dream
believe
imagine

The TLC Foundation
for BFRBs

SCIENTIFIC LITERACY 2021

What is TLC?
- family
- hope
- love
- acceptance
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First Quarter (December 2019-February 2020)

Second Quarter (March-June 2020)

Third Quarter (July-October 2020)

Fourth Quarter (October-December 2020)

Acknowledgments: this zine would not have been possible without the tremendous contributions of Tyler Costello, Rebecca Richter, and Kathleen Griffith.
2020 : A Year Unlike Any Other

2020 was a year that underscored the importance not only of science in general, but also of scientific literacy in particular. Last year was the year we all tuned into our various sources of news to learn about what spike proteins are, how viruses are transmitted through airborne particles, and how mRNA vaccines work. Many of us looked to the scientific literature for this information; many of us relied on other sources. All of us counted on experts to tell us what is accurate and what is speculation.

Last year was also the year that, even in spite of the absence of the conference, we celebrated the first publications from the Body-Focused Repetitive Behavior Precision Medicine initiative (BPM), a research undertaking unlike any other. This groundbreaking work would not have been possible without the BFRB community who funded it, participated in it, and are now waiting to bring its learnings into their everyday lives. As the research grows, it is only becoming more exciting to be part of the BFRB community.

The mission of the Scientific Literacy (SciLit) committee is to make scientific research about BFRBs accessible and understandable to the general public. When we formed in 2018, we had no idea where this little group would take us, but we were driven by our mutual passion for science and for our community. These past three years have been rewarding beyond my wildest dreams. I wish to extend an enormous thank you to the researchers and clinicians who have collaborated with us, to The TLC Foundation for supporting us every step of the way, and to everyone who has engaged with any of the work we've done. I hope you have learned something to help you advocate for yourself or your loved ones with BFRBs.

SciLit will continue to evolve over time, so I hope you will continue on this journey with us and see where it leads. For now, all that's left to say is: it's been lit.

Meet the SciLit Team

Kimi Vesel  
Age : 26  
Location : Boston, MA  
Occupation : clinical trial manager  
Dream destination : Las Vegas

Hannah Doyle  
Age : 24  
Location : Providence, RI  
Occupation : neuroscience PhD student  
Dream destination : Berlin

Hannah Thomson  
Age : 21  
Location : Pennsauken, NJ  
Occupation : college senior  
Dream destination : Nijmegen, the Netherlands
Repetitive Transcranial Magnetic Stimulation in the Treatment of Skin Picking Disorder: An Exploratory Trial


Repetitive Transcranial Magnetic Stimulation (rTMS) is a noninvasive form of brain stimulation that involves using high-powered magnets to manipulate the electrical currents in specific regions of the brain. In the past, rTMS has been used as an effective treatment for depression. Recent studies have demonstrated the efficacy of rTMS in the treatment of impulsive-compulsive disorders such as addiction, eating disorders and OCD-related disorders. The purpose of this study was to explore the efficacy of rTMS in the treatment of Skin Picking Disorder (SPD).

94 patients who were pre-diagnosed with SPD were screened to participate in the study. Exclusion criteria included anyone under the age of 18 or over the age of 65, anyone who scored higher than 17 on the Beck Depression Inventory, those with dementia, bipolar disorder and psychotic disorder, active suicide risk, alcohol or drug abuse within the last 1 month, serious medical diseases or presence of neurological disorders such as epilepsy or encephalitis, and anyone with internal metal implants like pacemakers or intracranial metal clips. The final test group consisted of 15 participants. At random, 8 patients were selected to receive active therapy and 7 for the sham group, in which patients were under the impression that they were receiving rTMS without actually getting the treatment.

All patients received five 20-minute rTMS sessions per week, for a total of 15 sessions. rTMS treatment was focused on the pre-supplementary motor area of the brain. This area of the brain plays a role in complex movements, like using your limbs. Clinical assessments were primarily made using the Turkish version of the Yale-Brown Obsessive-Compulsive Scale modified for Neurotic Excoriation (NE-YBOCS). Assessments were made on a weekly basis to show any changes in baseline as recorded via NE-YBOCS.

Treatment effectiveness was documented by comparing the patients’ clinical assessment scores to the original measurements taken at the beginning of the study. Results show that treatment response was achieved in 62.5% of the active rTMS group and 33.3% of the sham group. This was documented by a steady reduction of SPD severity based on NE-YBOCS scores for patients over the three-week period of treatment. Three patients in the active rTMS group did a three-month follow-up. All three patients saw deterioration as documented by increased NE-YBCOS scores (increased skin picking behaviors).

Researchers identified several limitations of this study, including the very small sample size, comorbidities of the patients and the influence that medications taken by the patients could have had on the results. In addition to these limitations, little was done to assess the blindness of the sham group.

In conclusion, the use of rTMS as treatment for SPD appears to be a worthy subject of future studies. This is an especially important topic for research considering the lack of SPD-specific pharmacological therapies. Future studies should focus on robust sample sizes and well-maintained control groups, as well as a more standardized SPD assessment scale.
REpetitive Transcranial Magnetic Stimulation (rTMS) is a noninvasive form of brain stimulation that uses high-powered magnets to manipulate the electrical currents in specific regions of the brain and has been reported as an effective treatment in OCD-related disorders.

14 patients with SPD

15 total over 3 weeks

20 minute sessions

62.5% of patients receiving active rTMS responded to treatment

In the sham control group, only 33.3% responded to treatment

This study shows that rTMS may have benefits for treating SPD

More research needs to be done to confirm rTMS as a credible treatment

TRICHOTILLOMANIA: PSYCHOPATHOLOGICAL CORRELATES AND ASSOCIATIONS WITH HEALTH-RELATED QUALITY OF LIFE IN A LARGE SAMPLE

What is the prevalence of TTM in a Brazilian Sample?

What psychiatric conditions are associated with TTM?

What impact does TTM have on quality of life?

