

The hidden epidemic of compulsive hair pulling

August 21 2018, by Sara Talpos



Credit: CC0 Public Domain

Christina Pearson was 14 years old when she started pulling out her hair, creating bald patches on her head. She was taken to a psychiatrist, but in 1970 there was no name for her disorder, and certainly no treatment.

The doctor issued a psychiatric discharge that removed Pearson from high school. In that moment, she felt relief. Going to high school meant that somebody might pull off her hat and reveal that her head was mostly bare – a possibility she found "so frightening that anything was better than that."

In the ensuing months, Pearson holed up at home, pulling out her [hair](#) and feeling, she says, like a monster. Scared and searching for relief, she eventually decided to leave. "I hitchhiked across Mexico at 14 and was doing peyote out in the desert, all kinds of things," she says. "I really lived a very fringe life." At 15, she started picking her skin, her body frequently covered with open sores. By 20, she was addicted to drugs and alcohol.

At the age of 30, Pearson "finally got sober." She had started a small telecommunications business with a friend in Santa Cruz, California. In 1989, she received a phone call from her mother, who had just listened to a story on the radio about a study published in the *New England Journal of Medicine*. "There's a name for what you used to do," Pearson's mother told her, not knowing that Pearson still pulled her hair. The news that there was a name – trichotillomania – "rocked my world," she says.

After decades of feeling shame and isolation, she began to feel hope:

there were others out there living with the same condition. Pearson started a support group. A Seattle news network invited Pearson to appear on air, where she spoke about her life and provided a number for a trichotillomania hotline that she planned to operate herself.

She returned home to over 600 messages.

"People were crying and sobbing and begging for help," says Pearson, who spent a week calling each person back. "It was the best therapy I ever had, because I heard my life coming out of other people's mouths."

One night in bed she had what she calls a peak experience, or spiritual vision. Pearson decided to walk away from her business and devote her life to improving public awareness of trichotillomania. "I was scared shitless. Me: I'm a drug addict, I'm a small-business person, I'm in sobriety, I have an eighth grade education, and I'm going to get out there and change the world and some weird pathological disorder?" says Pearson. "I just was terrified."

But then she adds: "When we receive that kind of inspiration, what I'll say is this: We are called all the time. Rarely do we choose to respond."

Step into any classroom or coffee shop and, the odds are, at least one person in the room has a body-focused repetitive behaviour (BFRB), such as trichotillomania or skin picking disorder.

People with BFRBs perform repetitive self-grooming activities such as picking, pulling or biting. These can cause emotional distress and damage to the body, but the people performing the behaviours can't stop. At their most extreme, these conditions are life-threatening.

A significant minority of people with trichotillomania (commonly called 'trich') ingest their pulled hairs. Over time, the hair can block the

intestine and require surgical removal. Skin picking can lead to infections that require intravenous antibiotics and skin grafting.

More commonly, BFRBs take an emotional and social toll. They often begin in late childhood or early adolescence, making kids vulnerable to bullies. Echoing the experiences of many, a man in his late 20s described middle school as "absolute hell" because kids perceived him as "the weird kid with missing eyelashes." Another woman, now 30, recalled watching her classmates play keep-away with the wig they had snatched off her head. Furthermore, BFRBs are often a source of conflict between child and parent, which can heighten a child's feelings of shame and isolation. Meanwhile, in adults the condition can lead to fear of intimacy, missed job interviews, and hours lost each day to picking and pulling.

Individuals living with BFRBs often keep their condition a secret, hiding the physical effects with make-up, wigs and layers of clothing.

As a result, many are surprised to learn just how common these disorders are. Some experts estimate that 2–5 per cent of people have trich and roughly 5 per cent of people have skin picking disorder, also referred to as 'dermatillomania' or 'excoriation disorder.'" Precise numbers are not available, however, because there has been no large-scale global study of BFRBs.

Although trich has appeared in the medical literature for over a century, it was not officially included in the DSM (the Diagnostic and Statistical Manual of Mental Disorders, published periodically by the American Psychiatric Association) until 1987 – a full 17 years after Pearson made her first visit to a psychiatrist, and six years after I entered the first grade and started pulling my hair too.

