www.143.ch/Beratung/Chat-Kontakt **Referral:** to your designated Health Care Professional
India participants	**Helpline Number**: Lifeline Foundation - +91 33 2474 4704 **Online Support:** 1Life Crisis Support : http://1life.org.in/contact-us
China participants	**Helpline Number:** 800-810-1117 or 010-82951332 **Online Support:** http://www.crisis.org.cn/
Jamaica participants	**Online Support:** www.yourlifeyourvoice.org/Pages/ways-to-get-help.aspx **Referral:** to your designated Health Care Professional
Brazil participants	**Helpline Number:** 55 11 31514109 **Online Support:** http://www.cvv.org.br/chat.php
UAE participants	**Online Support:** 1Life Crisis Support : http://1life.org.in/contact-us **Referral:** to your designated Health Care Professional

Morocco participants	**Helpline Number:** Befrienders +212 (5) 22 87 47 40 **Online Support:** www.sourire2reda.org
Mauritius participants	**Helpline Number:** Befrienders 46 48 889 or 800 93 93 **Referral:** to your designated Health Care Professional

If you have any questions, please feel free to contact me.

Please retain the Debrief Sheet, and keep for your records.

Thank you for your time in completing the online interview, your participation is appreciated.

Appendix Six – Email Interview Schedule

The first set of questions will focus on some basic demographic information (and will be used to help to frame later questions).

What is your gender?

What is your age?

Approximately what age did your Trichotillomania start, and how many years have you been "pulling" for?

What is your marital / relationship status?

What is your ethnicity?

Where do you currently live / and have you lived in this city your whole life?

Can you tell me about your education history? (example: high school / college / etc).

Can you tell me about your working history? (example: are you currently employed / in between jobs / what types of jobs have you done throughout your life, etc).

This set of questions will focus on general Trichotillomania themes. Please answer the questions based on your own experiences.

Please describe your full process of hair pulling (e.g. when do you pull / what do you pull / how do you pull / etc).

How do you feel before, and after you pull your hair?

Please describe the feelings / urges that make you pull out your hair.

Describe the process of your diagnosis – and your dealings with doctors about Trichotillomania

Please describe the environments where your hair pulling takes place.

Why do you think your hair-pulling started? Please discuss (e.g. a traumatic event, etc).

Are you left or right handed, and which hand do you mainly use to pull your hair?

Have you ever given yourself 'permission' to pull out your hair?

This set of questions will focus on general and social themes. Please answer the questions based on your own experiences.

Do you feel in control of your hair pulling? Please discuss

Describe how you feel about having Trichotillomania.

Do you have any other habits (e.g. skin picking, / lip biting / nail biting / other habits)?

Please can you describe the situations you avoid, because of your TTM (e.g. wind / water).

How do you think your family and friends see you, as a TTM sufferer?

How much time, effort and money have you spent trying to fix / hide your hair pulling?

How do you feel about visiting the hair dresser?

Have you ever felt excluded / rejected by your peers, because of your hair pulling? Please describe

This set of questions will focus on social themes. Please answer the questions based on your own experiences.

When you tell people you have Trichotillomania, what do you think they think about you?

Has TTM ever affected your school / academic life? Please discuss

Has TTM ever affected your work life? Please discuss

Has TTM ever affected the quality and quantity of your romantic relationships? Please discuss

Has TTM ever affected your friendships? Please discuss

Please describe your self-esteem and self-confidence, in relation to your TTM.

Describe your frustrations about your hair-pulling.

How would you say you cope with having TTM?

This set of questions will focus on health and wellbeing themes. Please answer the questions based on your own experiences

Please describe how you think Trichotillomania has impacted your life in general.

Do you think healthcare professionals are adequately trained to dealing with Trichotillomania? Please discuss

Please can you list all the treatments (e.g. behavioural, medical, herbal) you have tried, and describe if any have been successful / unsuccessful?

Does Trichotillomania have any impact on your health and wellbeing, in terms of stress and anxiety?

Do you have a history of depression, and do you think this is linked to your TTM? Please discuss

Do you have a history of anxiety, and do you think this is linked to your TTM? Please discuss

Does TTM cause you any distress? Please discuss

What are the negative emotions you feel, which are linked to your hair-pulling?

This set of questions will focus on health and wellbeing themes. Please answer the questions based on your own experiences

Have you ever had a history of substance abuse? Please discuss

Do you think you are impulsive? Impulsive behaviour can be shopping for needless things, gambling, and taking unnecessary risks. Please discuss

How do you view your relationship with Trichotillomania? Please discuss

What treatment options do you think could work, and what would you like to see offered by your GP / Health Provider?

How did you find participating in this email interview?

Are there any other questions you think I should ask you, about your TTM?

Regarding this Email Interview; is there anything you think could have been improved / done differently?

Is there anything else you would like to share about your experiences with Trichotillomania?

The last set of questions will focus on general themes. Please answer the questions based on your own experiences

In thinking of new ways of supporting people with TTM, how would you envisage your ideal treatment / support system?

In terms of a possible treatment option - who would you like to see deliver a Trichotillomania treatment plan?

In terms of a possible treatment - would you prefer face-to-face support, online support, or other support? Please discuss.

In terms of a possible treatment - how often would you like to be supported?

In terms of a possible treatment - what duration of time would you like to be supported for? (e.g. 8 weeks / 12 months, etc).

In your opinion, what were the strengths and weaknesses of this email interview?

