Migraine and Misunderstanding: From Science to Acceptance



A Series by **REALWORLDHEALTHCARE.org 2019**

Medical experts don't fully understand what causes migraines, and migraine sufferers often must cope with stigma attached to the condition.

Migraine and Misunderstanding: From Science to Acceptance is a recently published series of articles that both delves into the science behind migraine and its treatment and shines a light on the challenges facing migraine patients and their loved ones. Please accept this complimentary copy as our way of thanking you for your commitment to raising awareness of migraine and advocating for healthier futures.

founding sponsor



www.RealWorldHealthCare.org

CONTENTS

. 8
LO

First in Class Migraine Approval

By Emily Burke, Ph.D., Director of Curriculum Development, BiotechPrimer.com

Editor's Note: June is <u>National Migraine and Headache Awareness Month</u>. Medical experts don't fully understand <u>what causes migraines</u>, making the condition difficult to diagnose and treat. This week, Real World Health Care delves into the science behind migraine and its treatment, with this article written by Emily Burke of <u>Biotech Primer</u>. Next week, we'll bring you insights from the perspective of a family <u>caregiver</u> supporting a loved one with chronic migraine.

Migraine sufferers gained new hope last year when the FDA approved three new first-in-class drugs that prevent the onset of migraines, and significantly reduce the number of migraine days in difficult-to-treat (those that have failed 2 to 4 prior treatments) patient populations. In some patients dubbed "super responders," migraine occurrence went from several times a month to no occurrence for six months. This is a big breakthrough that will have significant impact on the quality of life for migraine suffers who have not been able to find other forms of relief. Let's take a look at the science behind migraines and how these new treatments work.



Emily Burke, BiotechPrimer.com

Attack of the Migraine

As many as 36 million Americans suffer from migraines—about 12 percent of the population. More than just a headache, migraines often include symptoms like intense pain, nausea, and extreme sensitivity to light or noise. They can last anywhere from a few hours to days on end. Episodes may be as frequent as several times a month, or as infrequent as a few times a year.

There are three distinct parts of a migraine episode; however, not all migraine sufferers experience these phases with the same intensity. Each set of symptoms is unique to the individual, and can include prodome, aura, or postdome phases.

- **Prodome** occurs in the hours or days before a migraine attack. It includes mood disturbances, stiff muscles, and sensitivity to smells or noise.
- Aura is the period just before the severe pain attacks. Visual distortions are the
 most common symptom, with sensory or motor disturbances potentially occurring
 as well.
- **Postdome** happens after the actual headache and includes symptoms such as lingering pain and cognitive difficulties.

The Science Behind the Episode

While the exact cause is largely unknown, there are a few theories:

- **Brain Stem Changes:** Research by the Mayo Clinic (Rochester, MN) suggests migraines derive from changes in the brain stem and its interaction with the trigeminal nerve. The trigeminal nerve supplies feeling to the face and is considered a pain-associated pathway in migraine attacks.
- Lowered Serotonin Levels: Another area of active research involves the neurotransmitter serotonin. Serotonin is most often associated with mood—antidepressants known as serotonin reuptake inhibitors increase levels of serotonin in the brain. This neurotransmitter is also implicated in migraine pain pathways, with levels dropping during an attack.
- **Hormonal Link:** Migraines are more common in women than men, so a hormonal link may be tied to the causality. There is often a reduction in symptoms after menopause.
- Glutamate Accumulation: In recent years, a few gene variations that appear to increase the risk of developing migraines have been identified through genomewide association studies. Two of these genes result in increased levels of the neurotransmitter glutamate, suggesting that accumulation of glutamate in synapses may be a trigger.