7,639
RESPONSES TO ONLINE SELF-REPORT MEASURES

1.4%
SCREENED POSITIVE FOR PROBABLE TTM

1.63%
WOMEN WHO SCREENED POSITIVE FOR PROBABLE TTM

0.95%
MEN WHO SCREENED POSITIVE FOR PROBABLE TTM

Three psychiatric disorders were associated with TTM

- Major Depressive Disorder
- Tobacco Use Disorder
- Alcohol Use Disorder

Childhood sexual abuse and suicidal ideation were also associated with TTM.

Quality of life was impaired in psychological and physical dimensions.

THE TLC FOUNDATION
for Body-Focused Repetitive Behaviors

Young Adult Action Council

Few studies have been done on the epidemiology of trichotillomania (TTM) and those that have been done have generally had small sample sizes and been performed in a clinical setting. The researchers in this study used self-report measures to examine the prevalence of trichotillomania in a Brazilian population, psychiatric comorbidities, and the impact of TTM on quality of life.

In this online study, researchers recruited 9,603 participants, of which 7,639 responses were used in the final analysis. Sociodemographic information was collected along with the self-report measures for psychiatric co-occurrences and quality of life. The co-occurrences examined were major depressive disorder (MDD), bipolar spectrum disorder, nicotine dependence, alcohol abuse, and suicidal ideation. 71.3% of participants were women, with an average age of 27.2 years. 110 of the participants screened positive for probable TTM. All measures were conducted using the Brazilian-Portuguese version.

Similar to previous studies, this study found the prevalence of TTM to be 1.4%, and found women to have a significantly higher prevalence (1.63% compared to 0.95% in men). MDD, tobacco use disorder, and alcohol use disorder were the only psychiatric conditions independently associated with TTM. MDD has previously been associated with TTM while tobacco use disorder and alcohol use disorder have not and therefore present a path for further research. The study also found a significant result with 44.5% of participants with probable TTM screening positive for suicidal ideation, a co-occurrence which hadn’t been previously investigated and should be examined further. TTM was found to be correlated with childhood sexual abuse, but no other dimensions of trauma were screened for. Physical and psychological quality of life were found to be impaired in participants with probable TTM.

This study has three major limitations. The majority of participants were young women, which is not representative of the general population. Diagnostic semi-structured interviews were not used to confirm diagnoses, though this was partially mitigated by the use of validated self-report measures. Online studies may attract a participant pool with a higher prevalence of mental disorders, which would lead to an overestimate of the prevalence of TTM. This study presents important and exciting areas for future research, especially around TTM and suicidal ideation. Furthermore, the study calls to the importance of early diagnosis of TTM and comorbidities.
Not Only Compulsivity: The SAPAP3-KO Mouse Reconsidered as a Comorbid Model Expressing a Spectrum of Pathological Repetitive Behaviors

H. Lamothe, C. Schreiweis, O. Lavielle, L. Mallet, & E. Burguière

Tourette Syndrome (TS), Obsessive-Compulsive Disorder (OCD), and trichotillomania (TTM) all present with repetitive behaviors as symptoms, which often complicates diagnosis and treatment of the appropriate condition. To better understand the repetitive behavior symptoms of these disorders, researchers in this study aimed to more completely analyze the behavior of the Sapap3 knockout mouse model. The Sapap3 knockout mouse, which lacks a protein that is strongly implicated in abnormal brain circuitry of OCD patients, has widely been used to study OCD because of the similarity between its behavior and that often seen in OCD patients.

Researchers aimed to better categorize the Sapap3 model by observing behavior of the knockout mice and treating them with a drug used to help people with TS. In the study, 9 knockout and 9 normal mice were videotaped for 24 hours. Additionally, 8 knockout mice were habituated to the videotaping environment for 30 hours. Then 4 of these mice were injected with a saline solution, followed with an injection of the drug aripiprazole, used to treat tic-like symptoms in patients with TTM and TS, the following day. The other 4 mice were injected first with aripiprazole and then saline the next day. Videos were analyzed using a free online scoring software, and several behaviors (self-grooming, scratching behavior, tic-like behavior) were objectively defined in the videos.

Sapap3 knockout mice had significantly more grooming events than did the normal mice, and there was a trend towards significantly more time spent grooming in the knockout mice, as well. Researchers also established a possible role for grooming types (i.e. short vs. long grooming episodes) as categories of their own. They also detected significantly more short and sudden head-body twitches and scratching events in the knockout mice compared to the normal mice. Although not previously described, duration of scratching was significantly larger in the knockout mice, as well. Aripiprazole treatment significantly lowered the duration of short, sudden grooming events and repetitive movements (head twitches and body jerks), suggesting that these two repetitive behaviors can predict tic-like symptoms in a human patient.

Behavioral and pharmacological evidence from the study suggest a distinction among types of self-grooming events (short vs. long). Short single grooming events are rescued by administration of aripiprazole, indicating tic-like behavior, while longer grooming events are not helped by the drug, putting them in a more compulsive-like behavioral category. Because the mouse model appears to present a comorbidity of repetitive behavioral symptoms common amongst three different neurobiological disorders, the authors suggest the model may be more translationally relevant when described as a model for repetitive behaviors.
THE SAPAP3-KNOCKOUT MOUSE MODEL MANIFESTS A SPECTRUM OF REPEETITIVE BEHAVIOURS

REPETITIVE BEHAVIORS ARE SYMPTOMS OF SEVERAL NEUROPSYCHIATRIC DISORDERS, INCLUDING TOURETTE SYNDROME (TS), OBSESSIVE-COMPULSIVE DISORDER (OCD), AND TRICHOTILLOMANIA (TTM)

THIS STUDY USES THE SAPAP3 KNOCKOUT MOUSE MODEL, WHICH IS USED TO STUDY OCD

What is the Sapap3 knockout mouse?
A mouse that lacks the Sapap3 gene and associated protein, leading to behavior similar to patients with OCD

8 Knockout & 9 Normal

Knockout mice groomed and scratched more and for longer, and had more tics

Found a distinction between two types of repetitive behaviors: short, tic-like behaviors, and long, compulsive-like behaviors

The tic-like behaviors were lowered when mice were treated with aripiprazole, a medication used to treat tic disorders

The results show the mouse model can be used to study several disorders, all of which are connected via repetitive behaviors, and thus the model should be considered as a more clinically relevant model for repetitive behaviors.

