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The Vestibular Patient Journey: An Interview with a Patient Diagnosed with Vestibular Migraine

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In this edition of "Striking the Right Balance," Erica Zaia, MSc, RAUD and Michael Vekasi, AuD, R.Aud, Aud(C), FAAA interview a patient presenting with dizziness and imbalance to look at how vestibular impairments negatively impact our patients' quality of life and how our interactions with them contribute to their patient journey. This is the second article in this patient-focused series, featuring a patient diagnosed with vestibular migraine.

Michael Vekasi, AuD, R.Aud, Aud(C), FAAA and Erica Zaia, MSc, RAUD are coordinating the "Striking the Right Balance," feature which will cover the latest information on 'all things vestibular.'

If you would like to be more involved in all things vestibular, please check out and like our Facebook page by searching for "CAA National Vestibular Special Interest Group" within Facebook. You can also reach us by email at CAAvestibular@gmail.com.

Introduction

During a recent vestibular conference that the authors attended, a panel presentation where a few vestibular patients shared their stories about their journey through the medical system to get their vestibular (or non-vestibular) diagnosis and treatment. We hope to recreate that in a written format here with a question-and-answer interview with a vestibular patient. This is the second patient story interview in a series that we will host over time, and this specific patient story focuses on a patient diagnosed with **vestibular migraine**. Future patient interviews will focus on other vestibular or balance-related diagnoses.

Anyone working with the vestibular population knows that the dizzy patient often comes to an appointment seeking answers and may be anxious. Unfortunately, these patients often get bounced around the medical system a fair bit before being referred to our clinics and can access proper treatment. In this patient's case, the vestibular assessment was instrumental and invaluable in guiding the patient's journey to recovery.

Interview

For our interview, the authors are represented by [EZ/MV] and the vestibular patient is represented by [VP] below.

[EZ/MV]: Thank you for agreeing to answer these questions for us! **How long from initial onset of symptoms until you received a vestibular diagnosis?**

[VP]: *Like many patients with vestibular migraine and post-concussion syndrome, I had vestibular symptoms for several years before getting the correct diagnosis. Once my symptoms became severe enough to ask for help, I was incorrectly diagnosed with vestibular neuritis, and that delayed my correct diagnosis (vestibular migraine with PPPD) and treatment by several months as well.*

[EZ/MV]: **How would you describe your quality of life during that time period between onset of symptoms and diagnosis?**

[VP]: *I would describe the slow burn of vestibular problems after my brain injury as frustrating* *more than anything. I learned how to adapt to having issues with balance and driving, and generally tried to make do with the limited clinical assistance that I had. When my classical migraines with head pain turned to chronic vestibular migraine – and before it was diagnosed and treated as such – I was severely, severely ill. I quickly lost the ability to drive, to use screens, to leave the house on my own, to work, to eat. I spent many months essentially bedbound, in the dark, with a torturous and constant internal sense of motion. To be quite clear: the symptoms were so bad that I was chronically suicidal for months. I was a shadow of my former self. The only thing that kept me going was a sense of stubbornness and anger towards the doctors who had either misdiagnosed me or refused to help, usually under the guise that vertigo is "mysterious" and "it just takes time to go away."*

EZ/MV]: **How did your audiologist help you with your dizziness or vertigo? Has your quality of life changed since?**

[VP]: *My audiologist performed key diagnostic tests that definitively ruled out vestibular neuritis and ruled in vestibular migraine. Based on that information, I was able to seek out a neurologist who specialized in vestibular migraine, was given the proper medication, and then was able to return to vestibular therapy with my audiologist. Dizziness and balance issues are very frightening experiences, and I benefited immensely from my audiologist's reassurance, based on her years of clinical experience, that what I was going through had a name, had treatment options, and most importantly, wasn't my fault. Vestibular therapy with an audiologist was important to me because of audiology's exquisite focus on the inner ear and its connection to the body's other balance systems. My quality of life continues to improve with medication, vestibular rehabilitation, and the knowledge that vertigo may be difficult to treat but is not simply a "mystery" that patients must be left to deal with on their own. I am not the same person as I was before a severe vestibular crisis - having your world literally turned upside down for so long is deeply traumatic, and I grieve the way I used to be able to move through the world - but I feel like a person again.*

[EZ/MV]: **If there is one thing you could tell your audiologist after you received your vestibular diagnosis, what would it be?**

[VP]: *Knowledge is power, and knowledge is healing. From my understanding and experience, vestibular disorders - regardless of their etiology - are intimately connected with anxiety, and a key part of treatment involves retraining the brain and the body to feel safe again. Diagnostics and a treatment plan can go a long way towards building safety, even if recovery is ultimately a very slow process.*

[EZ/MV]: **If there is one thing you could share with any and all health professionals about dealing with patients who report dizziness, what would it be?**

[VP]: *Dizziness and vertigo are such common experiences, but so poorly understood by primary care practitioners and even specialists, who are often trained to look for and treat very specific pathologies. That dizziness is common should not be equated to it being unserious; in fact, the distress associated with dizziness can be so profound that it merits very attentive and concerned care. I would absolutely encourage health professionals to build proactive relationships so that patients are able to be connected, as soon as possible, to people who specialize in dealing with vestibular disorders. Practitioners such as physiotherapists and audiologists are particularly well-positioned to connect with physicians in their area so that patients can find them more easily. Dizziness is treatable, and many people live good lives even with vestibular disorders: we need to* *offer patients hope, but the kind of hope that is grounded in good research and timely and accessible care.*

Concluding Remarks

We are hopeful that this interview about a vestibular patient’s journey will emphasize the importance that audiologists play in the lives of dizzy patients. We hope to have more patient stories over time that will focus on additional vestibular diagnoses and the journey of other patients. Thank you for taking the time to read this article, and an exceptional thank you to the vestibular patient who was interviewed for this article – as clinicians, we can learn more through our patients.