Hemiplegic Migraines: Raising Awareness is the Key

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Hemiplegic migraines (HM) are a rare form of migraines in which individuals present with weakness on one side of their body and migraine aura symptoms such as vision changes, impaired sensation, and speech prior to or with severe headaches. HMs can last anywhere from a couple of hours to four weeks. There are two types of HMs. The first is called Familial Hemiplegic Migraine (FHM). These individuals genetically inherit this type and have at least one first or second degree relative that has had HMs. The second are Sporadic Hemiplegic Migraines (SHM). They only occur in individuals with no history of HMs in their family. (American Migraine Foundation, 2022; Kumar et al., 2023)

About fifteen years ago I recall waking up to one of the worst headaches of my life. I reached over to grab what had become my best friend, a bottle of Excedrin. I had been taking a couple of pills everyday consistently for several months. So naturally I lifted my head off the pillow, but for some reason I felt as if part of the side of my face was left on the pillow. I shook my head a little to see if that would take the feeling away, but it did not. I started feeling the sensation of pins and needles on the right side of my face. I stood completely up, but apparently my brain and legs were not speaking because before I knew it, I was on the floor.

I thought I could pull myself up without waking my husband, but my legs were too weak. So, I lay on the floor thinking this will pass. Then I started feeling intense pressure building up on the right side of the top my head. The right side of my face started to tighten, and my eyes hurt so bad I thought they were going to pop. I tried to call out to my husband, but I could not speak. I could not move my right arm. The fingers of my right hand began to contract, and my heart was racing. I just knew I was having a stroke or a ruptured brain aneurysm.

Finally, my husband woke up and said, "Are you okay? Your face looks funny." Once he realized I could not respond he rushed me to the nearest hospital. They told him I would be admitted because it appeared that your wife had suffered a stroke. About four days into my hospitalization, a neurologist entered and told us after reviewing all the tests, I did not have a stroke, but I was diagnosed with multiple sclerosis (MS). The neurologist instructed that I would need to see a specialist once discharged. I was devastated!

In the meantime, they started me on medications to treat the symptoms, but nothing seemed to work. I went through more tests as the weeks and months went by before my initial visit with the neurologist. On my first visit with him, he immediately did additional tests and referrals to other specialists such as a neuromuscular specialist, cardiologist, and speech pathology. Once all tests and specialty visits were completed, I saw the Neurologist for my follow-up visit. I was so excited to discuss my treatment options, I was finally on the road to relief.

The neurologist stated that after reviewing test results and consultation visit records, he did not think I had MS. He recommended a neurologist that specializes in migraines and rare neurological conditions. To this day, I am grateful that they sent me to that specialist because he diagnosed me with FHM on my very first visit. He began treatment immediately. I was tired but my local neurologist never gave up on me. Although parts of my story may have made you laugh, it took almost two years of monthly hospitalizations, too many emergency room visits, monthly outpatient infusions, occipital blocks, daily preventative medications, strict dietary restrictions, multiple therapies, BotoxTM treatments every three months, and additional medication to take as needed for my life to return to "normal."

June is Headache/Migraine Awareness Month, however to me it is every day. HMs are rare and mimic strokes, seizures, and other neurological disorders, which can make them even more life threatening. According to the American Migraine Foundation (2022), there are 1 billion people throughout the world who have migraines, with 39 million residing in the U.S. Individuals that have been diagnosed with HMs only make up 0.01% (Kumar et al., 2023). This makes HMs even more dangerous, misdiagnosed, and untreated than any other type of migraine.

HMs are a debilitating neurological disease. Globally, migraines are one of the top leading reasons for people on disability. As a healthcare professional and a survivor, I continue to raise awareness by providing education, resources, support and advocacy. After reading this article, I hope that you will recognize the symptoms and seek help for loved ones. HMs are real and treatable if identified early. Ignoring the signs, which can start between the ages of 12-17, can be fatal.

Common Symptoms (Kumar et al., 2023)

- Severe migraine headache
- Visual impairment
- Light and/or sound sensitivity
- Numbness and/or tingling of extremities
- Muscle weakness
- Unilateral weakness that can go from side to side between or during attacks
- Occasional bilateral motor weakness
- Ataxia (poor muscle control, balance difficulty that can affect walking)
- Scotoma (blind spot)
- Hemianopia (partial blindness)
- Fever
- Lethargy in hand, arm and/or the face
- Muscle twitching

Severe Symptoms (Kumar et al., 2023)

- Severe hemiplegic migraine attack
- Nausea and/or vomiting
- Hemiplegia (one-sided paralysis)
- Severe visual impairment/blindness
- Difficulty concentrating and/or writing
- Muscle weakness or impaired motor function
- Disoriented/confused
- Aphasia (loss of language/speech difficulty)
- Dysphagia (difficulty swallowing)
- Unsteady Gait

- Problems with coordination
- Loss of Consciousness

Common Risk Factors (Kumar et al., 2023)

- Family history of Hemiplegic Migraines
- Female

Common Triggers (Kumar et al., 2023)

- Stress
- Certain foods and/or smells
- Little to no activity
- Unhealthy sleep habits
- Lights (especially bright, strobing lights)
- Head injury and/or illness
- Unhealthy eating

It is not uncommon for treating providers to prescribe medications to manage the symptoms of these attacks, however, prevention is key to managing this disease. Although research has not yet come up with a cure, as individuals age, some may experience a decrease in frequency and severity (1American Migraine Foundation, 2022; Kumar, 2023). As a holistic health practitioner, I found that implementing self-care routines (even 15-30 minutes) is a great option that can be very beneficial in reducing the severity and frequency of migraine attacks. It can also give an individual sense of control for this unpredictable disease. Some examples are:

- Take a walk by the water
- Take a warm relaxing bath
- Treat yourself to a spa day
- Journal
- Color/paint
- Listen to calming music
- Meditate with/without calming sounds or positive affirmations
- Relaxation and paced breathing exercises
- Go on a retreat
- Spend a day in your PJs, watching your favorite movie or TV show
- Take a social media break
- (American Migraine Foundation, 2021; American Migraine Foundation, 2023)

Do something each day that relaxes you. Whether you are having a good day or not, this can help reduce stress, thus reducing migraines. Self-care can improve our overall health. I always say when we take care of ourselves, our patients

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will receive better care. One of the most important lessons that I have learned through all of this was to never forget the oath we took as nurses. Especially, "devote myself to the welfare of those to my care." After 15 years of nursing, I unconsciously downplayed someone complaining of headaches, until it happened to me. It opened my eyes and gave me a new perspective. I learn something new from each of my clients, regardless of how long they have been with me. Listen, learn, educate, advocate, and raise awareness together. It is never too late!

References

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