My mother took me to a dermatologist, who didn't offer any advice. As

it turned out, I was part of a subset of kids – including toddlers and even babies – whose symptoms simply go away without any kind of treatment. By the end of the school year, my hair pulling had stopped. For most individuals, BFRBs are chronic, lasting years, even decades.

Skin picking disorder was added to the DSM in 2013. "We were over-the-moon ecstatic when it was given its own diagnostic label," says Nancy Keuthen, director of the Trichotillomania Clinic and Research Unit at Massachusetts General Hospital. A diagnostic label validates people's experiences and encourages them to seek treatment, she says. In the absence of a name, the tendency had been to think, "I don't know anybody else who has this, I must be really weird," explains Keuthen.

Now, both disorders are included in the chapter on obsessive–compulsive and related disorders. On the surface, OCD and BFRBs share similar characteristics: both involve strong urges to perform repetitive behaviours. But unlike OCD compulsions, BFRBs are soothing, even pleasurable. And the behaviours are rarely the result of the specific obsessions that characterise OCD.

This distinction matters because the conditions benefit from different kinds of behavioural therapies; and whereas medication is a first-line treatment for OCD in the USA, for example, there currently is no Food and Drug Administration-approved medication to treat BFRBs.

In fact, compared with better-known psychiatric conditions such as OCD, BFRBs remain markedly under-researched. "Historically, there has been almost no funding for these disorders," says Keuthen. Funding usually goes to conditions that are seen as significantly affecting quality of life or that make it difficult to function in the workplace.

BFRBs can do both, but, says Keuthen, they have been misunderstood as "bad habits that lazy people have." This obscures the critical distinction

between ordinary self-grooming (who doesn't occasionally pick a scab or pluck a hair?) and the clinical case where the behaviour goes on and on, causing significant distress or impairment, while the person feels wholly unable to stop.

Christina Pearson founded the Trichotillomania Learning Center (since renamed the TLC Foundation for Body-Focused Repetitive Behaviors) in 1991. Her goal was to help people, especially kids, avoid the fear and secrecy she had lived with for so long.

She wanted to offer authoritative information that could help people. There was just one problem: that information didn't exist.

There was also an incredible amount of stigma. At least some of this can be traced back to the medical literature of the 1950s and 60s, which tended to blame the parents, particularly mothers, of individuals who pulled their hair.

One report from that period examined 11 children with trich. The authors, professionals at the US National Institute of Mental Health, concluded that the children's behaviour stemmed from intense conflict "between the child and the original love object, the mother." The children, they wrote, pulled their hair "with large amounts of libido" and used hair pulling as a substitute for an emotionally unavailable mother.

About the fathers, they wrote: "[They] can best be described as passive-aggressive individuals, mostly of a passive type who were persistently controlled by their spouses."

Perhaps this is why when Pearson was taken for treatment, the psychiatrist asked her mother, "What are you doing to [your daughter]?" The question caused her mother to cry. "It was not good. It was very shaming," says Pearson.

This judgement and blame continued even after trichotillomania was added to the DSM. Pearson began renting booths at professional conferences. In the early years, psychologists would walk by and actually make fun of her, pulling their own hair. Pearson says that one dermatologist warned her that people who pick their skin and pull their hair are "often psychotic."

She recalls one young man who had been told by a mental health professional that pulling out his hair was like public masturbation and he needed to stop. In another conversation, a Swedish doctor insisted that Swedes don't get trich. Pearson suspects that some of the stigma stems from the fact that grooming is associated with other animals – cats, dogs, mice – and people don't want to acknowledge humans' connection to the animal kingdom.

Something else that contributed to the misunderstanding was that trich was considered an exceedingly rare disorder. The first prevalence study wasn't published until 1991, and at the time, the DSM criteria for trich were more stringent than they are today. In addition to having a strong impulse to pull hair resulting in hair loss, individuals needed to experience tension prior to pulling and "gratification or relief" while pulling.

Consequently, researchers found that 0.6 per cent of the general US college population had met the DSM criteria at some point in their lives, but noted that among the college population, pulling leading to visible hair loss was reported by 1.5 per cent of men and 3.5 per cent of women.

In 1990, Pearson attended one of the first-ever professional talks about trichotillomania, given by a psychologist called Charles Mansueto. There, she met a number of interested clinicians, including Carol Novak, a psychiatrist from Minnesota who had written a pamphlet about trich.

