



MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD-LEADING EXPERTS

# TRANSCRIPT



## HOW STIGMA WORSENS MIGRAINE BURDEN

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**Introduction (00:05):** And we found, unsurprisingly, that people who have chronic migraine are less likely to be full-time employed and more likely to have a self-identification of having disability. But we've found something else, which was very surprising to us, which is that people who have infrequent migraine — so they have diagnosis of migraine, but zero to three days with headaches per month — were more likely to be employed and less likely to self-identify as disabled than the group that was our control group from the general population. And what do we understand by that, or how do we, how do we interpret that? Well, it could be that people who have migraine actually have some skills that they may have learned or acquired, or maybe it's embedded or intrinsic to migraine, that makes them more resilient.

**Kellie Pokrifka (00:53):** The stigma surrounding migraine can come from so many sources. It can come from our co-workers, our loved ones, our employers, our doctors, and sometimes it can even come from ourselves. To help discuss how we can dismantle the stigma of migraine is one of the most prominent experts on the subject, Dr. Robert Shapiro. Dr. Shapiro, welcome back to the Migraine World Summit.

**Dr. Shapiro (01:16):** Thanks very much for having me back.

**Kellie Pokrifka (01:19):** OK. So, what is stigma?

**Dr. Shapiro (01:22):** Stigma is a social relationship — so, stigma that occurs when there is severe disapproval or rejection of someone because of a trait that they have which is perceived to be a deviance from a social norm. So, stigma is a kind of a disqualification from participation and full social acceptance. A stigmatized person is seen to be tainted or somehow discounted; that they shouldn't belong.

**Kellie Pokrifka (01:49):** OK, so: interesting. So originally, I thought, as long as I believed myself, and as long as my doctor believed me, I didn't really care about migraine stigma. And then, you taught me that everyone has to care about migraine stigma. We're not going to be able to do research, we're not going to be able to get better, until that stigma is dismantled. Can you help explain that?

**Dr. Shapiro (02:12):** So, this social relationship invests or imbues everything we do if we end up carrying this disease or if we have friends or family or know people who are experiencing this disease. The social environment in which the disease occurs ends up informing and actually limiting the ability for people to live full and productive lives as a consequence of its presence. And ignoring it actually is something which worsens it. So, migraine is a disease which is diagnosed based upon the symptoms that people describe. There are no physical examination findings. There are no laboratory tests which are specific for migraine. It's what people report. So, if people don't report it, or they don't show any evidence of it, then it's invisible. And when it's invisible, it's easily discounted. And unfortunately, migraine as its dominant symptom is headache. And headache is a discounted symptom to have.

**Dr. Shapiro (03:20):** We understand that headache is an extremely common experience within all populations, but migraine is actually a much less frequently described or experienced disease. But the fact that most people have some idea about what you're talking about with headache and it's inconsequential to them, means that they identify with migraine as being inconsequential, as well. And this leads to people hiding migraine; it leads to people being hesitant to seek care for it; and in many situations, whether it's within school or within employment situations, people who are experiencing migraine don't show it. They don't show it



because it's not a necessity to show it because their symptoms, which they can hide, and they learn at an early age that if they disclose that they have migraine, that they'll be punished for it. That there will be limiting opportunities for them to advance or, you know, live a full productive life. So migraine tends to be forced into hiding and that hiding tends to perpetuate it.

**Kellie Pokrifka (04:45):** So you explained that migraine doesn't have a biomarker. Do you feel like if it was able to be seen on a test like a blood test or an MRI, do you feel like we'd be more likely to be believed that this is a serious disease?

**Dr. Shapiro (04:57):** So to some extent, I do. I think that it would help to validate people's description that they have this going on at this time, and that there's a way to quantify the magnitude of it, that this is a particularly severe or prolonged event which is associated with disability. And so, I think that might be true. It remains to be seen. I'm very hopeful that over the next, oh, say, 15, 20 years, we will have validated and well-accepted and reasonably accessible biomarkers — that is, tests — to say, "You have migraine now," or, "You don't have migraine now."