Insights into recurrent body-focused repetitive behaviors: Evidenced by New York Times commenters

166 comments from the September 2019 New York Times article, "Fighting the Shame of Skin Picking" were analyzed.

- 69% of commenters were people with a BFRB
- 23.6% reported onychophagia (nail biting)
- 24.7% reported onychotillomania (nail picking)

Skin picking was endorsed most frequently at 38.2%

Topics in Comments:
- Drug and non-drug treatments
- Shame
- Appearance
- Social support
- Childhood trauma
- Anxiety/stress
- Physical complications
- Family history
- Physician support

Most frequent in females
More likely than other BFRBs to begin in early childhood
More likely to be paired with another psychiatric or dermatologic disease
Comments more likely to mention trauma in childhood

In spite of how commonly BFRBs occur (close to 2% of people have one), there is a deep knowledge gap among health care providers and the general population about basic features of BFRBs, including demographic characteristics. One way to ensure BFRB studies become more accurate and representative over time is to raise awareness through popular news and media outlets. The New York Times published an article in September of 2019 titled “Fighting the Shame of Skin Picking,” which drew a large nationwide audience; the aim of this study was to identify and analyze patterns and themes in comments on the NYT article.

The authors polled all comments left on the article’s webpage in the first 10-day window after its publication, which amounted to 166 total comments by 146 people. Based on the content of the comments, they qualitatively classified each commenter by type—patient, physician, therapist, family member, or layperson—as well as additional demographics for the patient commenters, including gender, diagnosis, and age of onset. They also categorized prominent themes based on the qualitative assessment.

69% of the commenters were patients, but there were also comments left by laypeople, family members, healthcare professionals, and therapists. Commenters endorsed skin picking disorder most frequently at 38.2%, but nail BFRBs were also endorsed by a high percentage of commenters, with 24.7% endorsing onychotillomania (nail picking) and 23.6% endorsing onychophagia (nail biting). This study uncovered some interesting trends about onychotillomania in particular that should be explored with more rigorous studies: they found it is more likely to begin in early childhood than most other BFRBs, it has a female predominance, it is more likely to be accompanied by another psychiatric (36.36%) or dermatologic (18.18%) disorder, and people with onychotillomania were also most likely to mention traumatic childhood experiences (41%).

Topics mentioned in the article’s comments covered a broad range. These included nonpharmacologic (i.e., non-drug) and pharmacologic treatments as the most common (31% and 26%, respectively), as well as embarrassment/shame, appearance, social support/awareness, childhood trauma, anxiety/stress, physical complications, family expression of BFRBs, and physician support. Commenters with skin picking were more likely to raise aesthetic concerns than commenters with trichotillomania (38% vs. 8%).

In totality, the analysis reinforces that all BFRBs are fairly common, including BFRBs concerning nails, like onychophagia and onychotillomania. As far as limitations, the BFRB-specific groups of commenters were too small to conduct more complex analyses, so many of these findings need to be studied further. In addition, the overall group of commenters was likely only a small fraction of people with BFRBs (ones with a paid subscription to NYT who have the willingness to post a comment in a public forum), so it may not be representative of most people with BFRBs. However, in general, this analysis speaks to the benefits of writing about BFRBs in the popular press and facilitating open discussion of BFRB-related topics.
Prevalence, Gender Correlates, and Co-Morbidity of Trichotillomania

J.E. Grant, D.D. Dougherty, & S.R. Chamberlain

Prior to this study, most research estimating the prevalence of trichotillomania (TTM) in the US population used data from small sample sizes of college-age adults. Seeking a more accurate depiction of the disorder affecting the general population, the authors of this study used a much larger, more representative sample of the nationwide population, characterized demographic variables in the US, compared prevalence (proportion of people who have a disorder at a particular time) across these variables, and determined the incidence (rate of people developing a disorder at a particular time) of co-occurring psychiatric disorders with TTM.

The study sample included 10,169 adults, ages 18-69 years old. Participants were screened through a convenience sampling method designed to recruit a sample representative of the current US demographics. Each participant completed a survey that assessed diagnosis of TTM and co-occurring disorders. People with current TTM were asked about diagnosis, severity, and life impact of the disorder as well. The recruiting email did not include any information to bias those who participated, and the survey was actively monitored to remove respondents who behaved inauthentically.

In total, reported current (who has it right now) prevalence was 1.7% and lifetime (people who have had it sometime in their life) prevalence was 2.5%. Contrary to previous studies with smaller sample sizes, current and lifetime rates of TTM did not differ based on gender (1.8% of males and 1.7% of females for current; 2.5% of males and 2.4% of females for lifetime). Interestingly, in the 30-49 age group, prevalence rate was significantly higher in men than in women. Prevalence was higher in people under 50 (2.2%-2.6%) and 0.98% of those with current TTM (mostly men) sought help from a medical professional. The age of onset for men was significantly higher than for women, with the average age of onset for males being 19 years old but for females being 14.8 years old. However, women appear to be more psychologically impacted by hair pulling, with significantly more females (42% and 32%) than males (18% and 12% respectively) reporting severe distress from pulling hair and experiencing a “major impact” on their lives from the disorder. TTM appears to co-occur frequently with many other mental health conditions. In the TTM sample of 175 patients, 24% had co-occurring skin picking disorder, 53% had an additional anxiety disorder, 45% also had depression, 29% also had ADHD, 29% with PTSD and 29% with OCD. In those with specific co-occurring disorders, 32.2% rated TTM more bothersome than anxiety, 32% rated TTM more bothersome than their depression, 54.9% were more bothered by TTM than their OCD, 53.3% were more bothered by TTM than their ADHD, and 52% were more bothered by TTM than their PTSD.