If you had the opportunity of telling a person who knew nothing about Trichotillomania, what it's like to live with Trichotillomania - what would you tell them?

This research will aim to give a 'voice' to people who struggle with Trichotillomania - if you have any thoughts / opinions / ideas you would like to share, please do so here:

Supplementary questions (used to gain more information, or used as a substitute for other questions depending on participant responses)

Do you ever feel ‘abnormal’? Please discuss

As you know, Trichotillomania is a mental health disorder - do you think you are mentally well or does having Trichotillomania mean you are mentally unwell?

Have you ever felt ashamed or embarrassed about your appearance due to trichotillomania?

How do you think your TTM is linked to your ability to be social?

Do you have difficulty focussing on day-to-day tasks, because of your hair-pulling?

What are your ‘triggers’ / what makes you pull your hair more?

Have you ever felt ashamed or embarrassed about your appearance due to trichotillomania?

Appendix Seven – Example of Coded Data Set (Email Interview)

TTM for 39 years Although degree educated – does menial jobs Don't value myself. On disability – feel worse about myself	**The first set of questions will focus on some basic demographic information (and will be used to help to frame later questions).** **What is your gender?** F **What is your age?** 49 **Approximately what age did your Trichotillomania start, and how many years have you been "pulling" for?** Age 10; 39 years. **What is your marital / relationship status?** Single **What is your ethnicity?** White **Where do you currently live / and have you lived in this city your whole life?** Middleboro, Ma., USA. Lived here off and on. **Can you tell me about your education history? (example: high school / college / etc).** 4 yr. college, degree in Illustration **Can you tell me about your working history? (example: are you currently employed / in between jobs / what types of jobs have you done throughout your life, etc).** Sporadic work history, because of trich cycles and subsequent social anxiety. Have done a lot of menial jobs (cleaning kennels, houses, etc.) where I'm alone or not close to people as I do my job. I prefer jobs with little stress, where I'm in the background. I also do my artwork, but make very little money at it because I'm afraid to market myself and attend functions (where people will notice my trich and possibly think less of me). Because of the trich, I don't value myself & utilize my skills and education to support myself, therefore I am on disability, which makes me feel even worse about myself.	Stays in the background / chooses to be alone – issue around self-esteem? On disability – often stigmatized, and exacerbates the negative perception she has of herself.
	This set of questions will focus on general Trichotillomania themes. Please answer the questions based on your own experiences.	

Eyelashes. Eyebrows. Scalp. Pubic. Textural pulling. 'fascinated'	**Please describe your full process of hair pulling (e.g. when do you pull / what do you pull / how do you pull / etc).** I pull eyelashes and eyebrows (which barely grow back any more, but there may be a stray one), also scalp hair, and pubic hair when I'm in the shower. Since it's mainly scalp hair, I'll run my fingers through it until I feel a rough hair, a curly or wiry one. I keep lightly pulling it, wanting it to come out on its own, but if it doesn't, then I pull it out. I always look at it first, feeling the texture and examining it. If there's a bulb, I touch it, and on rare occasion have touched it to my lips. I'm fascinated with the really kinky ones. Then I pile them up in a spot, and throw them away afterwards.	'Rituals' – examine the hair, feel texture, touch bulb. Occasionally place the hair on lips. Pile them up. Throw away.
Before: Angry, Anxious. During: Good After: Angry, Depressed	**How do you feel before, and after you pull your hair?** Angry and anxious before, good while I'm doing it, then angry and depressed afterwards.	'Cycle' of pulling. Talk about the antecedents, motivations, and consequences.
Angry. Taken advantage of Conflict Anxious Overwhelmed Relaxed-TV, Book	**Please describe the feelings / urges that make you pull out your hair**. I mostly pull when I'm angry, like when I feel like I'm being forced to do things I don't want to do, or act ways that I don't want to act. I pull when I feel being taken advantage of, or if a conflict has arisen and I don't feel that I can resolve it without a confrontation. I pull when I'm anxious or overwhelmed. I also pull when I'm settled down with the TV or a book, to relax.	Diverse environments (Anxious / Relaxed).
Hid it. Became unglued. Panic attacks, self-harm.	**Describe the process of your diagnosis – and your dealings with doctors about Trichotillomania** I wasn't diagnosed until age 21. I'd gone from pulling eyelashes to brows, and then to scalp hair. I hid it very well, but I was starting to come unglued and have panic attacks, cut myself, and not eat. A friend convinced me to see the college counselor, which I did. I saw him for 2 months, but I cried all session long and never did speak a word to him. He ended up leaving, so I saw 2 more doctors, also not speaking to them. I literally couldn't. Finally I saw another doctor, and she tried hard to get me to talk. I felt like she cared, so I ended up writing "I pull my hair out" on a piece of paper and gave it to her. Immediately she told me it was trich. I had	Secrecy. Comorbidity associated with TTM (anxiety / self-harm)

