

Trichotillomania: a perspective synthesised from neuroscience and lived experience

Clare E Mackay 

University of Oxford, Oxford, UK

Correspondence to

Dr Clare E Mackay, Department of Psychiatry, Warneford Hospital, University of Oxford, Oxford OX3 7JX, UK; clare.mackay@psych.ox.ac.uk

Received 9 June 2023

Accepted 25 August 2023

Published Online First

21 September 2023

ABSTRACT

Trichotillomania, or hair-pulling disorder, is one of a family of disorders called body-focused repetitive behaviours (BFRBs), which also include disordered skin-picking (dermatillomania) and nail-biting (onychophagia). The disorders affect 1%–2% of the population, cause high levels of distress and have high levels of comorbidity with other psychiatric diagnoses. The key facts and figures are briefly reviewed and some important points are further explored: (1) BFRBs are associated with psychological distress, but are distinct from other diagnoses, (2) The pathological behaviours mirror excessive self-grooming behaviours in other species, and may relate to immune-system mediated feedback loops, and (3) The resulting behaviours are stigmatised and cause intense shame and isolation for those who suffer, which might in itself maintain the feedback loop. These observations lead to the hypothesis that the core disorder is one of pathological grooming, which may have a basis in an immune response, with shame being both a consequence and a maintainer of the disorder. The major barrier to testing the hypotheses and potential interventions remains the stigma that keeps these disorders, and those who suffer from them, in the shadows.

Trichotillomania (trich) is a hair-pulling disorder, and is one of a family of disorders called body-focused repetitive behaviours (BFRBs), which also include disordered skin-picking (dermatillomania) and nail-biting (onychophagia). They are currently categorised as a subtype of obsessive-compulsive disorders in DSM V, having previously been categorised as impulse control disorders. These disorders are under-recognised, under-researched and underestimated in terms of their scale and impact. Here I will briefly review the background, draw attention to some key aspects of the pathology, and propose an immune- and shame-based pathological grooming model, including potential new therapeutic targets.

A BRIEF REVIEW OF FACTS AND FIGURES

A comprehensive review of the state of our understanding of trichotillomania is available here¹ and is updated here.² In brief, people who suffer from trichotillomania have irresistible urges to pull out their hair. The sites most commonly affected are the scalp, eyelashes and eyebrows, although any body hair can be targeted, and pulling from multiple sites is common.³ Triggers vary between individuals, with some describing sensory, emotional and cognitive precursors to the pulling behaviour, but many individuals describe being unaware of either the urge to pull

or even the pulling behaviour itself, with some even reporting pulling in their sleep.³

Large population surveys do not typically include questions related to disordered hair-pulling, so the only evidence we have for prevalence comes from relatively small samples, often of USA-based university students giving prevalence estimates of between 0.5%–2%.¹ One moderately sized community sample (n=10 169) estimated a prevalence of 1.7%,⁴ which would represent as many as 1.1 million people in the UK. Although samples of treatment/support-seeking individuals have around a 4:1 ratio of women to men,⁵ the community surveys suggest that disordered hair-pulling affects men and women equally.⁴ Interestingly, hair-pulling disorders appear to be equally prevalent across cultures and do not differentiate according to socioeconomic status or education level.⁴

People with these disorders suffer significant impacts to their quality of life. The Trichotillomania Impact Project surveyed 1697 people who self-reported symptoms consistent with a clinical diagnosis of trichotillomania.³ They reported high levels of distress (5.1/7) and mild to moderate impacts on quality of life across social, occupational, academic and psychological domains. Despite this, the majority of patients never seek treatment, and the majority of those who do find that their health-care provider knows little or nothing about the disorder.³

A range of behavioural and pharmacological treatments have been trialled, mostly in very low numbers of participants. A 2007 review of all available trials from 1980 to 2006⁵ contained a total of 240 participants across 13 trials. More recent reviews of both behavioural⁶ and pharmacological⁷ therapies suggest that there is some benefit from habit-reversal based therapy, but that there is little support for any beneficial effects of SSRIs or antipsychotics. Some single placebo controlled RCTs of repurposed agents look more promising.² For example, a recent RCT of a glutamate modulator (memantine) in 100 adults with either trichotillomania or skin-picking disorder yielded promising results, with 60.5% of the memantine group reporting much improved symptoms after 8 weeks of treatment, relative to only 8.3% of the placebo group.⁸

Comorbidities are common, particularly with anxiety disorders (55%), depression (43%), obsessive compulsive disorder (OCD, 29%), attention deficit hyperactivity disorder (ADHD, 29%), post traumatic stress disorder (29%), panic disorder (25%), bipolar disorder (19%) alcohol or drug abuse (18%), and eating disorder (17%).⁴ There is also a large degree of comorbidity within the category of BFRBs (eg, 24% with skin-picking disorder).⁴



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To cite: Mackay CE. *BMJ Ment Health* 2023;**26**:1–3.