This Just In

The hot new kid on the block is **calcitonin gene related peptide (CGRP) inhibitors**. CGRP spikes during migraine attacks and is thought to play a role in the brain pathways that process pain. The exact molecular mechanism of how the CGRP spike is related to migraine onset is not yet fully understood, but CGRP is thought to sensitize nerves in the face, neck, and jaw, as well as alongside blood vessels surrounding the brain. A 2002 study provided strong evidence of a key role for CGRP in driving migraines. Injecting volunteers *who were* migraine-prone with the CGRP peptide induced a migraine within hours; injecting volunteers *who were not* migraine-prone resulted in a mild headache at worst. These studies helped to form the scientific basis for this new class of migraine drugs. The first approved, erenumab, is a monoclonal antibody (mAb) that blocks activation of the CGRP receptor. The antibody binds the receptor but does not activate it, and in so doing, prevents CGRP from activating the receptor.

Fremanezumab and galcanezumab, the other CGRPN inhibitors approved last year, are mAbs directed at CGRP itself. The idea is for the mAb to "mop up" CGRP before it reaches the receptor and triggers a migraine.

Cocktail Fodder: A Headache of the Past

We sometimes blame migraines on the stress of modern living. In some cases, stress is a trigger, but the headaches are hardly a modern phenomenon. Descriptions consistent with migraines are found in the ancient Egyptian medical text Ebers Papyrus, dating from 1550 B.C., as well as Hippocratic texts dating from 200 B.C.

About the Author

Dr. Emily Burke is the Director of Curriculum for Biotech Primer and is responsible for customizing client training, delivering training sessions and writing the <u>Biotech Primer WEEKLY</u>, a free electronic newsletter that explains the science behind the headlines. She received her B.S. in biological sciences from Carnegie Mellon University and her Ph.D. in molecular biology from the University of Southern Alabama.

Readers are invited to subscribe to the free Biotech Primer WEEKLY.

Categories: General, Migraine, Pain Management

Tags: <u>headache</u>, <u>migraine</u>

The Cascading Effect of Migraine Disease

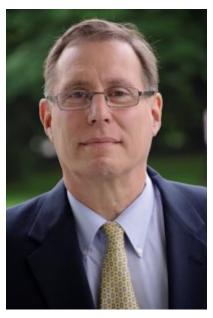
By Jim Carleton, for the Association of Migraine Disorders

Editor's Note: June is <u>National Migraine and Headache Awareness Month</u>. Medical experts don't fully understand <u>what causes migraines</u>, making the condition difficult to diagnose and treat. This week, Real World Health Care brings you insights from the perspective of a family <u>caregiver</u> supporting a loved one with chronic <u>migraine</u>.

"I never signed up for this"

Quote from a migraine sufferer's fiancée when he ended the engagement.

How is it possible that such a devastating illness in all its expressions could not have far-reaching, negative effects in all related areas of a migraine sufferer's life? It's not, of course. Only recently have we begun to see research that looks at subjects like family burden and the corollary disruption that episodic and chronic migraine causes in the lives of sufferers. Very few of us lead totally isolated lives, devoid of familial connections and other work and relationship associations. More often, the opposite is true. The vast majority of people are interconnected with others through family, relationships and work; these relationships are all compromised by migraine suffering. That's a lot of people.



Jim Carleton

Migraine Affects More Than the Patient

In the United States alone, we estimate that there are 36 million migraine sufferers. If we allow ourselves some statistical latitude and cede that each sufferer has two relationships affected by their migraines, the numbers grow exponentially. For the purpose of this argument "collateral" means a person in some level of a relationship with the migraine sufferer. Following this line of reasoning, there are about 108 million people, including the sufferers, whose lives are negatively impacted in a variety of ways. The population of the United States is 319 million at last count. Again, following our assumptions, 34 percent of the U.S. population has their lives disrupted to some degree, by migraine disorders. Remember, this assumption is based on two collaterals only. Most people have more than two relationships. So, if that is the case, the number affected would rise accordingly.

Admittedly, that is a pretty astonishing number. One may question what does "disruption" mean? Migraine sufferers and those that live and work with them would Table of Contents

not have any problem answering that question. So, in deference to the two-thirds or so of the U.S. population that may not understand the nature and level of problems caused by migraine attacks and experienced by collaterals, what follows is a less than a complete list. Broken relationships, lost jobs and income, family arguments, emotional distance, canceled family events and vacations, friendships lost, loss of self-esteem (both sufferers and collaterals), anxiety and a host of depressive symptoms, constant worry, and feelings of inadequacy. This list could be expanded greatly, I am sure. But one consequence stands out for me personally in my life with an episodic migraine sufferer: the frustration experienced when I am forced to stand by and watch my loved one's anguish while being unable to help her in any way.