Key takeaways include that contrary to most other studies, TTM seems to be as common in men as in women, prevalence is fairly consistent across ethnic groups and not affected much by socioeconomic status or education level, and TTM is frequently co-occurring with several other mental health conditions. Limitations of the study include using survey data instead of in-person clinical interviews and receiving the data from an external source conducting market research and thus not having access to additional information that could help understand these findings. Overall this study is the first to bring to light more realistic prevalence rates, demographic associations, and co-occurring expression of TTM in the US population.
PREVALENCE, GENDER CORRELATES, AND CO-MORBIDITY OF TRICHOTILLOMANIA

10,169 ADULTS TOOK A SURVEY TO ASSESS TTM DIAGNOSIS, SEVERITY, AND LIFE IMPACT

PREVALENCE
1.7% CURRENT
2.5% LIFETIME

GENDER
SIMILAR RATE OF CURRENT AND LIFETIME TTM IN MEN AND WOMEN

CO-MORBIDITY
ANXIETY DISORDERS ARE MORE LIKELY TO CO-OCCUR THAN OTHER BFRBS.
53% OF PARTICIPANTS HAD ANY ANXIETY DISORDER

KEY TAKEAWAYS INCLUDE A SIMILAR PREVALENCE BETWEEN GENDERS AND ACROSS DEMOGRAPHIC VARIABLES, AND FREQUENT CO-OCCURRENCE WITH OTHER MENTAL HEALTH CONDITIONS

THIS IS THE FIRST TTM PREVALENCE STUDY TO USE A MORE REPRESENTATIVE SAMPLE OF THE US POPULATION.
NAIL CARE FOR HEALTHCARE WORKERS DURING COVID-19 PANDEMIC

NAILS SERVE MANY FUNCTIONS:

SENSORY
PROTECTIVE
MOTOR

THEY CAN ALSO BE A HIDING PLACE FOR PATHOGENS INCLUDING THE COVID-19 VIRUS

NAIL CARE GUIDELINES

1. KEEP NAILS SHORT AND TRIMMED
2. DON’T SKIP UNDER YOUR NAILS WHEN WASHING YOUR HANDS
3. AVOID ACRYLICS, SURFACE COATINGS LIKE GELS, AND EVEN REGULAR NAIL POLISH AS MUCH AS POSSIBLE
4. CLEAN/STERILIZE NAIL CARE TOOLS, AND DON’T SHARE THEM WITH OTHER PEOPLE
5. MOISTURIZE HANDS OFTEN TO COMBAT DRYNESS FROM HAND SANITIZER / HAND WASHING
6. TRY NOT TO DAMAGE THE NAIL BARRIER, AND SEEK TREATMENT IF YOU SEE SIGNS OF A NAIL DISEASE OR INFECTION
7. IF YOU HAVE A NAIL-RELATED BFDB, KEEP YOUR FINGERTIPS COVERED BY BAND-AIDS, FINGER COVERS, ETC.
Nails serve important sensory, protective, and motor functions, and the nail area is often a place where pathogens can be carried. In light of the COVID-19 pandemic, and especially since the amount of time novel coronavirus remains stable on skin and nail surfaces is still not well-understood, a group of dermatologists authored a short article concerning nail care guidelines that healthcare workers should follow in order to minimize risk of virus transmission from the nails. People in the BFRB community (and beyond) should also be aware of these guidelines, even if they are not healthcare workers, in order to take appropriate action to keep themselves safe. The Center for Disease Control and Prevention (CDC) and the World Health Organization (WHO) have also set guidelines for hand hygiene specific to healthcare workers, but nail care is mentioned only briefly.

With respect to general nail care, it is recommended to keep nails short and well-trimmed, although not to excess, because excessive trimming or cuticle cutting can disrupt and expose the nail barrier. During handwashing, it is extremely important not to miss the undersurface of the nails. Acrylic nails or surface coatings like gel have low clearance of virus—meaning virus particles are more persistent on or underneath these surfaces—and even nail polish that has chipped or been worn for more than four days is more likely to harbor pathogens that are more resistant to handwashing. Nail care tools should be cleaned and sterilized after each use, and never shared. Additionally, frequent handwashing or use of alcohol-based hand sanitizers can dry out the hands, so it is highly recommended to moisturize hands often, at least twice a day.

Dermatologic diseases of the nail can include psoriasis or infections, and the article suggests to immediately seek treatment if signs of one of these diseases arises, in order to minimize risk of further infection. It also briefly mentions psychological nail disorders, like onychophagia (nail biting), onychotillomania (nail picking), and onychodaktyomania (nail biting/chewing between teeth). Nail biting or picking is strongly discouraged, and the authors recommend limiting access to fingertips covered with a variety of methods (e.g., band-aids or finger covers) in order to prevent contact between the nailbed and mouth.
In contrast to Obsessive Compulsive Disorder, trichotillomania (TTM) has significantly fewer studies using neuroimaging to examine brain structure and function differences. Even fewer studies are done in children. Prior studies found the pregenual anterior cingulate cortex (pACC), caudate, putamen, and white matter tracts in the cortico-striato-thalamo-cortical (CSTC) loop circuits to have differences in patients with TTM and OCD. The CSTC functions in movement, habit formation, reward processing, and emotion. In the CSTC, the neurotransmitters glutamate (Glu) and GABA work together as excitatory and inhibitory neurotransmitters, respectively, and an imbalance in that system could contribute to TTM symptoms. This study looks at Glu and GABA levels in areas of the CSTC before and after behavioral treatment in a pediatric sample, and looks for associations between Glu and GABA in CTSC structures and TTM diagnosis, severity, and treatment response.

This study used a sample of nine girls with TTM and no prior treatment history, and 13 female, age-matched controls. The patients with TTM completed psychiatric diagnostic interviews and TTM symptom severity inventories. The patients were given behavioral therapy once a week for eight weeks. Proton magnetic resonance spectroscopy (MRS) was used to assess the brain chemistry of the CSTC structures of interest.

Participants with more severe TTM symptoms had more Glu in their pACC and thalamus before behavioral treatment, while patients with less severe symptoms had higher GABA levels in the pACC. This means that there is more excitatory activity in the pACC and thalamus in more severe TTM. This finding suggests that TTM patients’ pACC may be more sensitive to the excitatory effect because the Glu levels were within normal range. The second finding in the study was that GABA levels increased by 69% in the putamen after behavioral treatment. This increase in GABA may affect the whole CSTC loop and ultimately decrease excitation of the brain cortex, reducing symptoms. Lastly, certain areas of the CSTC pathway had higher excitation pre-treatment while other areas had higher inhibition. Greater excitation in the putamen, caudate, thalamus, and white matter were predictive of better treatment response, while higher inhibition in the caudate and lower inhibition in the globus pallidus predicted worse treatment response. This demonstrates the cascade effect of the CSTC loop pathways, where an accumulation of minor changes can result in more severe TTM.