"Back in those days, we had no internet. Nobody knew the word trichotillomania," says Novak, who went on to become the founding director of the TLC Foundation's scientific advisory board. Around that time, Novak, Mansueto and Richard O'Sullivan, a psychiatrist who currently practises in Madison, Connecticut, attended a retreat that Pearson had organised for people with trich. Novak remembers the participants expressing frustration and anger with the mental health field "because they had been so mistreated by professionals." Soon thereafter, more professionals agreed to join the board and conduct research in the field.

The causes of BFRBs are still poorly understood, though individuals' responses to different medications may provide clues to BFRBs' biological underpinnings. For example, medications such as Prozac, which target the neurotransmitter serotonin, have not proven effective in reducing BFRBs for most people – though experts note that some individuals may benefit.

Two small randomised controlled trials testing N-acetylcysteine (NAC), an amino acid that can be purchased in health food stores, resulted in marked reductions in both hair pulling and skin picking for roughly half of study participants (though some receiving placebo also showed improvements – 16 per cent demonstrating reduced hair pulling, 19 per cent reduced skin picking). NAC influences glutamate, a neurotransmitter involved in reward pathways. A small neuroimaging study also showed impairment of reward pathways in people with trich, but larger studies are needed to confirm these findings.

One such study currently underway is the BFRB Precision Medicine Initiative, which has been funded by TLC donors. It's taking place at the Semel Institute for Neuroscience and Human Behavior at the University of California, Los Angeles, the University of Chicago Medicine, and Massachusetts General Hospital, an affiliate of Harvard Medical School.

The goal is to test up to 300 participants using a variety of methods, including interviews, imaging and bloodwork.

Nancy Keuthen is the principal investigator at Massachusetts General Hospital. She notes that up until now, researchers have tended to study BFRBs in narrow slices. For example, a research team might run a small brain-imaging study. While this approach could uncover an interesting abnormality, it isn't especially helpful without a broader network of data to illuminate the abnormality's cause and effects. Additionally, larger sample sizes are needed to ensure that study results are generalisable to a wider population.

Liz Atkin, a British artist with skin picking disorder, is at the front of the room, setting hand wipes on tables. She wears a red cardigan over a T-shirt sporting splotches of orange, yellow, green. "We're going to get messy!" she says to four girls sitting in the front row. Her enthusiasm seems entirely genuine yet impossible for 8.30am.

It's a Saturday in April, and I'm attending the 25th annual TLC conference for BFRBs. This year, it's in San Francisco. The conference is just one of the ways that TLC aims to help people directly. I'm here with nearly 500 others, including individuals with BFRBs, their families, clinicians and researchers. This session is an art class for kids aged 11 and under.

"What we're going to do is make our marks," says Atkin after roughly a dozen kids have taken seats and introduced themselves. She holds up a stick of charcoal and explains it's a piece of wood that's been burned. "I have compulsive skin picking, and charcoal really helps me."

Atkin distributes the charcoal and paper and asks the kids to make a dot.

"Paul Klee said "A line is a dot taking a walk,"" she says, holding up her

own sheet of paper and making a black spot. From there, she demonstrates various rubbing and smudging techniques, before bringing out pastels so the kids can add colour.

"I think my drawing's going to end up looking like my cat," says the girl sitting next to me, wearing a Toronto Maple Leafs sweatshirt. Her picture does indeed resemble a calico cat with patches of black and orange.

Atkin asks if anyone wants music, and someone requests Prince.

Above the music, Atkin asks, "Is drawing a nice thing to do? Why do we like drawing?"

The group offers varying responses: Drawing calms your mind. You can express yourself. There's no wrong way to do it.

"Why are we working with stuff that's messy? Why is that useful? We're using materials that have a texture to them." Later, she'll explain to me that for many, BFRBs are texture-based disorders. Art engages the body and mind, giving the person a focus other than the BFRB.

I'm sitting in a row with a boy and a girl. I overhear the boy ask, "What's your thing? Mine's skin picking." The girl says matter-of-factly, "Mine's trichotillomania."

They fall back into silence, drawing on the black paper.

It's taken science some time to catch up with what people with BFRBs have known for years: for many, there's a strong sensory component to the disorder.