**Dr. Shapiro (05:44):** This comes up in emergency department settings often, where people may have claims about what they're experiencing, and they may be discounted because they don't seem to have what is regarded as the appropriate pain behaviors that people assume must be present if someone's actually experiencing pain. And the other symptoms of migraine are equally prevalent. And as they occur often, and they may also be the source of just as much impairment or disability, and they may be equally invisible. So, things like cognitive problems, inability to focus or concentrate, difficulty with environments which have bright lights or loud noises or odors. These are all situations where people may have impairments due to migraine, but their co-workers or employers can't see them.

**Kellie Pokrifka (06:44):** So, you mentioned appropriate pain behaviors in seeking care in the ER, and that's a huge fear for so many of us. We go in, we have no idea if we're going to be believed, if we're going to be actually treated, or if people are going to be like, "Oh, you're exaggerating," you know, "Get out of here." And it's terrible. It's so hard to go into an ER where there's ridiculous lights happening, there's so many sounds, it's so stressful. How do we deal with that? And what are appropriate pain behaviors, like you were discussing?

**Dr. Shapiro (07:15):** So if you cut yourself or stub your toe or any other acute pain injury, you're typically going to have certain ways that people will obviously know that this has occurred. So, you withdraw your hand from a flame; people may wince or cry, or they may hold the area that's been injured. And people with migraine just don't do that — at least that's my experience in caring for thousands of people with migraine. When they come to my clinic, they're not holding their head and wincing from pain. They may be trying to avoid bright light, but it's not because their pain is actually forcing their eyes closed, the way people perceive this to be true. So in 2021, I collaborated with a group of investigators at the Danish Headache Center to look at what were the most obvious ways that migraine's portrayed in images on the internet.

**Dr. Shapiro (08:16):** And what we found was that the image of somebody with migraine coalesced around a particular image, and that image was of a relatively young white woman who was particularly thin and was wincing and holding her temples with her hands. And that was overwhelmingly what you will get as the popular or socially understood look of what migraine looks like. And while it's certainly the case that three-quarters of people with migraine are women, and it tends to occur more among women of childbearing and working age than it is



children or the elderly, it's not something which is particularly true among thin women versus overweight women. And as I said, certainly the people who I see who have migraine in clinic are not wincing and holding their temples.

**Dr. Shapiro (09:16):** And so when people go to the emergency department, they may not have these behaviors that people expect. And that leads to a kind of a disconnect between the expectations on the part of healthcare providers and the experience of people who have migraine. And in the current situation, where opioid-seeking is something which is highlighted in emergency departments, anyone who comes in with a complaint that includes pain will be potentially a suspect that they're actually there to seek opioids. And if their behavior doesn't meet expectations, then there leads to a potentially harmed relationship between healthcare and the person who's receiving the care.

**Dr. Shapiro (10:10):** This is a difficult, difficult problem to solve, because it requires, really, an education about what migraine is and what it isn't within the healthcare profession. Even among doctors, there's this identification that migraine is headache, when migraine is not headache; headache's just one of many symptoms that occur in the setting of migraine. And if people are not comporting, they're not behaving the way there's expectations, then that ends up leading to difficulties. So we need education. We need education throughout society, but we need particularly better education among those who are most likely to be taking care of people with migraine. And by that, I do not mean headache specialists, because there are fewer than a thousand of them in the United States, and for, depending upon how you measure it, between 45 and 60 million Americans will have migraine this year. So primary care is really the area that is really where care for migraine occurs and for acute migraine in emergency department settings. And there's just not enough education yet in primary care or emergency medicine to appreciate that migraine isn't going to look like what people assume it will look like.

