

# Researcher probes the stigma of migraine

February 18 2013, by Stacey Burling, The Philadelphia Inquirer

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For years, neurologist William Young of Thomas Jefferson University Hospital's Headache Center has heard his patients say how bad they felt when other people did not take their migraines seriously.

"Every day, I hear stories of the ignorant or mean-spirited things people say to them about having their disease," he said. "People make it obvious that they think they're morally weak because they're not functioning well because of a mere headache."

He says the federal government has the same attitude when it comes to researching the condition, which affects 12 percent of the adult population and can leave some people in terrible pain more days than not.

So, when an intern asked about a research topic, Young jumped at the chance to study stigma in migraine patients. He and co-author Joanna Kempner, a Rutgers University sociologist, decided to compare migraine to epilepsy, "a poster child for a stigmatized disease," Young said. Epilepsy was once thought to be a sign of possession by the devil.

Through surveys of 146 patients at the Jefferson Headache Center and 62 [epilepsy patients](#) at the Jefferson Comprehensive Epilepsy Center, the team found that people with [epilepsy](#) and migraines scored similarly on a stigma scale. Migraine patients were especially troubled when symptoms were bad enough to keep them from working.

The researchers say their study is important because stigma not only

compounds patients' pain but makes migraine a less attractive research topic. "We believe that stigma has a profound effect on the quality of life," he said.

Young and Kempner suffer migraines - she is one of his patients - and want to change the disease's image.

Kempner, who studies the links between medicine and culture, started studying migraine in grad school. She found it had largely been ignored by doctors and [sociologists](#).

"From my own life, I knew migraine was incredibly debilitating," she said. "I couldn't believe that nobody was paying attention to it."

She has theories as to why. "It's invisible. It's not fatal," she said. "We associate migraine with people who are weak or neurotic or who can't handle the stress of life. And very often we associate migraine with women."

Migraines are far worse than standard headaches. They last for hours and often include nausea plus sensitivity to light and noise. The scalps of some sufferers become so sensitive that wind ruffling their hair hurts.

The head pain tends to be focused and throbbing. Kempner described hers: "My head is pounding. I'm throwing up, and I'm in bed in the dark. It feels like my head is literally splitting in half, and I can't do anything. I'm completely down for the count."

The link between migraine and stress is unclear, but some people think stress is a trigger. Migraine is associated with depression, anxiety, and other pain syndromes. People who have migraine with aura, or visual disturbances, are at higher risk for strokes.

One to 2 percent of the population has chronic migraine, defined as more than 14 headaches a month including eight migraines. Young said more than 45 percent of his clinic's chronic patients cannot hold a job. "I have patients who will not have had a headache-free minute in decades," he said.

This spectrum of pain and frequency may be part of the image problem. Many of us know people who function quite well with occasional migraines. That makes it harder to sympathize with those who create more inconvenience for their friends, family, and co-workers.

Young gets a migraine about once a week. Kempner would not say how often she suffers. Citing the stigma, she said, "I don't even want to talk about why I don't want to talk about it."

Young said medications work for most patients but many cannot find effective treatment. Stephen Silberstein, who directs the Jefferson Headache Center, said that doctors don't know what causes the symptoms, but that migraine patients have abnormal electrical and chemical brain activity.

A study by the World Health Organization equated the degree of disability from severe migraines to that from dementia and quadriplegia, he noted.

Young and Kempner's study, published in the journal Plos One, found that people with chronic migraine felt more stigma than those who had symptoms less often. The chronic sufferers also scored particularly high on "internalized" stigma as opposed to "enacted" stigma. The latter measures overt behavior by others toward the patient. The other shows how much patients believe others think ill of them.

That raises an obvious question. Isn't it possible for patients to think they

are being stigmatized when they are not? Kempner says internalized [stigma](#) is a legitimate measure of cultural norms.

"Our feelings of discrimination, our feelings of shame, come from a broad set of cultural messages," she said. Those messages explain why migraine sufferers hide their pain or feel bad about their inability to work and care for their families.

Megan Oltman, 53, one of Young's patients, said she gave up work in a high-powered law firm because of migraines and had sometimes found it hard to practice law even part time. She sometimes faced "intense questioning" from clients, adversaries and court clerks when symptoms kept her from a court date. She said even people with less severe migraines were not always sympathetic.

She, too, says she thinks her internal feelings are as important as overt discrimination. "Worrying about people thinking ill of you has an effect, just as having people actually thinking ill of you has an effect," she said.

Like Young and Kempner, Teri Robert, a migraine patient and advocate in Washington, W.Va., says patients and doctors need to do better lobbying for more money and respect. One step she takes is calling her symptoms a "migraine attack" instead of a headache.

Juanita Brown, 43, whose migraines are so intense she has applied for disability, said she had to educate her minister after he sermonized about the need for miracles for something horrible and incurable like cancer. "I'm not talking about [migraine](#) headaches," he said.

Brown, who said her migraines feel like someone is trying to poke her eyes out from inside her head, finally told him how she felt. "You don't know what I go through," she said, her voice shaking. "I need a miracle."

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