A pair of studies published in 2017 and 2018 were the first to report that

individuals with BFRBs have higher rates of sensory over-responsivity to external sensations than the general population. In other words, they respond intensely to things like sounds and textures. The phenomenon – also sometimes referred to as 'sensory integration dysfunction' or 'sensory processing disorder' – was first described in the 1970s by the occupational therapist Jean Ayres. Since then, sensory over-responsivity has been most frequently studied in association with autism, and more recently in OCD.

In one of the studies, people with trich were twice as likely to have severe to extreme sensory over-responsivity to touch and sound. One study participant described her struggle with clothing: "My tactile discomfort lies in how I feel in clothes. They always feel too tight and uncomfortable as soon as I step out of the house. For this reason, I only go out when absolutely necessary – school or work."

Later that day, it occurred to me that I have had my own experiences with sensory over-responsivity. As a child, I found almost any type of clothing itchy: tights, cardigans, sweaters, sleeves that tapered into elasticated cuffs (as seemingly all kids' clothes did in the late Seventies). I have a vague memory of being left standing in a department store after my mother had walked away, exasperated with trying to find me a winter coat.

Others at the conference share similar experiences: "I used to throw things at my brother, who was just regularly playing. I'd throw books at him because noises were too much," says one woman who still struggles with high-pitched sounds. Like many others with trich, when she pulls her hair, she's looking for a certain type.

"I'm looking for coarseness in those hairs... I'm looking for hairs that aren't straight, hairs that are curly, hairs that don't feel right – that are too long or too short. For me, it's a very tactile disorder," she says.

When researchers talk about BFRBs, they often speak of 'subtypes' to acknowledge, among other things, that people with BFRBs may pick and pull for very different reasons.

One person might pull her hair at night as a way of winding down for sleep. Another might pick his skin out of boredom. Another might pull out his eyelashes under stress. For some people, all these things and more might be triggers. Why? No one can say for sure, but many of my conversations with affected individuals included mention of the work of a psychologist named Fred Penzel.

In the early 2000s, Penzel introduced the stimulus regulation model of trichotillomania, based on his work with patients.

"It would appear that pulling might therefore be an external attempt on the part of a genetically prone individual to regulate an internal state of sensory imbalance," he writes.

According to this model, a person with a BFRB is exposed to the same levels of environmental stimulation as others, but their nervous system is unable to easily manage it. "It is as if the person is standing in the centre of a seesaw, or on a high-wire, with overstimulation on one side, and understimulation on the other, and must lean in either direction (by pulling) at different times, to remain balanced," he writes.

"Picking or pulling adds or subtracts stimulation," says Karen Pickett, an Ohio-based therapist. "I have yet to find someone that this [model] doesn't apply to, to some degree." Why does this matter? Because the picking and pulling actually serve a purpose. This is why the behaviours can be so difficult to stop.

A number of studies have found that some individuals with BFRBs have difficulty regulating their emotions. A 2013 review notes that as a group,

people with BFRBs have higher rates of psychiatric conditions such as depression and anxiety than the general population. In addition, many report that their BFRBs provide relief from negative emotions, including boredom, tension, anxiety and frustration.

Several of the people I interviewed told me their BFRBs started during a period of negative emotion. Aneela Idnani started pulling her eyebrows and eyelashes as an adolescent, after moving to a new town where she felt like an outsider and was bullied at school. For her, pulling served as a coping mechanism.

A couple of years later, Idnani's father died of cancer. "I didn't know how to deal with it," she says. "[As a society] we don't talk about uncomfortable things, and so we have to find ways to deal with them." She hid her condition into adulthood. Three years ago, she started seeing a psychologist, who helped her unpack some of her emotions.

Haley O'Sullivan started picking her skin at the age of 20, a year after a traumatic sexual experience. "It started with two hours in the mirror picking at ingrown hairs like on my armpits or my bikini line," she recalls. "It was also picking at zits on my face and other places on my body." For several years, O'Sullivan led a support group in Boston, and she's working on starting a group in New Hampshire, where she lives now. She is careful to point out that not everyone with a BFRB has experienced trauma. In her case, however, skin picking is "my body's way of trying to say, "Hey, I'm not OK."" Skin picking creates a positive sensation for her, at least in the short term: "Obviously it doesn't feel good emotionally afterwards when you're like, "Oh man, look at this damage I caused.""