Attempts have been made to factor-analyse the comorbidities,⁹ with three clusters emerging: trichotillomania with no comorbidities (21%), + major depression (16%) and ‘complex’ (63%).

Focusing on some salient points

Three important aspects of our understanding of trichotillomania are the basis of this perspective:

First, the high incidence of comorbidities associated with trichotillomania are likely contributors to the high rate of both underdiagnosis and misdiagnosis.¹ We are lacking any large-scale epidemiological data in the UK, and there is little more than anecdotal information available about referral/treatment pathways or outcomes. In at least two US-based independent samples, there is a consistent minority of 21% of individuals who meet diagnostic criteria for trichotillomania but no other condition.^{4,9} A greater understanding of trichotillomania and other BFRBs, and how they relate to other disorders (eg, anxiety, ADHD, mood disorders, OCD, self-harm, etc), is required.

Second, the symptoms of BFRBs (hair-pulling, skin-picking and nail-biting) might be considered as disordered extremes of normal primate grooming behaviour.¹⁰ Importantly, the phenomenology of these disordered behaviours is often described as subconscious, like scratching an itch. Pulling/picking/biting are all examples of self-grooming, which can be observed in many animal species, not least in non-human primates, where they contribute to the creation and maintenance of social bonds.¹¹ Indeed a number of species have been noted to pull out their own hair when in captivity,¹² and there is a mouse model of OCD which exhibits excessive self-grooming.¹³ In a study of self-directed behaviour in macaque monkeys, three potential drivers were described: ectoparasite defence (immune), environmental and social,¹⁴ and there have been suggestions of inflammatory biomarker differences in people with BFRBs.^{15,16} It is likely that there are genetically determined individual differences in sensitivity threshold, which might explain the high heritability of BFRBs.¹⁷ Multiple brain systems are involved in the initiation, modulation and maintenance of self-directed behaviours.¹⁸ These might form the basis of some cognitive and neural differences that have been observed in people with trichotillomania.^{1,2}

Third, many studies (as well as lived-experience accounts) of trichotillomania refer to the intense shame and isolation experienced by those who suffer, and the lengths to which individuals go to hide their disorder. Despite being commonly reported, little attention has been given to the extent to which shame could be both a consequence and a maintainer of the disordered behaviour. One study described one of the drivers of self-grooming behaviour in macaques as ‘social uncertainty’,¹⁴ and the behaviour itself is described as ‘displacement activity’.¹⁹ This might align with the lived experience of those who often associate the onset of the disorder with a socially/emotionally stressful life event and describe the sensation of pulling/picking/biting as soothing. The majority of psychological therapies that have been trialled in these disorders focus on the behaviour itself (eg, habit-reversal therapy), and although the short-term outcomes show some efficacy, long-term relapse is common.⁶ Therapies that specifically target shame²⁰ might increase the efficacy of behavioural interventions.

A model of immune-based and shame-based disordered grooming

The initiation and maintenance of BFRBs like trichotillomania are thus complex, involving autonomic/immune, limbic and executive brain systems. One potential model is that people with trichotillomania are genetically predisposed to have a heightened immune or ‘ectoparasitic’ response to sensory stimuli which

leads to an increased propensity to pull hair, pick skin and/or bite nails. This behaviour might be influenced by other immune responses (eg, behaviours might be attenuated by an individual’s immune status relating to infections), but might also be kept at a subdisordered level until an additional social or emotional stressor exceeds an internal threshold, and the pulling/picking/biting behaviour becomes disordered. The manifestations of the disorder are highly stigmatising, causing intense shame, which maintains an elevated state of threat, creating a feedback loop which keeps the individual trapped in repetitive self-grooming activities that are functionally impairing.

This model gives rise to a number of individual testable hypotheses and potential therapeutic targets, but our ability to test them is severely limited by the stigma which keeps these disorders, and those who suffer, in the shadows. For example, the major mental health charity websites carry little or no mention of these disorders, or have them hidden away as subcategories of other disorders. This is despite the prevalence being potentially higher than OCD or psychosis, alongside high levels of distress. Action is needed to raise awareness and reduce stigma in the general public, healthcare and educational settings, and funding is needed for research that will help these disorders throw off their cloak of shame and receive the attention, and relief, that they deserve.

Twitter Clare E Mackay @thetrichprof

Funding This study was funded by NIHR Oxford Health Biomedical Research Centre.

Competing interests CM is supported by the NIHR Oxford Health Biomedical Research Centre, and is a co-founder/shareholder of Exprodo Software Ltd.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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ORCID iD

Clare E Mackay <http://orcid.org/0000-0001-6111-8318>

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