**Kellie Pokrifka (11:28):** So, one of our users, named Virginia, she wants to talk about migraine and the stigma of that within the migraine community. So, you'll have some people — because it's such a spectrum disease — you'll have some people thinking, like, "Oh, you don't need to take off work for that, because if I have a migraine attack, you know, I can take an ibuprofen, some caffeine, and I'll be good to go." And then you have other people who will be like, "If you were really having a migraine attack, there's no way you could be doing that, you know, because I have to be completely in bed, I'm in front of the toilet for all day ...." How do we deal with people who don't really understand that it's fully a spectrum, and just because we look fine doesn't mean that we're not struggling?

**Dr. Shapiro (12:11):** Those who have the most burdensome forms of disease — chronic migraine is when headache symptoms occur at least 15 or more days per month — they carry, through all studies they carry a higher measure of disability and burden than people who have infrequent migraine. And another study that I'm involved with — collaborators from Lundbeck, which we reported out in 2021 — looked at about 4,500 people who have migraine, as a general U.S. survey population, and compared these people to a control group pulled in the same study, matched for age and sex and health characteristics. So, a comparative group. And we found, unsurprisingly, that people who have chronic migraine are less likely to be full-time employed and more likely to have a self-identification of having disability. But we've found something else, which was very surprising to us, which is that people who have infrequent migraine — so they have diagnosis of migraine, but zero to three days with headaches per month — were more likely to be employed and less likely to self-identify as disabled than the group that was our control group from the general population. And what do we understand by that, or how do we



interpret that? Well, it could be that people who have migraine actually have some skills that they may have learned or acquired, or maybe it's embedded or intrinsic to migraine, that makes them more resilient. That makes them more able to be managing or multitasking employment with disease and other things.

**Dr. Shapiro (13:56):** And what that means is that if we can provide opportunities for people who have more frequent migraine to have the accommodations in the workplace and so forth, and appropriate medical care, that they can reduce their frequency, then they may end up being as advantaged in a way as those people have a relatively infrequent migraine. And that change, that equity, in availability for people to live their best lives and not have migraine interrupt that, that may narrow this apparent gap in appreciation of the disease between those who have it infrequently and those who have it nearly daily. And I'm hopeful that if workplace programs for migraine are fully implemented and healthcare — particularly with the new therapies that have become available — becomes fully available, then this may allow people who have migraine to be the most productive people and the most sought-after employees.

**Kellie Pokrifka (15:05):** OK. So, both you and I work on a nonprofit coalition called Migraine at Work. Can you go over the stigma of how employers may view people with migraine?

**Dr. Shapiro (15:16):** Sure. Migraine is invisible to employers. They are not inclined to see it, and they're even less inclined to do something about it because it entails costs to them. So, people with migraine typically hide migraine if they're working with it, and they're capable of doing that because there are no physical signs which betray that they're experiencing it. And so, they may work and appear to be unimpaired, but their productivity may dip at times when they're experiencing migraine, whether it's due to the pain or whether it's due to cognitive changes or environmental difficulties. This is a common issue with respect to people who are living with migraine. And employers typically measure in the U.S. how impactful a disease is to their employees based upon the claims that are made for medical care — healthcare.

**Dr. Shapiro (16:16):** You have a condition where 40% of the people are undiagnosed — they don't know they have it — and of those that are diagnosed, half of them hesitate to seek care. You can see that the claims may be much lower than you would expect for a disease that has the prevalence in the workplace that migraine has. But even if it was fully claimed in terms of the healthcare costs, the cost to productivity is much, much greater, or multiple, of the cost to the employer, but those costs tend to be invisible to the employer. It's hard to measure lost productivity if you aren't even aware that it's there. And in order to consider it or measure it, you have to take migraine seriously, and employers are not inclined to do that. So, this leads to employers not regarding migraine as a serious condition.

