



What We Talk About When We Talk About Headache

The stigma associated with words *headache* and *migraine* carries over to those stricken in a way that no other neurologic condition does.

By Peter McAllister, MD



There Are Many Definitions of Headache

Head·ache (hed āk/) *noun*

1. A continuous pain in the head. A pain located in the head, as over the eyes, at the temples, or at the base of the skull.

Synonyms: pain in the head; migraine.

2. A thing or person that causes worry or trouble; a problem. An annoying or bothersome person, situation, activity, etc. Any cause of worry, difficulty, or annoyance.

Synonyms: nuisance, problem, bother, pest, worry, vexation, bugbear, thorn in one's side.¹

In 1981, American author Raymond Carver (1938-1988) wrote a short story, *What We Talk About When We Talk About Love*.² In it, 2 couples, fueled by their passion for the subject and several bottles of “cheapo” gin, debate the true meaning of love in all its various forms. It becomes increasingly clear, as the story progresses, that each carries vastly disparate concepts of love with them, and when they speak of love, each means something very different. That a simple 4-letter word can have such diverse connotations applies as well to our 8-letter word, headache. Language is the primary way we humans express ourselves and words matter. In headache medicine we—and more importantly our patients—battle with the negative baggage that the word *headache* conjures up, particularly among those not afflicted. The stigma associated with the words *headache* and *migraine* carries over to those stricken in a way that no other neurologic condition does.

We talk a lot about headache, but what do we really mean? Are we referring to actual head pain and if so, what type and severity? Is it the common nuisance of a tension-type headache, the want-to-end-it-all misery of cluster headache, or the dull throb of a deadly glioblastoma)? Or are we instead pejoratively referring to a person as in “my boss is such a headache”; an action as in “grading homework is nothing but a headache”; or an idea

as in “computers can be such a headache”? And why is headache—a pain in the head—different from, say, rotator cuff pain, chest pain, or gout? Perhaps because our consciousness, our ego (or in current scientific parlance, our default mode network [DMN]) lies not in our shoulder, chest, or great toe, but rather is firmly fixed in our cerebrum. An ache in the head is a pain—and an attack upon—the very center of who we are. When we say “Not tonight dear, I have a headache,” we’re invoking something deeper than just any old pain. We mean something is amiss in the organ that creates and defines the nature of who we are. That is likely why you’ll never hear “Not tonight honey, I have neuropathy.” For although nerve pain is “out there,” headache is “in here.”

Peruse the *Urban Thesaurus* and you’ll come across more than 550 slang terms for headache, most of which equate headache with annoyance.³ Human resources is referred to as the *headache department*, a liquor store is the *headache house* (eg, “I stopped at the headache house to pick up some supplies.”). Even migraine has more than 50 slang references. A particularly fun one is *mongraine*, describing a migraine that occurs only on Mondays, preventing those afflicted from going to work. Compare that with a scant 5 entries for neuropathy, and none for other pain syndromes like radiculopathy, costochondritis, pancreatitis, or bony fracture. There is something fundamentally different about headache, both in terms of its occurrence within us and the long-held negative associations it invokes. I might say “writing this article gave me a headache,” but it would be unthinkable to utter “writing this article gave me sinus pain, burning mouth syndrome, trigeminal neuralgia, or a toothache,” even though all of these structures lay on or about the head.

Headache and Stigma

Throughout the decades, when we talk about it in movies and literature, headache is most often portrayed



▶▶ Box. Quotes About Headache

“‘I’m very brave generally,’ he went on in a low voice: ‘Only today, I happen to have a headache.’”—Tweedledum

—*Through the Looking Glass*, Lewis Carroll

“Mrs. Beaufort, languid and afflicted with headache, said little.”

—*Night and Morning, Complete*
Edward Bulwer-Lytton

“He went to dinner, but she did not appear: she had a headache, his hostess explained.”

—*The Greater Inclination*, Edith Wharton

Illustration of Tweedledum by Sir John Tenniel



as affecting women and almost universally used as a metaphor for weakness of character. This is the stigma of headache. Consider the quotes from well-known works of literature in the Box.

The concept of headache, and specifically migraine, stigma has received a great deal of attention in recent years, thanks in large part to the efforts of Drs. William Young and Robert Shapiro. Young says stigma is “an established construct in the social sciences that describes a characteristic, trait, or diagnosis that discredits individuals and leads to prejudice, discrimination, and loss of status.”⁴ “Stigma,” Dr. Young says, “has health implications because it affects the way individuals experiencing stigma seek and access medical care, and because the lack of social belonging is stressful and incurs negative health outcomes.” Stigmatized diseases such as migraine tend to receive less research funding.

Robert Shapiro found that when the lay public thinks of migraine, they think about its most common symptom: headache. And headache turns out to be mostly thought of as an annoyance, a worry, or a vexation, rather than a physical pain in one’s head. Dr. Shapiro also discovered that most people think of migraine as simply a slightly worse version of the common and mild tension-type headache that almost all of us experience, coupled with poor coping skills.⁵

Is stigma regarding headache a matter of linguistics? Is it that the same word for physical head pain also has an alternative definition of annoyance? One can conjure a thought experiment, then, where in a parallel universe the word *colitis* possesses this duality, meaning both severe abdominal pain and annoyance/vexation. Would Crohn’s disease and patients with ulcerative colitis be stigmatized,

in this parallel universe, with the general public believing colitis to be a tummy ache plus poor coping skills?