This study was limited by a very small sample size and gender homogeneity. There are also limitations to MRS studies in how the amount of a neurotransmitter correlates to the total quantity of the neurotransmitter. The imaging also was not able to get metabolite endpoints for every area of interest due to quality control. It is important to show the chemical changes in the brain that behavioral therapy provides, because the concrete evidence of brain changes and mechanisms support the efficacy of treatment. Furthermore, response prediction could play an important role in getting patients a therapy targeted for their type of trichotillomania and speed up symptom relief.
NEUROCHEMICAL CORRELATES OF BEHAVIORAL TREATMENT OF PEDIATRIC TRICHOTILLOMANIA

Neuroimaging studies are an important part of psychiatric research, and few have been done in trichotillomania, especially in children.

Controls

9

13

With TTM

Measured GABA and glutamate in CTSC loop structures before and after therapy.

Glutamate = excitatory

GABA = inhibitory

69% increase in GABA in the putamen after therapy.

CTSC loop is important in movement, habit formation, reward processing, and emotion.

Glutamate in pACC and thalamus in patients with severe symptoms.

Higher glutamate levels in several areas before treatment predicted better response.

Higher GABA levels in the caudate and lower GABA in the globus pallidus before treatment predicted better response.

Knowledge of behavioral treatment effects and predictors of response could lead to more targeted behavioral and pharmacologic treatments.

By the Numbers

# Total Publications

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<th>Year</th>
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Participant Age Groups in Experimental Studies

- **10%** Older adults (age 51-99)
- **51%** Adults (age 23-50)
- **42%** Children (age 0-10)
- **18%** College-age (age 18-22)
- **16%** Adolescents (age 11-17)

Lead authors from **55** countries

1. United States
2. India
3. Turkey
4. United Kingdom
5. Pakistan
6. Brazil
7. Australia
8. Italy
9. Germany
10. South Korea
By the Numbers

3 Years
And….

37 Article summaries
17 Misconception Mondays

3 Journal clubs
3 Conference zines
2 Awareness weeks
1 Conference panel

Thank YOU for your support ! 🔥
BFRBS ARE ASSOCIATED WITH BEING A 'CREATURE OF HABIT'

WHY DO SOME PEOPLE DEVELOP A BFRB?
Some think it may be because people with BFRBs have a 'habitual personality type' (i.e., people who rely most on habits and routine in life are those most likely to develop a BFRB).

PARTICIPANTS AND METHODS
40 adults with BFRBs and 40 adults without were tested on how much they prefer familiarity over novelty in their life and how often they performed 6 types of habitual behaviors:
- "core" BFRBs
- other BFRBs
- object-focused behaviors
- movement behaviors
- mental routines
- checking behaviors

RESULTS
People with BFRBs performed behaviors in all 6 categories higher than people without them. They also had a higher preference for routine, even after taking anxiety levels into account.

WHAT DOES THIS MEAN?
The study provided evidence for the role of excessive habit learning in BFRBs and that BFRBs may also be a manifestation of a broader executive control deficit in the brain. The evidence isn't strong enough to make causal claims but provides a link to investigate further.


THE TLC FOUNDATION
Young Adult Action Council
Body-Focused Repetitive Behaviours are Associated with Being a ‘Creature of Habit’

C.M. Dodds & D. Windget

Of the numerous theories on the possible causes of BFRBs, one of the most popular is emotion regulation theory, which claims engaging in BFRBs provides relief from most negative emotional states, like anxiety. However, the major gap in this theory is that it doesn’t explain how BFRBs become deeply ingrained habits, nor does it explain which people are most prone to developing BFRBs. A potential solution is the idea of a ‘habitual personality type,’ where the people who tend to prefer routine to excess are the same people most likely to develop compulsive behaviors like OCD or BFRBs. Routinization, or the execution of behaviors in the same manner over time, tends to increase with age, is associated with negative emotions and poor cognitive flexibility, and is also linked to OCD symptoms. The purpose of this study was to explore the possibility of a habitual personality type in BFRBs – the authors hypothesized that people with BFRBs will also report a wider range of habitual behaviors than a control group, and a higher preference for familiarity over novelty in their everyday lives.

The sample consisted of 80 adults aged 18-50 in the UK, 40 people who regularly engaged in at least one BFRB and 40 controls. Each participant was given the Habitual Behaviors Checklist questionnaire, which looked at how often participants performed behaviors in six categories: BFRBs (‘core’ BFRBs like hair pulling or skin picking), other BFRBs, object-focused behaviors (touching/handling a possession in a special pattern), movement behaviors (repeating an activity a certain number of times or until it ‘feels right’), mental routines (like spelling or counting internally), and checking behaviors (like in OCD). They were also given the Creature of Habit Scale (COHS), which assessed their preferences for familiarity over novelty in everyday life.

People with BFRBs were found to perform all six types of habitual behaviors significantly more often than people without BFRBs. Unsurprisingly, the BFRB category was the most frequently performed of all the categories with the exception of checking behaviors, which occurred even more frequently than the BFRBs. The BFRB group also scored higher than controls on the COHS, even after controlling for general and social anxiety, which was also higher in people in BFRBs. The results supported the authors’ hypotheses that BFRBs are associated with a widespread presence of habit and routine across the daily lives of people with BFRBs.