None of the meds helped TTM. Hyponosis – temporary help. Ruining my body NEED Musculoskeletal problems Daily pain meds	thought I was the only one. She also got me into a hospital psych ward because I had told her I was suicidal. That began my journey of 7 hospitalizations, numerous meds, and hypnosis. None of the meds helped the trich. The hypnosis did, but lasted just 3 months. Behavioral therapy only worked to get me aware of when I pulled, but I was not able to stop. I've now been in therapy for almost 30 years. The only thing that is getting me to stop slowly is the knowledge that I'm ruining my body with the repetitive motions. I NEED to stop. I have many musculoskeletal problems, and am on pain meds every day.	punitive thoughts to stop hair-pulling (ultimatum) NEED to stop, because you're ruining your body.
Environments: Alone. Watching TV On telephone On computer Reading Driving	**Please describe the environments where your hair pulling takes place.** When I'm alone, mainly in front of the TV and on the telephone, but I have pulled in front of the computer and while reading. Also while driving.	Alone but in a diverse range of environments.
Started at puberty. Angry. Overachiever. Shy, overwhelmed by attention from boys. Emotional abuse. No support. Felt alone. Adopted (abandoned by birth family). Passive. Bullied. Self-abusive behaviours.	**Why do you think your hair-pulling started? Please discuss (e.g. a traumatic event, etc).** I remember the exact moment, and how I felt. I was 10, and very, very angry at having to do a book report. I was an overachiever, so I never felt like I could slack off on an assignment. I was starting puberty, and was an awkward mess. All the other girls were starting to talk to the boys, and I was too shy, scared, and overwhelmed by my feelings when a boy paid any attention to me. My mother was emotionally abusive and my father was away a lot, so I had no one to talk to about my feelings. My sister was beautiful and all the boys loved her, plus we didn't get along so I couldn't talk to her. I felt very alone (also, I was adopted and felt my birth family had abandoned me.) I was passive and bullied, and super-angry at having to do everything I was told, whether it was a good thing or not. This started me on self-abusive behaviors, taking my anger out on my body.	Lack of support system + feeling abandoned by birth parents. Being bullied, and Self-abusive behaviours - can be seen as a rebellious act, or cry for help.
Left handed. Use both to pull	**Are you left or right handed, and which hand do you mainly use to pull your hair?** Left-handed, but have used both. Forced to slow down with it now because I have arthritic fingers and rotator cuff problems in both shoulders.	Permission:

	Have you ever given yourself '*permission*' to pull out your hair? Yes.	Can TTM be used to self-soothe? Or is permission given to exercise control.
Tentative control. Tiring cycles Get my hopes up, destroyed when another cycle starts. Will never think I've beaten it. Will always be there	**This set of questions will focus on General and Social Themes. Please answer the questions based on your own experiences.** **Do you feel in control of your hair pulling? Please discuss** I am tentatively in control at the moment--it's been a couple of months with almost no pulling (and this is only because I feel like I HAVE to stop, as my hair is not growing back well in my favorite pulling spots). But I would never state that I'm in complete control of it; that it is cured. After so many tiring cycles of it, where I get my hopes up only to have them destroyed when another cycle starts, I will never again think that I have beaten it. It will always be there.	Awareness that TTM will always be there – and it can not be controlled fully.
Ruled my life. Destroyed S-E. History of self-harm Avoid crowds Avoid dating Avoid eye contact Live alone Feel separate No enjoying life, waiting to die	**Describe how you feel about having Trichotillomania.** It has ruled my life and destroyed my self-esteem. Even after 30 yrs of therapy I still have very little. I've battled depression since i was 10, and attempted suicide a few times. I've cut, gouged, and punched myself. I avoid crowds and dating because of it. I have great trouble looking people in the eye for more than a few seconds (I'm always cringing and waiting for that light of discovery in their eyes…when their eyes widen and eyebrows furrow with the realization that I don't have eyelashes or eyebrows.) I live alone and feel separate from others. I'm not actively suicidal any more, but there are many times when I'm not enjoying my existence, and I'm just waiting to die.	TTM impacted self-esteem. Avoids people, and relationships. (Pulls when alone)
Peel lips and fingertips. Pick scabs and blemishes. Binge eat. Avoid windy days Avoid swimming Smart events	**Do you have any other habits (e.g. skin picking, / lip biting / nail biting / other related habits)?** I peel my lips and fingertips, and pick at scabs and blemishes (fortunately I don't have many to pick at, so I don't consider it as a problem). I also binge eat, but I don't know if that's relatable. **Please can you describe the situations you avoid, because of your TTM (e.g. windy days / swimming, etc).**	Dermatillomania Impulse control re: binge eating.

Avoid not wearing a hat. Sleepovers Sitting with people behind you.	Depending on my cycle of hair-pulling, I will avoid windy days, swimming, functions where I have to dress up and and not wear a hat. When I was a kid I would avoid sleepovers. I avoid sitting where my back is to people- I feel like they're looking at me and talking about me.	Avoid situations that make you feel vulnerable Perhaps an act of self-protection.
Family and friends avoid talking about it. Insensitive. Hush-hush topic Wish they would ask me questions / talk about it	**How do you think your family and friends see you, as a TTM sufferer?** They don't talk about it, and in fact seem to forget that I have it (freely discussing hair issues that they think they have--" having no eyelashes" -when they have a full set but their lashes are blonde, etc., or complimenting each other on how their eyes look when made up with mascara.) Either that or they're being insensitive, I'm not sure. It's always been a hush-hush topic, like no one knows how to approach it (even after 39 years…) I wish they would ask me questions and talk about it, just to normalize it for me.	Acknowledging TTM may create a sense of normalcy
Spent majority of life trying to hide it.	**How much time, effort and money have you spent trying to fix / hide your hair pulling?** I couldn't begin to put a number to this question; it's been so long…I've spent a great deal of my life trying to hide it.	Cost and labour intensive.
Avoid hair dresser	**How do you feel about visiting the hair dresser?** I don't go, I try to do my own hair. For the past several years I've just been shaving it. If I'm desperate, I can have my sister do it; she went to school to be a hair dresser.	Links to self-esteem and self-confidence. Appearing vulnerable in front of a professional who may judge.
School was a nightmare. Never felt desirable Felt sub-human Bullied. Excluded myself. Melted into background.	**Have you ever felt excluded / rejected by your peers, because of your hair pulling? Please describe** Yes. School was a nightmare for me. Boys would rarely speak to me. I never felt like I was desirable, like the other girls. In fact, I gradually ended up feeling like I wasn't even human, much less female. I felt sub-human. I was bullied by random kids that didn't even know me--I got things thrown at me, punched in the head, and one boy ran by and spit in my eye. I don't even know if I was excluded from anything, because I excluded myself. I hid, made excuses, and melted into the background.	Feelings of being undesirable have carried over into later life (avoids relationships). Fear of Rejection? Excluded herself & melted into the background (has also transferred into later life – excludes herself from possible work events, hinders potential career).

