24 Oct - Written By Samantha Lincroft

Diet, Anorexia and Orthorexia in Histamine Disorders… What the Hist? Part 4

Diet, Anorexia, and Orthorexia in Histamine Disorders

TW: This post discusses anorexia and orthorexia as well as the diagnosis of eating disorders in chronically ill patients

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Dietary intervention is a key part of histamine disorder treatment and people with histamine disorders understandably have a complex relationship with food. Keeping a balance between using food as medicine, avoiding reactions and avoiding malnutrition is difficult.

Despite this, I believe that the low histamine community has some serious issues with promoting disordered eating, especially orthorexia. While there are plenty of people who do not do this, some do.

There is also a massive stigma against discussing eating disorders among chronically ill people because doctors often incorrectly assume young female patients to have eating disorders when they really have complex dietary needs and digestive failure.

I want to start by acknowledging some basic facts. Histamine disorders respond strongly to a low histamine diet. Many traditionally "unhealthy" foods like packaged snacks full of additives, MSG, artificial colors and flavors and so forth do trigger histamine release and can range from uncomfortable to life-threatening for people with histamine disorders to consume.

It is not irrational to avoid food that makes you feel sick. Just eating a low histamine diet because you have to in order to control your symptoms is not an eating disorder. Patients who cannot tolerate any foods without reacting should not be forced to eat or labeled with eating disorders, they should be given medication to allow them to tolerate food. Forcing a patient to "prove" their reaction by eating something that causes anaphylaxis is abuse.

Everyone has different dietary preferences and medical struggles. You cannot tell simply from someone's diet if they have an eating disorder, you have to understand their reasoning and medical needs.

The Mental Challenge of Histamine Sensitivity

Just like any illness that causes symptoms after eating, being sensitive to histamine greatly impacts your relationship to food. When you know eating comes with risk, food can be scary. This is normal.

Everyone has a different relationship to food. It is deeply tied to our cultural background and a part of who we are. Food brings people together, it is often communal. When necessary dietary restrictions cut us off from those social ties to food it can be easy to start seeing food as an enemy, a challenge to overcome, as opposed to essential nourishment and a joyful part of life.

Additionally, many people with histamine disorders suffer from other chronic illnesses. They may be under intense financial pressure and have little ability to cook. This puts a further strain on the relationship to food with some people having no choice but to eat things that they know will cause them symptoms or eat nothing at all.

It is easy to see how someone who has very few non-reactive foods to eat may begin restricting calories. Weight loss is generally greeted by approval and commendation by doctors, and in extreme cases can be seen as evidence of how sick someone is. This provides strong incentive for anorexia to develop.

Additionally, if a patient already associates food with negative symptoms, they will have a legitimate reason to fear eating many foods. It is not hard for this to turn into a general fear of food.

Orthorexia

A lesser-known eating disorder orthorexia is defined as an obsession with eating healthy food. While eating healthy is generally a good thing, in patients with orthorexia the obsession with food quality takes over their life and causes severe anxiety around eating anything they deem "unhealthy."

This eating disorder is extremely prevalent in the chronic illness community in part because people with chronic illness are frequently blamed for their illness if they eat anything judged as "unhealthy."

In patients with histamine intollerance, the reactivity to additives like MSG frequently villainized by health food gurus sets up an easy path to orthorexia. This is despite the fact that many healthy things like fermented food, seaweed and spinach are very high histamine and villianized foods like butter. gluten and sugar are very low histamine.

The Anxiety Food Trap

Because stress is a major trigger for histamine release, developing orthorexia or anorexia when you have an histamine disorder can be a difficult trap to get out of. For example, if someone has anorexia and has come to fear all food they will stress even when eating a very low histamine meal which will mean histamine is still released and symptoms occur. This further cements the belief that all food is

It is this anxiety histamine trap that mental health care is needed to address. While acknowledging dietary needs it is also possible to help patients avoid getting overwhelmed by stress around eating and in doing so allow them more access to nutrition with less histamine release.

Avoiding Promoting Orthorexia On Food Blogs

The anxiety to histamine reaction cycle above is why it is so important that anyone writing for a histamine-intolerant audience be extremely careful about what they say about the safety of various foods.

If you are gluten intolerant that is fine. It is okay to share recipes that are both low histamine and gluten-free. But if you imply that gluten is a universal trigger than the anxiety that may provoke in your readers can cause them to have a stress-based histamine reaction to gluten even if it is completely safe for them. Other common intolerances include eggs and dairy which similarly are separate intolerances from histamine intolerance.

I see many low histamine blogs preaching constantly about how natural is always better, how you have to buy organic produce, and how processed sugar or gluten are the devil. These blogs are also providing important information about low histamine diets, but if patients feel better on low histamine diets they are likely to believe everything they read which at best costs a lot of money and stress and at worst can lead to orthorexia.

Avoid Promoting Anorexia On Forums and Social Media

The primary promotion of anorexia I see is on social media and facebook groups. The "disability olympics" are real and toxic. People receive sympathy and acknowledgment of their illness when they are not eating or become deathly thin.

If someone is clearly are not getting enough nutrition talk with them about getting help from a doctor or nutritionist to find more things they can safely eat or an alternative nutritional solution like a feeding tube.

Summary

Histamine disorders are conditions that respond strongly to dietary intervention.

Many additives, artificial colors, and flavors can be strong triggers for histamine release.

It is not irrational to not want to eat something that you expect to cause severe symptoms or a life-threatening emergency.

Anorexia and orthorexia can be real complications of histamine disorders and can make histamine disorders even more challenging to manage.

We can acknowledge rational basis for an eating disorder and still provide help.

The low histamine community and chronic illness community has to be careful to avoid promoting eating disorders.

Mast Cell Activation and Anaphylaxis are scary. Having Anxiety around food when you never know what food could kill you is rational. But sometimes these fears can turn into #DisorderedEating, and when we aren't careful the Low Histamine and MCAS / MCAD community can promote #anorexia and #orthorexia. So while this subject is nuanced and difficult, we also need to talk about it.

This part 4 of my series on mast Cell and histamine Disorders is a bit different, but it is important.

malnutrition must have an eating disorder. This stereotype kills. It is used to deny patients with very Severe ME gastroparesis crohns MCAS and other severe chronic Illness the care and support they need. Believe Patients. It is never appropriate to force patients into severe reactions to "prove" their physical illness. I also do not deny the life-changing power of modifying your diet to avoid intolerances.

But two things can be true at once. You can have both severe physical reactions to food and disordered thinking around food. Indeed, these two things are often linked.

There is no single diet for mast cell activation or for histamine intolerance. Everyone's reactions are different, and even within a single person our reactions change over time. For this reason, it felt irresponsible for the part of this series addressing food to provide any sort of prescriptive diet. Indeed, overly prescriptive diets are in my opinion one of the major issues with discussing food and mast Cell Disease.

Instead, I hope that this post sheds light on the complex mental challenge that living with constant danger of food reactions poses. That it can both validate your fear, and also help you to feel more confident in discussing and exploring your relationship to food.

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