This brings us to the bottom line: migraine suffering is not limited to the migraine sufferer alone. The misery spreads throughout the lives of associated individuals, not unlike other chronic, disabling conditions. At present, with about one-third of our country's population touched negatively by this neurological illness, why is so little being done to search for a cure? What will it take?

Some interesting research has been done in the area of caregiver stress. If you would like to read some interesting articles as a follow-up, consider:

Caregiver stress focusing on self-care

http://adrenalfatiguesolution.com/caregiver-stress/

Family support essential to surviving migraines

http://www.practicalpainmanagement.com/patient/conditions/headache/family-support-crucial-surviving-chronic-migraine

CaMEO research studies the burden of migraine on families, among other variables

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4430584/

The <u>Association of Migraine Disorders</u> strives to expand the understanding of migraine and its true scope by supporting research, education and awareness.

Categories: Caregiving, General, Migraine, Pain Management

Tags: caregiver, headache, migraine

Caring for a Child with Migraine

By The American Migraine Foundation

Editor's Note: The following is reprinted with permission from the <u>American Migraine</u> <u>Foundation</u>. Visit the American Migraine Foundation web site to <u>download a copy of the full guide</u>, which includes additional information on pharmacological and non-pharmacological treatments.

Nothing hurts more than seeing your child in pain. Between four and ten percent of children experience migraine, and kids display different symptoms than adults. Early diagnosis, an open dialogue and specialized treatment plan can equip you and your child with the tools to best manage their migraine.

Maintain a Dialogue

An ongoing dialogue with your child is critical to getting an accurate diagnosis and finding a treatment plan that works. Your child's migraine management plan will evolve as they grow older and their daily routines change. Being able to talk about migraine openly will help you adapt as a team.

Find a Common Language

Younger children might have a hard time describing their symptoms. Use non-verbal cues, like pointing to your tummy or making pained facial expressions, to find out where and how severe their pain is.

Keep Your Focus on Them

It can be scary when your child is having severe pain or other migraine symptoms, but kids will pick up on your anxiety and it can add to their stress. Put on a brave face, offer your child reassurance and empathy, and seek the consolation you need from your own support systems.

Work Together to Find Solutions

Involve your child in the process of finding a headache specialist and devising a treatment plan. It can be as simple as asking them what they thought of a new doctor after a first meeting, or keeping track of healthy behaviors and rewarding them for practicing good headache hygiene.

Leave the Conversation Open-Ended

A diagnosis and treatment plan are only the beginning. Encourage your child to keep you informed about their symptoms, and invite any questions or concerns they have about their medication or daily routine. Then, work together to find alternatives, and get the whole family involved in following through.

Establish Healthy Habits

Establishing a healthy routine is essential for the migraine brain, so it's recommended that parents sit down with their children and discuss fundamental healthy habits.

Children should be sleeping a minimum of nine hours a night, while teenagers should get at least eight hours. Discourage your child from taking naps or staying up past their bedtimes.

Work with your child to make sure they don't skip breakfast and have access to three well-balanced meals a day. They should also drink enough water; eight 8-ounce glasses a day is a good rule of thumb.

Get the whole family involved: track how much water each family member is drinking, sit down for dinner together every night, and establish regular bedtimes for everyone.

Finding a Headache Doctor

When it comes to caring for your child with migraine, you are not alone. A headache specialist plays a critical role in any migraine management strategy and can help you and your child explore your options and find an effective treatment plan. Visit americanmigrainefoundation.org to find a headache specialist near you to get your child the treatment and care they deserve.