	This set of questions will focus on Social Themes. Please answer the questions based on your own experiences.	
Crazy Flawed Someone to avoid Dirty Contagious	**When you tell people you have Trichotillomania, what do you think they think about you?** I think that they think I am crazy, flawed, and someone to avoid. That it makes me dirty and possibly contagious somehow.	Belief that others will have an unfavourable perception of people with TTM
Shy Avoid activities Didn't want to get close to anyone Avoid parties Avoid dates Felt left out	**Has TTM ever affected your school / academic life? Please discuss** Yes, it made me painfully shy, and I avoided joining in extracurricular activities and sports. I didn't want to get close to anyone socially, especially boys, so I avoided parties and gatherings and dates. I felt really left out.	Self-exclusion and feelings of isolation
Sporadic work life Menial jobs Avoid customer service. Quiet panic Can't think / function Shrink inside Get uncomfortable	**Has TTM ever affected your work life? Please discuss** Yes. I've had a very sporadic work life. I've done menial jobs even though I have a degree, and I've avoided customer service because I don't want anyone to notice my trich. When I am too physically close to people and I feel that they are looking at me, I go into "quiet panic" mode, where I can't think right or function at my job. Whenever someone focuses their gaze and attention on me, I shrink inside and get very uncomfortable.	Self-worth affected by TTM? Paranoia and panic at what others may be thinking.
Certain point of closeness, panic and shutdown. No longer try. Single for 15 yrs.	**Has TTM ever affected the quality and quantity of your romantic relationships? Please discuss** Yes. Whenever I would get to a certain point of closeness to someone, I would panic and shut down. I've run away from several relationships. I no longer try, and have been single for 15 years.	Sabotage relationships Defeated.
She dropped me with no explanation. Felt she was actually afraid of me. It still hurts.	**Has TTM ever affected your friendships? Please discuss** I had a very good friend in high school who I adored, and after I told her about my trich and hospitalizations, she dropped me with no explanation. I saw her once after that, and I distinctly felt that she was actually afraid of me. It still hurts, even 30 yrs later.	Rejection. Stigma Misunderstood disorder.
Little self-esteem	**Please describe your self-esteem and self-confidence, in relation to your TTM.** I have little self-esteem, though more than I have had in the past. I also have a little more confidence than I did, but not enough to have a steady job and make something of myself. Whenever opportunities arise for me, I let them slide by, because I don't think	Low self-esteem and self-confidence linked to TTM affects quality of life. Issues with coping.

Not enough confidence to have a steady job. Let opportunities slide by. Angry a lot. Self-destructive thoughts. Jealous of others. Envy. ''why me'' feelings Fail again Thoughts about death. Don't cope well. Would like to embrace and accept it – but cannot. Angry at myself.	I could face the social interactions (people noticing my trich and my subsequent worries about what they're thinking) and demands that those opportunities present. **Describe your frustrations about your hair-pulling.** I am angry a lot of the time, and often have self-destructive thoughts. I'm also very jealous of other people, and always look at their hair and eyelashes with envy. I have "why me" feelings. I've had so many cycles of pulling and stopping, and thinking this new thing "just might work" only to fail again miserably, that a lot of times I think about death. **How would you say you cope with having TTM?** I don't think I cope as well as I'd like to…I want to be able to just accept and embrace it, so that I can be out in public and not care what people may think. But I cannot, and feel angry at myself for not finding the strength to do so.	Negative thoughts associated with TTM (jealousy, envy, self-destructive thoughts). Relapse common. Negative self-perception (anger and lacking strength to control / stop pulling).
Stunted growth socially. Drained me of confidence & feeling of belonging. Secretive and solitary life. Taken away dreams. A factor in suicidal thoughts. No adequate training. No sensitivity training.	**This set of questions will focus on Health and Wellbeing Themes. Please answer the questions based on your own experiences.** **Please describe how you think Trichotillomania has impacted your life in general**. It has stunted my growth socially, and drained me of confidence and the feeling of belonging. It has led me to live a secretive and solitary life. It has taken away many of my dreams, and been a factor in me contemplating (and attempting) suicide at times in the past. **Do you think healthcare professionals are adequately trained to dealing with Trichotillomania? Please discuss** In my 30+ years of experience with professionals on this matter, I don't think they're adequately trained, especially when it comes to sensitivity. I had an eye doctor once that read me the riot act--"why are you doing that? Stop it! Don't you know eyelashes serve a purpose? What's wrong with you!". At another point, a hospital mental health worker asked me why I would want to ruin my looks (when I had shaved my head to finally get some relief from the TTM---which was a huge step of my taking control of it, an action	TTM has affected social and personal growth. Secretive and solitary life. Previous self-harm and Suicidal ideation. Lack of training. Healthcare professionals have made judgemental comments. Lack of sensitivity.