**Dr. Shapiro (17:14):** And there was a survey that was made a few years ago in Britain of a thousand employers. And they were given a menu of about nine different conditions and asked whether this was a serious enough reason for an employee to be calling out sick from work. And unsurprisingly to me, and perhaps to you, migraine was at the bottom of the list of legitimate reasons for an employee to call out sick from work. Only 22% of employers thought that it was a legitimate reason to call out sick. And in that setting, it becomes pretty clear to employees that it's not worth it to them to risk their job to state that, "Right now I'm not as fully present for my work as I would like to be or could be."

**Kellie Pokrifka (18:08):** What kind of accommodations can help for migraine at work?



**Dr. Shapiro (18:12):** The remarkable thing is that the adjustments — the accommodations that are available at relatively low cost to employers to make the environment such that people can work to their full potential and full productivity — are relatively straightforward: allowing people to adjust their work environment to have appropriate lighting, and sound, and odors; allowing them to adjust the timing of their work so that they can work at the times when they're least likely to feel impaired.

**Kellie Pokrifka (18:51):** So across the board, what can be done about stigma?

**Dr. Shapiro (18:55):** If stigma is a social relationship, and it is really driven by a misunderstanding or misperception of what someone is experiencing, and as a consequence, people tend to hide it, that ends up perpetuating this reservoir of stigmatizing attitudes. Studies have been done looking at what helps to reduce stigma for other healthcare conditions or health conditions which are stigmatized — for instance, mental health conditions or addiction conditions and so forth, particularly those that are invisible in that way. The method that has been reported really to have the most effectiveness is what's called "contact." Contact is, quite simply, someone who carries a stigmatizing attitude interacting directly with somebody who is stigmatized, to deflate: to reduce this perception that they are actually different, that they are tainted, that they're somebody who is not worthy of being included.

**Dr. Shapiro (20:14):** And what that means is that people who have migraine have to do something courageous — which is contrary to everything they've learned about the disease from living with it — which is that they should acknowledge that this is there. And unfortunately, that means — where we are right now — that this will potentially put you at risk for people to discredit this. So it requires being a self-advocate. You have to come forward and say, "Look, this is what I'm living with, and these are the things which we understand can help reduce it." So educating yourself about the disease is really a helpful thing, so that you can explain to others what you're experiencing. And if you're really interested in getting involved in this to help reduce the stigma that occurs structurally in society, that is, in public policy or in the federal government and so forth, there is actually a way to get involved.

**Dr. Shapiro (21:22):** So, we have an organization called the Alliance for Headache Disorders Advocacy. And each year, for the past 15 years, we've gone to Washington and lobbied Congress to try to change some of the structural problems, which are embedded in law, which limit the fulfillment and welfare for people living with migraine and other headache disorders. And we do this with an event which we call Headache on the Hill. So if this is something that you're interested in, certainly go to the Alliance for Headache Disorders Advocacy website, and there will be an opportunity potentially to apply for this event, which occurs every year.

**Kellie Pokrifka (22:05):** All right, stigma from loved ones. A viewer named Virginia wrote in and she said: "How do I stop feeling like such a burden to my loved ones?" Which is so hard, and I think is a really important point about this. For people with chronic illness, seeing themselves as a burden to their loved ones is actually one of the leading factors of suicidal ideation. So I think this is incredibly important that we address this one. How do we stop feeling like such a burden?

**Dr. Shapiro (22:33):** It takes different forms. This is a big problem, and it takes different forms in different family situations. In many families, migraine is something which has been effectively inherited. There's a strong genetic predisposition for migraine. So that may lead to both positive and negative effects: So, positive in the sense that loved ones or family members may understand what you're experiencing, without you really having to get into great detail about



your descriptions of it, but negative in the sense that the coping mechanisms, which they may have adopted for themselves, which may be perpetuating the problem — hiding migraine, for example — may not be actually healthy ways to approach the problem. And there may be tension between how you experience migraine and how they do.