Maybe, but there seems to be something else at play, something fundamentally different about headache when compared with pain below the neck. Neurologic conditions involving the sacred space between one’s ears that don’t have a significant pain component (eg, depression, panic disorder, or epilepsy) are also stigmatized to a greater degree than more southerly corporal conditions like asthma or peptic ulcer disease. Perhaps it’s the location—the brain, the epicenter of who we are—that makes us, even unconsciously, shun and stigmatize people with headaches: A severe headache indicates on some level a disruption of, or a flaw within, the thing that makes us, well, us.

Headache and Self

In 2001 Marcus Raichle discovered a group of brain structures composed of cortical, limbic, and hippocampal regions that activated on functional MRI (fMRI) when healthy subjects relaxed and were not attending to tasks or the environment—a network that turns on the moment you stop thinking, the DMN.⁶ As noted earlier, the DMN has been identified as the physical counterpart of the autobiographic self, or the ego, in Freudian parlance. The DMN seems to organize the brain, acting as the orchestral conductor, the chief executive officer, or the “adult in the room.”⁷ The DMN also establishes a boundary between the internal self and the external world (note that this boundary may be temporarily dissolved by ingesting psychedelic substances such as lysergic acid diethylamide [LSD] and psilocybin—more on this in next month’s column). Finally, the DMN, a group of evolutionarily recent cortical structures linked to primi-



tive regions subserving emotion and memory, seems to play a role in both physical and psychologic pain. Studies with fMRI have shown that the DMN becomes hyperactive with rumination and distress, and in the face of depression, alcoholism, or the existential fear of dying experienced by patients with cancer it may become a hard-wired, maladaptive loop.

What about the DMN and headache? We have some tantalizing early evidence that the DMN is disrupted in the face of persistent pain and, perhaps more interesting, uncontrolled pain like chronic migraine and cluster headache may permanently rewire the DMN. One fMRI study of 13 persons with migraine and 19 healthy control subjects demonstrated that the chronicity and intensity of pain correlated with persistent reorganization of the DMN.⁸ This suggests it may be possible that when not successfully treated, the pain and suffering of severe headache can make a person with headache become truly a different person (ie, develop a different DMN).

What Patients Mean When They Talk About Headache

How do patients talk to physicians about headache? When patients reports their symptoms to us, are they, like the characters in *What We Talk About When We Talk About Love*, saying a word that means something very different to them than it does to their doctors? When listening to their symptoms we can certainly apply diagnostic criteria, but then what? How can we conceptualize their meaning of the word *headache*? Jacqui Murray, a writer, blogger, and sufferer of “chronic, unrelenting headaches” believes it is quite difficult. In a March 30, 2015 blog she asks, “How do they [persons with migraine in this case] effectively communicate a misery truly only understood by other people who get them?” Murray goes on in her blog to lament, “I had a neurologist once tell me that he worked with his headaches, so I could too. Clearly, the unrelenting monster in his skull had chewed through his bedside manner.”⁹

How Should We Talk About Headache?

So, what do we talk about when we talk about headache? The answer is nuanced and multilayered. Like *love*, *headache* is an emotionally charged word that means many things to many people, and language is slippery and constantly evolving. We speak a different English than we did 50 years ago, with many more *likes* and *litterallys* now, and wholly new *bon mots* such as *photobomb*, *glamping*, and “LOL”). The word *headache* has many more slang associations than it did a generation ago. Who knows what we’ll mean when we talk about headache, or love for that matter, 50 years from now?

There exist a number of explanations for the landmines we encounter when we talk about headache. We have linguistics working against us. The idea that migraine equals headache and headache equals annoyance, coupled with the fluidity of language. We may have sexist preconceptions working against us: We know that women get many more headaches than men, and Robert Shapiro tells us men stigmatize headache more than women. The portrayal of those with head pain in movies and literature works against us: emphasizing headache as a fundamental weakness or character flaw. And finally, we have the notion—consciously or not—of headache as an assault on the essence of who we are, and therefore as something to be shunned and stigmatized: the disrupted DMN hypothesis.

Conclusion

To paraphrase Sun Tzu: Know your enemy.¹⁰ As a headache practitioner, it is useful to understand the myriad issues we’re up against as we venture to talk about headache with our patients. Like love, the dice are loaded. *Headache*—that ambiguous, weighty word—is burdened with impedimenta like no other medical condition. Understand this chasm of concepts, this amalgam of preconceptions, and you’ll no doubt be better equipped to communicate successfully, to the extent that’s possible, with your headache patient. The English poet Robert Graves wrote, “Love is a universal migraine. A bright stain on the vision, blotting out reason.”¹¹ Perhaps so. Understanding the meaning of migraine and other headaches, like understanding love, is an arduous process, but nevertheless a journey worth taking. ■

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