About the American Migraine Foundation

The American Migraine Foundation provides education, support and resources for the millions of men, women and children living with migraine. Our mission is to advance migraine research, promote patient advocacy and expand access to care for patients worldwide. Migraine, and other disabling diseases that cause severe head pain, impact more than 37 million people in the United States alone. By educating caregivers and giving patients the tools to advocate for themselves, we have cultivated a movement that gives a collective voice to the migraine community. For more information, please visit www.americanmigrainefoundation.org. Together we are as relentless as migraine.

Categories: <u>Caregiving</u>, <u>General</u>

Tags: <u>caregiver</u>, <u>caregiving</u>, <u>headache</u>, <u>migraine</u>, <u>pediatrics</u>

What People with Migraine Attacks Hate to Hear

By National Headache Foundation

Editor's Note: Real World Health Care is pleased to close out our 2019 series on migraine by sharing an article originally published by the National Headache Foundation. Here, they share advice for helping patients respond to caregivers and others when faced with stigma associated with migraine disease. You can read the original article here, and learn more about migraines from the National Headache Foundation blog.

It can be difficult to explain the excruciating pain of a migraine to those who don't experience it. In fact, there's a stigma attached to this disorder stemming from a lack of knowledge on the severity of symptoms associated with migraine and headache. Migraine is not just a headache, and the attack may include nausea, vomiting and sensitivity to light and sound. Anyone who experiences migraine attacks has surely been frustrated with well-meaning friends and family offering dismissive advice that's not only unhelpful but can make the situation worse.

We took to social media to discover the most common comments and advice that people with migraine hear when they discuss their condition. We compiled the 10 most common in a list below.

- 1. Take some Advil
- 2. Did you take something?
- 3. Have you been drinking enough water?
- 4. You've got another headache?
- 5. Again?
- 6. I get bad headaches too.
- 7. It's just a headache.
- 8. I have some Tylenol if you want it.
- 9. Just push through it!
- 10. I think you just want an excuse.

Chances are, you've heard one or more of these pieces of "advice" at some point in your life. One comment in particular—"It's just a headache"—encapsulates the popular misconception about a disorder that affects around 40 million Americans. It's frustrating to feel that no one understands what you're going through, and some, out of their own lack of knowledge, may even think you're faking symptoms.

In order to demystify the stigma surrounding migraine disease, here are a few steps you can take to educate those around you about this debilitating neurological disorder.

Explain the Migraine Triggers

While <u>migraine triggers</u> differ from person to person, there are a few common causes that will bring about symptoms in many sufferers. For example, a naturally-occurring compound called Tyramine—often found in aged, smoked or cured meats and vegetables—has been found to be a major trigger of migraine attacks. If friends, family and coworkers have a better understanding of your migraine triggers, they're more likely to notice when you're experiencing an attack and can respond accordingly.

Provide Migraine Resources

Of course, you don't need to justify your condition to everyone with whom you interact, but migraine symptoms can cause a strain on certain close relationships. For example, a boss or supervisor doubting the severity of your condition may cause you additional stress, which can negatively impact **work performance** or compound the pain. Fortunately, the National Headache Foundation has an abundance of **resources** that help skeptics and allies alike get a better understanding of migraine and headache. Sharing these informative sources with those closest to you can help alleviate the burden of constantly explaining your condition.

Seek Migraine Treatment from a Headache Specialist

Understanding the specifics of your condition makes it far easier to explain them to others. **Seek out a headache specialist** to receive an appropriate diagnosis. The health care practitioner will likely diagnose you based on your medical history, symptoms and a physical and neurological examination. This could include blood tests, magnetic resonance imaging (MRI) or computerized tomography (CT) scan. (It is critical to visit a medical professional who specializes in headache and migraine, as they will be able to **best diagnose and treat the pain**.)

There will always be those who doubt the severity of migraine symptoms. However, by educating yourself and those around you, you can help tear down the stigma associated with migraine disease and, in the process, make living with migraine attacks a bit easier.

Categories: <u>Caregiving</u>, <u>General</u>, <u>Migraine</u>

Tags: <u>caregiver</u>, <u>caregiving</u>, <u>headache</u>, <u>migraine</u>