Don't feel they ever understood. Gave up on me too easily. Repulsed by it.	which should have been applauded). Other doctors have tried to be sensitive and useful, but I don't feel they ever quite understood. They gave up on me too easily, or tried to push drugs at me. With some, I even got a sense that they were repulsed by it.	'Push drugs at me' = lack of a person-centred approach to healthcare.
Antidepressants Anxiety meds Behavioural techniques Meditation Wear a hat Keep hands busy. Tape on fingers. Slice fingertips. Hypnosis. Shaving head. Setting goals. NEED to stop.	**Please can you list all the treatments (behavioural / medical / herbal) you have tried, and describe if any have been successful / unsuccessful?** I've tried many antidepressants, anxiety meds, behavioral techniques (keeping track of hairs pulled and when, elastic on the wrist, gloves, etc..) . None of these worked (though the keeping track helped me become more aware). I've tried meditation, keeping a hat on, and playing with something to keep my fingers busy, but those didn't work. What has worked briefly in the past was taping my fingers, and slicing my fingertips with a blade. Hypnosis worked for 3 months straight, no pulling at all, but for some reason I started up again. Shaving my head has kept it at bay off and on, at least until it grows long enough for me to pull again. I've recently had 2 more episodes of no pulling, or very little pulling. Once was because I set a definitive goal for myself, and this ongoing time now, because I've noticed that the hair is not growing back well and I NEED to stop, or I'll be hiding it forever and always feel ashamed. It also hurts my fingers and shoulders now to have a pulling session. So I would venture to say that arthritis is a good cure for trich. ;)	Treatments mainly unsuccessful, except limited success with hypnotherapy. Punitive mindset (MUST stop, or won't grow back).
Muscle spasms Headaches Panic attacks Social anxiety Assume people laughing about me. Rarely comfortable in public.	**Does Trichotillomania have any impact on your health and wellbeing, in terms of stress and anxiety?** I have stress-related muscle spasms from tenseness and rigidity in my back and neck. I've had a lot of headaches. I have had panic attacks and social anxiety. I feel very uncomfortable when my back is to people, such as in restaurants and lines. When I hear laughter nearby, I automatically assume someone is laughing about me. Same as hearing whispering. I judge who I want to be with according to how much I think they may look down on me and talk behind my back. I'm rarely comfortable in public.	Co-morbidity (muscle tension, panic, anxiety). Paranoia and uncomfortable in public.

History of depression – coincides with the onset of TTM. Moody / shy, the TTM shut me down socially.	**Do you have a history of depression, and do you think this is linked to your TTM? Please discuss** I do have a history of depression, and I do think it's linked to the TTM. It coincides with the onset of it, at age 10. Before that, I think I had a propensity for it, but the TTM brought it out. I was always a moody and shy kid, and socially awkward, but the TTM just shut me right down socially.	Propensity for depressive episodes, and feeling socially disengaged.
History of anxiety. Social anxiety and ensuing frustration and exasperation. Angry abusive device. Frustration relieving tool	**Do you have a history of anxiety, and do you think this is linked to your TTM? Please discuss** I do have a history of anxiety, starting from having a difficult time knowing how I should act socially as a child. I think this set me up for the horrible frustration I felt that first led me to pull my hair out. It's all been connected to social anxiety and the ensuing frustration and exasperation. So the TTM has been an angry, abusive device for me, as well as a frustration-relieving tool.	History of social anxiety. TTM can be used to relieve frustration, or as an abusive tool.
Ruled my life.	**Does TTM cause you distress? Please discuss** Yes, every day. It has ruled my life.	Distress from TTM has ruled my life.
Tension. Anger. Sadness. Despair. Self-loathing. Jealousy.	**What are the negative emotions you feel, which are linked to your hair-pulling?** Tension, great anger, sadness, self-loathing, despair. Jealousy toward others for their beautiful heads of hair, and eyelashes.	TTM commonly linked to emotional turmoil.
	This set of questions will focus on Health and Wellbeing themes. Please answer the questions based on your own experiences.	
No history of substance abuse.	**Have you ever had a history of substance abuse? Please discuss** No.	-
Food binging.	**Do you think you are impulsive? Impulsive behaviour can be shopping for needless things, gambling, and taking unnecessary risks. Please discuss** Rarely. Only impulsive with food binging.	Impulse control – food binging.
Anger, hatred, envy, regret.	**How do you view your relationship with Trichotillomania? Please discuss** A relationship of anger, hatred, ENVY, and regret.	Relationship with TTM viewed negatively.
Hypnosis. DBT	**What treatment options do you think could work, and what would you like to see offered by your GP / Health Provider**? I would try hypnosis again, or more Dialectical Behavior Therapy work.	Would like more hypnosis & DBT.

