Pulling My Hair Out...Literally

Contributed by Jill Matson, CPNP, RN, Clinical Specialist & Navigator Manager

When asked to write an article on Trichotillomania (TTM) or ‘Trich’ for short, I knew this was one of the rare times when the benefit of my personal experience with one child at home outweighed what I knew as a clinician with experience treating thousands of children with autism. I knew the personal and family frustration of years of trying to resolve hair pulling through a myriad of medical, therapeutic, and behavioral approaches.

Trichotillomania is an impulse control disorder where one can not resist the urge to pull hair out of the scalp, eyebrows, eyelashes, and sometimes facial hair, arms or legs. Body Focused Repetitive Behaviors (BFRBs) are classified under Obsessive Compulsive Related Disorders in the DSM-V.

My son is an extremely loving, gentle spirit, except when he is not. He hears everything and is unabashedly funny, which can be embarrassing to his teenage sister.

cont.
Lastly, he has the most gorgeous, thick, wavy hair...sometimes in patches.

Trichotillomania is certainly not limited to the autism population, and the diagnosis crosses all ages from infants well into adulthood. In the Trichotillomania support community 51% of those surveyed reported that they had not mentioned the concern to their doctor either due to embarrassment, lack of recognition that the condition was a recognized disorder, or felt that their physician could not help them. It most often develops in childhood, exacerbated in the teen years, with episodes brought on by stress. TTM occurs more frequently in females than males, by adulthood a 3 to 1 prevalence. Severity can range from a minor frustration, not notable to others, to severe cases involving trichophagia (swallowing of hair) which can lead to fatal gastrointestinal obstruction.

As with many issues in the medical community, there are preliminary genetic studies demonstrating a genetic vulnerability to TTM. This is supported by the incidence of cases seen in well-cared for infants, who have not experienced any trauma, demonstrating TTM. Most cases in young children under the age of 5 will resolve untreated. Those that persist have been most responsive to cognitive behavioral treatment (CBT), psychotherapies, and skilled medication management. In cases requiring treatment, the pulling can become automatic and patients engage in ‘passive pulling' without awareness. Technology is assisting with the development of wearable devices that monitor the position of one’s hands, to let the patient know through vibrations that they are pulling. Anxiety, and diet culprits (sugar, alcohol, and caffeine), have been seen to increase the urge to pull. Given frequent comorbidities with other mental health disorders, such as anxiety disorders, treatment strategies should be considered carefully and addressed with a psychologist or psychiatrist with experience treating TTM.

It does get better. I can admire my handsome, charming son with the head of thick, wavy hair from across the room. No longer am I monitoring out of the corner of my eye where his hands are, or whether he is pulling.
Self-Stimulatory Behavior: More Than Just a Label

Contributed by Tammy Morris, M.A., CCC-SLP, Chief Program Officer

For those outside of the autism world, the term ‘self-stimulatory behavior’ may be misinterpreted. For those inside the autism world, we often abbreviate as ‘stimming.’ This month we wanted to repay a visit to self-stimulatory behavior, an area where dismissing with a label may in fact be a disservice to those who require the understanding and extra sensory input that is gained from engaging in self-stimulatory behaviors.

There are no such things as ‘autistic behaviors,’ only human behaviors. Observing someone engaging in self-stimulatory behavior does not mean that they have autism. There is no set ‘list, but rather a limitless number of ways that individuals may use sensory input to regulate their own unique systems, inhibitory, and excitatory feelings. Yet, at the top of our list of self-stimulatory behaviors, observed in individuals with autism, many may begin with high input behaviors such as hand flapping, rocking, self-biting, head banging, scratching, jumping, and spinning. For neurotypical individuals with different needs, and also with well-established self-monitoring skills, our list might begin with foot-tapping, doodling, gum chewing, hair twirling, nail biting, and pacing. The calming effect may be similar.

During AAoM’s Michigan’s Autism Safety Training (MAST), first responders are instructed to distinguish situations where a potentially dangerous behavior is occurring, from those where a behavior has been inappropriate, irritating, annoying, or distracting. In the clinical environment, we prioritize behaviors that are self-harming, may cause physical harm to others, or disrupt social interaction. We rely on standardized sensory assessments and occupational therapists to fully evaluate sensory seeking and avoidance behaviors. We target behaviors that interfere with goal attainment, as the literature guides us, and apply steps to diminish when necessary.

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As we work together as a community to understand individuals with autism spectrum disorders, we tend to rely on labels to offer insights into those behaviors that are unique to the population. However, simply labelling ‘stimming’ or the ‘meltdown’ as sensory processing dysfunction may not tell the full story. In many cases, the history or experience of any one individual is often overlooked, limiting our ability to treat maintaining factors that contribute to the problem. Here is another example of why AAoM continues to promote a multidisciplinary approach to treating autism.
**Autism Alliance of Michigan is Moving!**

Please update your records to show, AAoM is now located at:

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