O'Sullivan has seen several therapists and been successfully treated for post-traumatic stress disorder and depression. But she says she feels a little stuck in her BFRB recovery. She has done a lot of research, but

lacks access to a specialised clinician. There simply aren't enough therapists with expertise, she says. And even once you find someone, the clinician may have a long waiting list and insurance might only cover a handful of sessions. "It's not really conducive to a full recovery," she says.

Currently, the treatment for BFRBs with the most empirical support is a type of cognitive behavioural therapy called habit reversal training, developed in the 1970s as a treatment for tics. During this therapy, a person learns to recognise the context in which pulling or picking is most likely to occur. With this awareness, people can then plan to substitute a competing response. For example, when faced with an urge to pick, someone might instead make a fist, or play with a fidget toy. In some studies, more than half of adults with trich achieve short-term improvement. However, some find it difficult to maintain the results over time.

Psychologist Omar Rahman recently conducted a promising study of habit reversal training in kids with trich. He says that the goal of the therapy is to give the brain an opportunity to become habituated to the urge, meaning you can ignore it or respond with a substitute behaviour.

Over the years, Rahman has come to believe that there's really no real way around this if you can't learn to manage the urge, which may explain why habit reversal training doesn't help everyone, or why improvement doesn't always last.

For this reason, researchers and clinicians have increasingly sought to augment habit reversal training with other means of helping people with their urges. For example, mindfulness-based strategies can help a person observe and accept negative emotions, sensations and urges without needing to act on them by pulling or picking.

Christina Pearson stumbled into mindfulness in the early 1990s after a series of therapists and medications were unable to help her. "Nobody knew what to do," she says. So she started paying attention, observing her thoughts, feelings and muscle movements. "I'd been always seeking higher awareness," she says, "but now I wanted to identify the roadmap that would free me from a behavioural prison."

She notes that the kids who get BFRBs are sensitive and smart. "Do you want to drug that away? No. What you want to do is say, "Hey, how do I create the psychological trellis for this being to evolve and be of service to the world?""

Around this time, the psychologist Charles Mansueto had been seeing BFRB clients and developed the Comprehensive Model for Behavioral Treatment (ComB). This model recognises that a variety of triggers may cause someone to want to pick or pull: thoughts, emotions, sensory experiences, specific body movements (such as stroking one's hair) and environment. Today, Mansueto and his colleagues are in the process of running a randomised controlled trial to test the approach.

"We may seem like we have it together now, but we haven't always," says Bridget Perez. She and her 19-year-old daughter Gessie are leading a conference session titled "Parent/Child Journey: Building a relationship and finding acceptance." They're both wearing T-shirts that Gessie designed that say "Trichster" on the front. The room is packed.

Bridget recalls one morning when Gessie was 14 and sitting at the table eating breakfast. "I'm standing over her, and I go, "Oh my God!", because there was a huge bald spot in the back of her head." Gessie had always had very long curly hair. But over the ensuing years, she went from a "gorgeous long-curly-haired girl to having bald spots, to hiding the bald spots, to the hair thinning out and just kind of hanging."

"I screamed, I cried. I yelled. I mourned the loss of her hair," says Bridget. Like many parents, her first response was to want to fix the problem.

Unlike an earlier generation of parents, Bridget knew the word [trichotillomania](#) and was able to use the internet to find out information. They attended their first TLC conference several years ago, says Bridget. She realised: "It's not about the hair. It's about being there for your children. Supporting them, loving them, no matter what they look like."

Gessie agrees the first conference was life-changing. Living with trich had been hard. Even today, she has no eyebrows and keeps her hair short, but she considers herself in recovery "because trich doesn't control my life any more." The pulling comes and goes, but she doesn't focus on stopping.

"For me, cutting my hair, shaving my head, realising that I'm not defined by my appearance was..."

"Was pivotal," offers her mother.

They both agree that trich has made them stronger, individually and together.

Gessie says that after the first conference, she used social media to share her story. People from all over the world have reached out to ask her questions and offer their support.

"I can honestly say that I am thankful for this journey," she says. "These friends are so much better than having hair."