Brought up emotions Healing in a way Someone is finally interested and cared. No further questions No improvements. Thorough. Hope it becomes an acceptable disorder. Hiding, feeling abnormal and unaccepted.	**How did you find participating in this email interview?** I found it brought up a lot of emotions that I thought were behind me, such as the rage and depressive pain. I also found it healing in a way, to be able to tell my story. I felt like someone was finally interested, cared, and wanted to do something about trich by exposing it via a study. I hope my answers can be helpful to another. **Are there any other questions you think I should ask you, about your TTM?** No, I think you covered everything. **Regarding this Email Interview; is there anything you think could have been improved / done differently?** No, I think it was just right, and very thorough. **Is there anything else you would like to share about your experiences with Trichotillomania?** Not really. I just hope it becomes a more acceptable disorder through the sharing of stories and experiences. A huge part of the pain of trich is the hiding, and the feeling of being abnormal and unaccepted.	Cathartic. Valued participation (hope that it will help others in the future). No suggestions for further questions. No suggested improvements. Hope that TTM becomes more accepted / less stigmatized.
Support groups helpful. Acceptance without stigma. GP Psychologist Face-to-face Online. Twice per month	**The final set of questions will focus on General themes. Please answer the questions based on your own experiences.** **In thinking of new ways of supporting people with Trich - how would you envisage your ideal treatment / support system?** I think groups are very helpful. Acceptance with no stigma is also very important. The worst part is when you're treated like you're not a normal, intelligent person. **In terms of a possible treatment option - who would you like to see deliver your Trich treatment plan?** My GP or my psychologist. **In terms of a possible treatment - would you prefer face-to-face support, online support, or other support? Please discuss.** Either face-to-face, or online support. **In terms of a possible treatment - how often would you like to be supported?** About 2x a month	Support groups. GP Psychologist Face-to-face Online Twice per month

12 months (unless relapse)	**In terms of a possible treatment - what duration of time would you like to be supported for? *(e.g. 8 weeks / 12 months / lifetime, etc).*** 12 months or so, unless I started up again and needed support again.	12 months. (unless relapse)
Thorough. No weaknesses	**In your opinion, what were the strengths and weaknesses of this Email Interview?** It was a very thorough interview; I saw no weaknesses.	Thorough. No weaknesses
Awful, decades-long affliction We are normal people with an unusual behaviour	**If you had the opportunity of telling a person who knew nothing about Trich, what it's like to live with Trich - what would you tell them?** I would tell them that it's an awful, usually decades-long affliction. And I would say that we are all normal people with an unusual behavior; we are from all races and cultures, and we all just want to be accepted and allowed to live our lives like everyone else.	Often long-term and challenging disorder. Normal people.
Reiterate that we are normal. Does not mean we are retarded or mentally unbalanced. Not contagious. Behaviour might diminish with more acceptance / less bullying. TTM secretive monster.	**This research will aim to give a 'voice' to people who struggle with Trich - if you have any thoughts / opinions / ideas you would like to share, please do so here:** I'd just like to reiterate that we are all as normal as the next person; that trich does not mean that we are retarded, or mentally unbalanced. Trich is not "contagious" either. We just want acceptance. If we were accepted more and bullied less, the behavior might diminish, or at least cease to be the horrible, secretive monster that it is.	More acceptance would reduce idea that people with TTM are mentally unstable. Hair-pulling may reduce with acceptance from peers.

Appendix Eight – Visual Representation of Hair Loss

(P18 – Female, 31)

(P16 – Female, 42)

(P1 – Female, 49)

(P2 – Female, 44)

Appendix Nine – Summary of Themes and Subthemes discussed in Chapter Five

Data Source	Themes	Subthemes
Email Interview	The Cycle of TTM	
Email Interview	A Journey of Uphill Battles	Demonization and Hate of TTM Shame and Distress
Email Interview	The Implications of Fearing Judgement	Coping by Concealment Perceived Stigma, Secrecy and Non-Disclosure Embarrassment and Avoidances
Email Interview	Persistent and Extensive Effects	Academic Work Relationships Self-Identity and Lost Opportunities
Email Interview	Coexisting Health Implications	Physical Implications Psychological Impulse Control and Permission Giving Behaviours
Email Interview	Successful Treatments	Behavioural Treatments Pharmacological Treatments A Combined Approach
Email Interview	Unsuccessful Treatments	Behavioural Treatments Pharmacological Treatments
Email Interview	Lapse in Duty of Care	Inadequate Training of Healthcare Professionals
Email Interview	Ideal Treatment Intervention	Dual-Phase Combined Treatment Approach Working with Mental Health Professionals Face-to-Face Support Frequency and Duration
Email Interview	Acceptability and Feasibility of the Email Interview Method	
Blog Posts	Societal View of Beauty	Secrecy and Shame Stigma
Blog Posts	Acceptance	
Blog Posts	An Endless Cycle that causes Distress	