The authors claim the results of this study suggest BFRBs should be treated as one manifestation of a broader executive control defect in the brain that is not limited just to grooming behaviors. However, the evidence is not quite strong enough to make this claim. The average behavior severity in the BFRB group was lower than what’s required to warrant a clinical diagnosis, and the results were only proof of an association, not a causal link. It is also unclear how multiple habitual behaviors interact to influence BFRB symptoms, or how rigorously the COHS survey was tested beforehand. Despite the limitations, the study is an excellent starting point in providing support for excessive habit formation in the brain as an important component of why people develop BFRBs, with individual differences in preference for habits as one part of the explanation for the variation in BFRB symptoms.
Prevalence of Skin Picking (Excoriation) Disorder

J.E. Grant & S.R. Chamberlain

This study is the first nationwide assessment of the prevalence of skin picking disorder (SPD). Previous studies were limited by small sample sizes and age range, leading to variable estimates of SPD prevalence. The authors of this study sought to determine SPD prevalence from a large sample size representative of the United States population, rates of co-occurring disorders in people with SPD, and the gender distribution of the disorder.

The sample consisted of 10,169 adults, aged 18-69 years old, and data were collected as part of market research for a client interested in developing new treatments for trichotillomania. Demographically the age, gender, education, race and annual household income reflected the general U.S. population. Overall, 2.1% of participants reported currently having SPD, and 3.1% reported having SPD in their lifetime. 55.8% of those with SPD identified as female, and the average age of those with the disorder was 38.8 years. Participants with current SPD were significantly younger (average 38.8 vs. 43.5 years) and more likely to be female compared to those who have never had SPD. Those with SPD were more likely to be white (84%) compared to those who have never had SPD (73.8%). The most commonly co-occurring disorder with SPD was generalized anxiety disorder (63.4%), followed by depression (53.1%), panic disorder (27.7%), PTSD (27.2%), OCD (26.3%), ADHD (23.5%), eating disorder (19.3%), drug or alcohol abuse (16%), trichotillomania (12.7%), bipolar disorder (12.2%), and tic disorder (7%). Interestingly, SPD co-occurred with mood disorders like depression and anxiety more highly than with other BFRBs, like TTM. Overall, this is the most definitive study to date showing SPD to be a prevalent mental health disorder in the U.S. population, co-occurring frequently with mood/anxiety disorders, impulsive, and compulsive conditions.

One major limitation of this study was the lack of ability to deduce information from the sample regarding age of onset, triggers and neurobiology of SPD since the study was based on market research data provided to the authors. Additionally, self-reported data might not accurately reflect rate of SPD diagnoses from clinical assessments. However, the design allowed for a very large sample size, making this study the first to assess SPD prevalence in a sample that is demographically representative of the United States population.
PREVALENCE OF SKIN PICKING (EXCORIATION) DISORDER

10,169
LARGEST SAMPLE IN A PREVALENCE STUDY

2.1% HAD CURRENT SPD
3.1% HAD LIFETIME SPD

REPRESENTATIVE OF THE US IN TERMS OF AGE, GENDER, EDUCATION, RACE, AND HOUSEHOLD INCOME

CO-OCCURRING DISORDERS

SPD IS A COMMON DISORDER IN THE US, GIVING THE DIAGNOSIS LEGITIMACY AND HOPEFULLY LEADING TO FUTURE TREATMENTS.

THE LARGE SAMPLE SIZE MAKES THIS STUDY POWERFUL.

SPD CO-OCCURS WITH MOOD AND ANXIETY DISORDERS MORE THAN TRICHOTILLOMANIA.

THUMB SUCKING OR NAIL BITING IN CHILDHOOD AND ADOLESCENCE IS ASSOCIATED WITH AN INCREASED RISK OF CROHN’S DISEASE: RESULTS FROM A LARGE CASE-CONTROL STUDY

The researchers hypothesize that nail biters and thumb suckers will have lower rates of IBD. Irritable bowel diseases, like Ulcerative Colitis (UC) and Crohn’s Disease (CD), have many suspected causes and risk factors. Nail biters and thumb suckers have been found to have higher bacterial counts and variety in their oral cavities.

THE HYGIENE HYPOTHESIS
A prevailing theory on the development of Inflammatory Bowel Diseases. It states that strong hygiene practices in childhood reduces microbial exposure, creating immunological imbalances which increases the risk for IBDs.

918 pairs of UC or CD patients and an unaffected sibling

Participants completed a survey on disease, characteristics, environmental factors, and nail biting/thumb sucking in childhood

49% of IBD patients reported nail biting or thumb sucking

while only 44% of their unaffected siblings did

This result was investigated further, and found that the difference only existed between CD patients and siblings, and not the UC pairs.

The data from the study contradicted the researchers’ hypothesis and the hygiene hypothesis, by demonstrating that more IBD patients were nail biters or thumb suckers in childhood than non-affected siblings.

This study leaves room for more research into nail biting and thumb sucking as risk factors of IBD.

Ulcerative colitis (UC) and Crohn’s disease (CD) are types of inflammatory bowel diseases (IBD) with a suspected multifactorial cause, including genetic and environmental factors. One of the prevailing hypotheses for the development of these diseases is the hygiene hypothesis, which suggests improved hygiene practices in childhood create immunological imbalances in the intestine due to less microbial exposure, which leads to greater rates of UC and CD. Childhood and adolescent nail biting is considered harmless and usually disappears, though it can be associated with psychological disorders, including onychophagia (compulsive nail biting disorder). Previous studies have shown higher counts and variety of bacteria in the oral cavity of nail biters compared to non nail biters. This paper theorizes that the higher count and variety of pathogens that nail biters and thumb suckers are exposed to in childhood and adolescence would lead to a decreased risk of IBD later in life.

918 pairs of UC or CD adults and their closest-age sibling without UC or CD were studied. Patients and siblings filled out the same survey asking questions about characteristics, environmental factors, and nail biting and thumb sucking in childhood and early adulthood.

The study found that 49% of IBD patients reported occasional or frequent thumb sucking or nail biting, while only 44% of their non affected siblings did. Further analysis on this relationship found that it only applied to CD pairs (50% vs. 41%), not UC pairs (49% vs. 48%). Furthermore, the difference between CD patients and siblings nail biting and thumb sucking habits were significant at both school enrollment and coming-of-age time points. The researchers looked closer into CD subtypes and characteristics, and found the largest differences between siblings in patients with fistulizing CD, women, and patients who were diagnosed over the age of 20.