For all the obvious good that the TLC conference does, it's important to note that it isn't necessarily easy to attend, especially for first-timers.

One mother I spoke with described her first conference as overwhelming. "I cried a lot," she says. "You think you're going to come and fix it, and then you realise that you're in it for the long haul."

And that long haul is not clearly mapped. After all, when children are sick, you take them to a doctor. But when your child is performing an unusual yet soothing behaviour that lacks a simple cure, the choice of how to move forward is not clear cut. Parents may feel torn about how much financial and emotional energy to invest in treatment compared to accepting the condition and supporting their child in other ways.

These tensions can play out in adults, too.

For example, many people with BFRBs say that complete abstinence from picking or pulling is an unhelpful goal that may magnify self-criticism and frustration. Yet, one woman spoke positively about her experiences in Hair Pullers Anonymous, based on Alcoholics Anonymous. "We celebrate abstinence. Just think of any AA programme," she says. They use the same literature and spiritual tools. She joined the support group in January and says in the three months since that, "My hair pulling is down so much – you wouldn't even believe it." She has a sponsor she can call if she feels like she wants to pull her hair. And she's also working on self-care, a big emphasis of TLC. "Maybe that's why I'm having success," she speculates, "because I'm hitting all these things."

At the conference, the last session I go to is "Standing Tall in Our Awesomeness." It's led by Christina Pearson, who left TLC in 2013 and founded the [Heart and Soul Academy](#) in 2014. Roughly 20 kids are sitting in chairs in a horseshoe shape. I take a seat next to the girl with the Maple Leafs sweatshirt. She's here, along with the rest of the kids from the charcoal drawing session as well as others up to the age of 14.

Pearson comes in with a pink fascinator atop her head, holding feathery string puppets. "I'm the lady who grew up just like you, and I started TLC," she says. She greets each child individually.

Then she asks each kid what they liked most about the conference. Among the most common answers: making friends, everything, all of it. To one girl, whom Pearson seems to have spoken with before, she says, "You have a huge heart and a sensitive nervous system." The girl appears to be holding back tears.

Next, Pearson pulls out a ribbon, gives the end to a child at the front of the horseshoe, then asks her to hold it and pass the rest around.

"Feel the ribbon in your hands. It is connected to each one of you." I close my eyes. The ribbon is smooth. I'm thinking of the girl in the Maple Leafs sweatshirt, just a bit older than I was when I started pulling. Unexpectedly, I find myself holding back tears.

Pearson leads us up out of our chairs, towards the door: "This is your world," she says, as we leave the conference room. I'm walking, holding on to the ribbon, surrounded on either side by kids who are three-quarters my height. Surrounded by kids in hats, with bald heads, kids who pick their skin. We walk out through the hotel lobby, past the people dining and reading. And outside the hotel, to a startling view of the San Francisco Bay.

Pearson turns her back to the water to face us. The sun is slowly climbing. Planes are taking off from the nearby airport. She asks us to stand on the earth. Then she asks us to wiggle our bodies. "Close your eyes. What do you smell?" Then we do a wiggle again: "What do you hear?" We can do this any time, she tells us. Baby steps toward mindfulness.

Once we're back in the room, Pearson asks the [kids](#) to write something that they like about themselves on a triangle of felt. Each goes around and says something.

One says, "Compassion."

Pearson: "We develop incredibly deep compassion. Why? Because we know what it's like to suffer. We know what it's like to be different. And we can see that in other people."

They start gluing sequins, puffy hearts, strips of ribbon on to their pennants.

Persistent. Wild. Compassionate. Brave.

"Here's the thing about bravery," says Pearson. "It doesn't mean you're not scared. It means you do something anyway."

More information: Susan E. Swedo et al. A Double-Blind Comparison of Clomipramine and Desipramine in the Treatment of Trichotillomania (Hair Pulling), *New England Journal of Medicine* (2010). [DOI: 10.1056/NEJM198908243210803](https://doi.org/10.1056/NEJM198908243210803)

This [article](#) first appeared on [Mosaic](#) and is republished here under a Creative Commons licence.

Provided by Mosaic

Citation: The hidden epidemic of compulsive hair pulling (2018, August 21) retrieved 24 April 2024 from <https://medicalxpress.com/news/2018-08-hidden-epidemic-compulsive-hair.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.