Appendix Ten: Example of Theme and Subtheme Development

Extract Quotes and Participant Code	Descriptive Coding	Interpretative Coding	Sub-theme	Theme
'I hate having Trichotillomania. It's a burden' (4)	Hate having it. Burden	Burden		
'I hate it with all my being but what terrifies me more is that my kids might have it. I survived but I don't want this life for them' (2)	Hate it. Terrifies me kids may have it. Don't want this life for them.	Hate TTM. Worried hereditary		
'My relationship with trichotillomania is one of hate, self-loathing, and disappointment. It's the worst thing in my whole life, by far. Life is supposed to be an enjoyable adventure, but with Trichotillomania it is a traumatic journey of hate and self-doubt' (3)	Hate. Self loathing. Disappointment. Worst thing in life. Traumatic journey of hate / doubt.	Hate. Burden		
'Trichotollomania is like a demon or satan and it's a constant fight in myself to fight the urges. I hate Trich although I have learn to live with it' (6)	Demon or satan. Constant fight. Fight urges. Hate TTM. Have to learn to live with it.	Demonizing TTM Battle Hate		
'Trichotillomania is an unwelcome evil in my life. I hate it, and I hate myself for having it. We only have this one life and I fear mine will be ruined because I have these hairpulling problems' (7)	Unwelcome evil in life. Hate it. Hate myself for it. Fear my life will be ruined.	Demonizing TTM Hate Burden / Distress	**Demonization and Hate of TTM**	
'Trichotillomannia is like this very dark cloud hanging over my head, it brings despair and heartache. I hate it' (8)	Dark cloud hanging over my head. Brings despair, heartache. Hate it.	Hate / Distress Burden? (Dark Cloud)		
'I despise trich, it's the bane of my life' (9)	Despise TTM. Bane	Hate TTM. Burden		
'My relationship with trichotillomania is unwanted. I hate it and I hate my life with trich in it' (10)	Unwanted relationship. Hate it. Hate my life with TTM.	Unwanted. Hate		
'My relationship with trich is like a mental war zone that I constantly find myself in. Some times I will feel as if I have conquered my trich, like I do now. But just like what has happened in the past, I might relapse again very soon' (13)	Mental war zone. Sometimes I feel like I have conquered it, but might relapse soon.	Distress. Burden. Relapse (False sense of hope?)		
'I hate having Trichotillomania. It's a burden' (4)	Hate TTM. Burden	Hate. Burden.		

'No matter how hard I try, the hairpulling does not stop and cannot be controlled. This is the most frustrating thing of all. No one understands the consequences of these actions, the self doubt and feelings of unworthiness and self hate and feeligs of undesirability, just because of HAIR. I really hate my life and sometimes I hate myself' (7)	TTM does not stop. Cannot be controlled. Frustrating. No one understands consequences of TTM Self-doubt, unworthiness, undesirability. Hate my life, hate myself.	Battle. Negative emotional consequences. Hate		**A Journey of Uphill Battles**
'in the past I used to give myself permission. I don't bother anymore. I hate feeling so defeated and useless' (14)	Do not bother giving myself permission. Feel defeated, useless.	Defeated.		
'a hateful, toxic, and stressful relationship. I hate that I have to be the one with such a disorder. It is toxic because I know it is not good for me, yet I must continue to keep giving into it' (19)	Hateful, toxic, stressful relationship. Continue to give into it.	Negative emotional consequences. Hate		
'it's more the end result I hate, being bald. If hair could grow back immediately I don't think I'd have a problem with it at all' (2)	Hate end result, being bald.	Hate hair loss		
'*Love / Hate. I love how it feels and how it makes me feel while I'm doing it. I hate the after effect' (16)*	Love / hate. Love feeling, hate after effects.	In conflict		
'I have been dealing with trich for half my life now and I still hate it. I live with it and have lived a good life, but the life I have lead has been far more difficult with trich' (17)	Hate TTM. Life has been more difficult with TTM.	Hate. Distress. Struggle.		
'After the pulling I have very strong feelings of self hate, shame and guilt and frustration' (11)	Strong feelings of self-hate, shame, guilt, frustration.	Negative emotional consequences.		
'controls my thoughts very often and it is very unwelcome in my life' (3)	Controls thoughts. TTM is unwelcome in my life.	Dominate thoughts Burden	**Shame and Distress**	
'trichotillomania has caused much distress in my lifetime. It used to control my life before I shaved my head' (3)	Causes distress in my lifetime. Controlled my life before shaving.	Distress. Burden		
'Trichotillomania has ruined my life' (4)	Ruined my life.	Negative life impact		
'its an on going battle' (5)	Ongoing battle.	Battle.		

'*It is my own burden to bear. A silent struggle' (8)*	Burden. Silent struggle.	Burden. Struggle.		
'It causes me distress on a daily basis. I spend many hours per week pulling the hairs and then I live in fear that it will be uncovered' (8)	Daily distress. Fear it will be uncovered.	Distress. Fear (secrecy?)		
'I fear that trichotillomania will impact my whole life until my death. I fear that Trichotillomania will always control me, that I will never lead a normal life' (8)	Fear TTM will impact whole life until death. Always control me. Never lead normal life.	Negative life impact. Lack of control. Abnormal		
'trich causes me distress in my daily thoughts. It impacts my daily life, I'm often running late because I've been distracted by thoughts or pulling. I think the struggles with trichotillomania comes in waves; it's never constant, some days it's fine and other days are a nightmare' (9)	Daily distress, daily impact. Struggles with TTM come in waves. Never constant.	Distress. Negative life impact. TTM Fluctuates.		
'In my younger years it caused me a lot of distress. I'm in my 50's now and am more accepting of it now, it still does cause distress occasionally, but I am better equipped to deal with the distress after all these years experience dealing with it' (17)	Distress in younger years. Still causes distress, but better equipped to deal with it now.	Distress across lifetime.		
'The trich is still a real and daily struggle. I don't even say I live a good fulfill life – I think I survive life' (10)	Daily struggle. Do not live a fulfilled life, I survive life.	Daily impact. Unfulfilled.		
'*It's a terrible burden living with Trichotillomania, which not many people can fully understand' (11)*	Terrible burden. Not many people understand.	Burden. Lack of empathy by others		
'Trich has ruled my life for many years, and it dominates my thoughts. Thinking about how to stop, what I can do to re-grow my patchy bits, worrying if it will ever grow back… it's exhausting' (12)	Ruled my life. Dominated thoughts. How to stop, re-grow patchy bits, will it grow back? Exhausting.	Dominate thoughts Burden.		
'Trichotllomania is a constant battle… you have to fight it every single day, sometimes you win and sometimes you lose… but you can't give up' (9)	Constant battle. Can't give up.	Battle. Determined (positive)		
'It's just a terrible, heartbreaking, emotionally taxing, upsetting, and disgusting disorder. I think that my life would be completely different if I didn't have Trich…and when I think about how it	Terrible, heartbreaking, emotionally taxing, upsetting, disgusting	Negative emotional		