The results from this study actually contradicted the hypothesis the researchers formulated, as well as the hygiene hypothesis. Unexpectedly, nail biting or thumb sucking in childhood and adolescence was associated with a higher risk of IBD, especially of CD. The study was a retrospective study, which brings in the possibility of recall bias, though some of it may have been mitigated by using a sibling as the control so that environmental experiences were shared. Another weakness of the study is the difficulty of defining ‘occasional’ and ‘frequent’ nail biting or thumb sucking retrospectively. The study’s results focus only on labeling thumb sucking and nail biting as possible new risk factors for IBD that need further investigation. More research could also yield recommendations for people who are at higher risk of IBD to avoid nail biting or thumb sucking to help reduce risk.
Identifying Subtypes of Trichotillomania (Hair Pulling Disorder) and Excoriation (Skin Picking Disorder) Using Mixture Modeling in a Multicenter Sample

J.E. Grant, T.S. Peris, E.J. Ricketts, C. Lochner, D.J. Stein, J. Stochl, & N.J. Keuthen

One major objective of recent BFRB research has been to generate a strong set of subtypes. We know there is a great deal of variation in hair pulling and skin picking because many people relapse from even the best-quality treatments, and they may differ widely on clinical characteristics (like perfectionism or sensory sensitivity). Past studies have had small sample sizes and inconsistent findings, so as part of the BPM Initiative—the large-scale study conducted to gain more detailed understanding of the features of BFRBs—this study aimed to be the largest study so far to subtype hair pulling and skin picking disorders, using gold-standard questionnaires and statistics.

279 adults were recruited—100 with hair pulling disorder (HPD), 81 with skin picking disorder (SPD), 40 with both, and 58 controls without any psychiatric problems. The three clinical groups were all between 83-90% female. Subjects had a diagnostic interview with a clinician to confirm their BFRB diagnosis, completed a computer test with different cognitive tasks, and filled out a long set of questionnaires. The questionnaires included questions on BFRB symptom severity, other psychiatric disorders, family psychiatric history, quality of life, picking/pulling style, emotion regulation, sensory sensitivity, disability, perfectionism, and impulsivity. The authors used mixture modeling, a statistical technique that finds ‘hidden’ variables in large amounts of data and proposes classes of subtypes. After identifying the subtypes based mainly on BFRB-specific variables (e.g., severity of urges and pulling/picking style), the subtypes were then compared on all the other variables (e.g., perfectionism, impulsivity, etc.) to see if they differed.

Using this method, the authors found 3 different subtypes of HPD and 2 subtypes of SPD. The first category of hair pulling, which had the fewest people, was labeled ‘sensory sensitive pullers’ for this group’s high scores in sensory sensitivity, along with lower frequency of pulling and urges overall. The second category had the most people, was called ‘low awareness pullers’, and was characterized by high automatic pulling and high impulsivity and ADHD. The third category, ‘impulsive/perfectionist pullers’ had the highest scores on both impulsivity and perfectionism, with high depression and low ability to regulate emotions, and would pull mainly to control negative emotions. The first category of skin picking, which had twice as many people as the other category and was labeled ‘emotional/reward pickers’, had strong and frequent urges to pick, with both focused and automatic qualities, high perfectionism and low emotion regulation, and high levels of ADHD/mood disorders. The second category, referred to as ‘functional pickers’, had fewer emotional problems, higher sensory sensitivity, with less severe picking overall. One of the main issues with the study was that these subtypes have too much overlap to easily tell which subtype someone would belong to; subjects could easily fall into multiple subtypes, or be unclear which subtype best applies to them.

This study is a milestone when it comes to how BFRBs are categorized. First, the finding that HPD and SPD have different subtypes supports their being treated separately, rather than like 1 general BFRB disorder. It describes in detail the clinical characteristics of each subtype, which could be used as treatment targets, and it rules other characteristics less important as previously thought, like age of onset. There are still some uncertainties, particularly around the SPD subtypes, which look like they could just be a spectrum of severity instead of distinct subtypes. Overall, the study needs to be confirmed by other research, and it also needs to be translated in a way that makes it simple for people (and their therapists) to tell what subtype they fall into. But as the first publication out of the BPM Initiative, it makes for a long-overdue and well-executed starting point.
Identifying Subtypes of Trichotillomania (Hair Pulling Disorder) and Excoriation (Skin Picking) Disorder Using Mixture Modeling in a Multicenter Sample

1st paper to be published from TLC’s BFRB Precision Medicine Initiative (BPM)!

Goal: to come up with subtypes for hair pulling disorder (HPD) and skin picking disorder (SPD)

279 adults:
100 HPD, 81 SPD, 40 both, 58 controls

2 stages:
1. using a statistical model to come up with subtypes based on BFRB-specific variables
2. comparing the different subtypes across other variables (like perfectionism, ADHD, etc.)

3 subtypes of HPD:
1. Sensory sensitive pullers: smallest category, high sensory sensitivity, low urges, low pulling
2. Low awareness pullers: largest category, high automatic pulling, high impulsivity, high ADHD
3. Impulsive/perfectionist pullers: high impulsivity, high perfectionism, low mood, low emotion regulation, high focused pulling

2 subtypes of SPD:
1. Emotional/reward pickers: largest category, high urges, both focused and automatic, high perfectionism, low emotion regulation, high ADHD, low mood
2. Functional pickers: smallest category, high sensory sensitivity, low ADHD / depression, low urges, low picking

HPD and SPD having different subtypes supports the idea they are different disorders!

This study was only a first step – next, it needs to be:
- Confirmed by other research
- Translated into a way to easily find out what subtype you’re in

Cognitive Reappraisal and Types of Skin Picking - A Longitudinal Study with Pre-Pandemic and COVID-19 Pandemic Data

This study examined changes in skin picking during the COVID-19 pandemic, between automatic and focused pickers, and how cognitive reappraisal, a flexibility technique that reevaluates negative stimuli, affected picking.

Both psychological and demographic measurements were taken at three different time points: before the pandemic, during strict lockdown, and during eased restrictions.

Cognitive reappraisal and time did not have an effect on automatic picking, but cognitive reappraisal did decrease focused picking.