would be different / what could have been, I feel so disappointed and unsatisfied with my current life' (14)	disorder. Disappointed and unsatisfied with life.	consequences of TTM. Life impact		
'I wish I could reject it but it's stayed with me for 26 years. No matter how much I try to stop it or control it, it's like a dark shadow looming around' (17)	Want to reject it, but can't stop or control it. Dark shadow looming.	Unwanted. Lack of control. Dark Shadow (Burden?)		
'It's like constantly fighting a battle against yourself' (20)	Fighting battle against yourself	Battle.		
'Trich has affected my whole life. I sometimes think that I would have so much free time if I wasn't worried about Trich. It's always on my mind. ALWAYS' (4)	Affected whole life. Always on my mind. ALWAYS.	Impact on Life Dominate thoughts		
'Trich is life impacting, and dominates my thoughts very often. It causes me distress in the sense that I worry if I'll ever live a normal life' (12)	Life impacting. Dominates thoughts, causes distress. Worry about leading a normal life	Life impacting. Dominate thoughts Distress		
'I am very frustrated with hair pulling. I am so frustrated that I cannot even find the right words to describe my frustration. I just want to stop, stop, stop, stop. But I cannot' (13)	Frustrated. Can't find the right words. Want to stop, stop, stop	Frustration.		
'I suppose I'm grateful that I don't have a life threatening or terminal illness… there is no expiration on my life due to an illness. Having said that, Trichotilomania has a huge impact on my life and my emotional wellness – I have learned to live with it, but it's still a daily struggle!' (14)	Grateful no terminal illness, but TTM has huge impact on life and emotional wellness. Daily struggle.	Life impacting. Daily impact. Struggle / burden.		
'Trichotillomania controls every single day of my life. Just imagine having something weighing on your mind so heavily, every single day…. it's a terrible way to live' (14)	Controls every single day of life. Weighing on mind heavily. Terrible way to live.	Dominate thoughts Burden		
'Its just something I live with now…. But the effects of it (paranoia, fear, low self esteem) do cause regular distress' (14)	Effects of TTM cause distress.	Distress Negative effects		
'I'm totally embarrassed, ashamed and disgusted in myself at the moment that EVERYTHING is so bad and that my kids and husband have to see a bald patchy haired ugly Mum at home' (2)	Embarrassed, ashamed, disgusted in myself. EVERYTHING is bad. Bald patchy hair ugly mum.	Embarrassment shame, disgust Life impacting.		

'urgh! Why the hell do I do this to myself?! why cant i stop?! why do i feel so ashamed?! why me?! all the hours i have wasted picking hairs!! grrrrrrrrrrrrrrrrrrr..... this is the best way to describe my frustration' (18)	Why can't I stop? Why do I feel so ashamed? Why me. Wasted time hair-pulling. Frustrated	''Why me'' mindset (victim role?) Frustration. Shame		
'I've noticed that the hair is not growing back well and I NEED to stop, or I'll be hiding it forever and always feel ashamed' (1)	not growing back well. NEED to stop. Hiding it forever, ashamed.	Desperation. Secrecy. Shame		
'Its hard for people to understand that we destroy our bodies because it feels so nice, but then we have the most overwhelming feelings of shame and guilt, which causes more pulling to seek that pleasurable sensation again' (11)	Hard to understand we destroy our bodies, feels nice. Then overwhelming shame, guilt. Causes more pulling to seek pleasure again	Shame / Guilt. Misunderstood disorder		
'I do feel ashamed that I wear a wig because it feels like I am lying to people about my appearance' (10)	Feel ashamed to wear a wig. Feels like I'm lying about my appearance	Shame. Concealment (Lying by omission?)		
'I feel sickened and ashamed of my body and my compulsive uncontrollable NEED to pull the hairs out' (8)	Sickened and ashamed of my body Compulsive. Uncontrollable NEED	Shame. Lack of control.		
'all the time, I negotiate with myself, If I pull 1 hair per day, I'll have it under control. Even when I negotiate with myself, allowing myself to pull 1 hair per day (as a form of control), the 1 hair turns into 5 which turns into 10 and then I've lost all control. The feelings of shame and guilt are tremendous' (9)	Negotiate with myself. Allow myself to pull 1 hair per day. Then lose control. Feelings of shame and guilt are tremendous.	Permission-giving behaviours. Lack of control. Shame / negative emotions		