Time and cognitive reappraisal combined decreased automatic picking, but only during the first time point (before the pandemic).

These results showed that picking did not change significantly during the pandemic and that there was no difference between automatic and focused picking during either lockdown time:
- There was also no change in perceived stress and loneliness during either lockdown time.
- Authors think this may be because participants were locked down with family or other people.

Cognitive reappraisal, however, was shown to decrease picking, confirming results from previous studies.

Skin picking has been shown to have different subtypes: focused and automatic. Focused picking occurs in the person’s consciousness, while automatic occurs outside of consciousness. It is also common to find mixed pickers who engage in some of both. Prior research has found that states of exaggerated tension/overstimulation and understimulation can trigger picking, which demonstrates that picking may be used to regulate emotional states. Cognitive reappraisal is a flexibility technique that re-evaluates emotional stimuli to change the intensity, usually of negative emotional stimuli. The major changes during the COVID-19 pandemic were abrupt and had the potential to increase anxiety and worry. The authors hypothesized that both focused and automatic skin picking would increase during the COVID-19 pandemic, but that a tendency to use cognitive reappraisal would decrease picking.

Participants in this study were recruited via the internet with 190 in the first time period (pre-COVID-19 pandemic), 49 in the second time period (during lockdowns), and 32 in the third time period (lighter lockdowns). Participants took several psychological measurements looking at skin picking, emotion regulation, loneliness, stress, and other demographic and environmental factors.

Cognitive reappraisal and time combined did not have an effect in automatic picking, while in focused skin picking, cognitive reappraisal did have an effect, but not of time. The effect of both cognitive reappraisal and time together was also investigated for both types of picking. The combination effect was significant in the case of automatic picking, and when examined closer, this effect was only significant at time one, before the pandemic. The combination effect was not significant during any time point or overall for focused picking.

The data collected in this study did not confirm the researchers’ hypothesis. Instead, it showed that skin picking did not increase during the pandemic, and that there was also no difference between automatic and focused pickers in the full lockdown and lightened restrictions time periods. This lack of changes also matches with the lack of significant change in perceived stress and loneliness measurements. The authors suggest that this may be because participants were quarantining with family or other people, so no one was completely isolated. The results from this study did confirm that cognitive reappraisal is correlated with decreased skin picking, as previous studies have shown. Some weaknesses in the study are that it was all self-report based, the participant number dropped significantly from time point 1 to time points 2 and 3, and baseline stress and loneliness were not measured.
TTM often co-occurs with OCD, but some cognitive functions might differentiate the two, including performance monitoring, which can be measured via error-related negativity (ERN), and inhibitory control. ERN is a brain activity response that can be seen when someone realizes they have made an error while doing a cognitive task. Electroencephalogram (EEG) is a non-invasive way to measure electrical activity in the brain, and in this study, researchers used EEG to track ERNs during incorrect trials and to measure inhibitory control during correct responses. This is the first study using EEG to look at TTM and OCD differences in children.

The sample consisted of 22 children with TTM, 22 with OCD, and 19 healthy controls. EEG recordings were taken during a version of the Eriksen Flanker Task, which has been shown to reliably evoke ERNs during error trials. Researchers found that at one EEG location, ERNs were larger for OCD patients compared to controls, but insignificantly different between TTM patients and controls, suggesting that performance monitoring is impaired in children with OCD but not in children with TTM. Overall, brain activity between TTM and control groups was similar in frontal and central brain regions, whereas brain activity between TTM and OCD groups was similar in the parietal (side) region of the brain. The TTM group had higher theta power than the OCD group in frontal and central brain regions (theta wave range tends to occur during inhibitory control processes in healthy controls, so the TTM group was more similar to the controls). Theta power indicates a specific frequency of brain waves that underlies various aspects of cognition, or the inhibitory control process in this study.

Overall, results suggest that electrophysiological patterns in TTM resemble controls in terms of cognitive inhibitory control, and patterns more similar to OCD in terms of global functioning and clinical impairment. Limitations to this study include a relatively small sample size, the fact that OCD patients were not grouped by subtype, and the fact that participants were not screened for co-occurring psychiatric disorders. The study results will help researchers determine EEG markers that could be used to inform future treatment for TTM patients involving resetting EEG wave patterns in the brain.
Shared and Unique Neural Mechanisms Underlying Pediatric Trichotillomania and Obsessive Compulsive Disorder

There have been no EEG studies in pediatric TTM and OCD populations.

The Eriksen Flanker task was used to look at performance monitoring and inhibitory control.

Participants have to indicate the direction of the middle arrow as quickly and accurately as possible.

EEG is a non-invasive way to measure electrical activity in the brain.

This study included 22 OCD, 22 TTM, and 19 Controls.

More negative activity in OCD vs. controls, compared to TTM vs. controls.

Performance monitoring may not be impacted in children with TTM.

Activity in the frontal and central regions in TTM was similar to controls.

Activity in the parietal region in TTM was similar to OCD.

EEG patterns in TTM patients looked similar to controls for inhibitory control.

EEG patterns in TTM vs. OCD vs. control groups may help better inform researchers about potential treatments for TTM involving re-setting EEG wave patterns in the brain.

Professor YAAC Breaks Down the BPM

What is our goal?

Find new, more effective treatments for BFRBs through behavioral, genetic, and biological aspects that can be individualized.

2014 - 2023
- $2.6 million raised for phase 1
- Recruitment begins
- Recruitment complete
- 311 adults
- 53 kids
- Phase 1 complete
- Journal articles submitted
- Phase 2 treatment research

BPM = BFRB Precision Medicine Initiative

Data Collection → Data Analysis

- BFRB subtypes based on questionnaires and analysis of clinical differences
  - Structural and connectivity analyses
  - Under review
- Clinical comparison of response inhibition
  - Complete draft
- Understanding of neural correlates of reward learning and associative learning task performance
  - Preliminary findings
- Developmental features of BFRBs during childhood and adolescence
  - Genetic analysis of TTM heritability and heritability between TTM and other ODRS
- 

Brain and DNA strands symbolize the genetic and behavioral aspects.