**Dr. Shapiro (23:31):** So, I have a patient who's now 58, who has told me that her mother had chronic migraine. And her very earliest memory at age 4 was her mother telling her, "Whatever you do, never tell anyone about your headache or no one will want to be your friend." And it took her into her 20s before she actually got the diagnosis. And all through school, she was effectively told that she was stupid, because migraine interfered with her ability to concentrate and achieve what she would've achieved otherwise. And within this environment, if you are calling out that you have migraine, and you're asking for accommodations which other family members have chosen not to ask for, then that can lead to tension. So the same self-advocacy issue, which I mentioned before, really applies to families.

**Kellie Pokrifka (24:31):** Absolutely. So at any chance we can get, we need to start talking about this. We need to share our stories, we need to show that, you know, we are not weak. We are valuable members of society. We can do basically anything. And even if we're feeling weak, even if we need to stay in bed, we still matter, you know; there's nothing wrong with us. And so, yeah, share your story, help dismantle the stigma. So earlier in 2022, you helped lead the OVERCOME study. Can you tell us what that told us?

**Dr. Shapiro (25:08):** The OVERCOME study is extremely important to understand because it's the very largest population-based study of migraine ever undertaken. Somewhat [more] than 60,000 people with migraine were polled over several years about many, many aspects of their disease. But one of the things that we looked at — and the OVERCOME study is sponsored by Lilly, it's important to recognize — one of the important things that we looked at were attitudes towards migraine itself. And we asked people who had migraine. We also asked another group that was polled at the same time who did not have migraine. And the people who had migraine were asked a series of 12 questions that began: "How often have you felt that others viewed your migraine or severe headache in a particular type of way?" And the questions coalesced around two major themes, and one of them we call "secondary gain" and the other we call "minimizing burden."

**Dr. Shapiro (26:13):** So, secondary gain is where it's — people believe that people with migraine are using migraine for some underhanded reason. That is, they're using it to avoid obligations or commitments or work, when they may or may not even have any problem at all. And minimizing burden is where people who have migraine believe others believe — felt that others believed — that the migraine itself, the condition itself, was not consequential. So the secondary gain was effectively a stigma towards people who have the disease. And the minimizing burden was stigma towards the disease itself. And what we found was that about a third of people with migraine often or very often felt that either secondary gain, minimizing burden, or both of these types of stigma were present. And we also looked at people who did not have migraine and asked them a similar set of questions about their attitude towards migraine.

**Dr. Shapiro (27:32):** And again, about a third of them really felt that migraine itself was a disorder where people exaggerate their symptoms for some type of advantage, that it's their own fault because of unhealthy behaviors, and that they may use it to avoid commitments. So, what are the consequences of this? So, another aspect of this study was that we asked people who had migraine a series of questions which measure their disability burden, and also a



measure of what's called quality of life. But what we found was, if you tossed in the stigma issue for those that often or very often experienced stigma, it dramatically magnified the disability increase or the quality of life decrease regardless of the number of days with headaches per month. So much so, that for people who had zero to three days with headaches per month and felt the maximum stigma, their quality of life was worse than people who felt no stigma at all but had headaches every single day. And this is a really extraordinary thing. It suggests that the social context of the disease — the stigma that surrounds it — may be of greater consequence to the quality of people's lives from people who have migraine than headache, which people of course identify as, "Well, that's all a migraine is, right?"

**Kellie Pokrifka (29:10):** Wow. That is a huge statistic. So being around people who judge us, judge this condition, or don't see migraine as serious can actually worsen our own health.

**Dr. Shapiro (29:26):** Dramatically so. And you don't even have to be around them; you just have to believe that that's how your disease is perceived.

**Kellie Pokrifka (29:34):** Wow. That is huge. Stigma is not only impacting our care, our research, but it's actually impacting our health.

**Dr. Shapiro (29:42):** Yes.

**Kellie Pokrifka (29:43):** Would you recommend any resources?

**Dr. Shapiro (29:45):** I think that the websites for the American Migraine Foundation, the National Headache Foundation, the American Headache Society, and the Alliance for Headache Disorders Advocacy. These are all websites which have great content and, in particular, suggestions about how you can get involved in advocacy to try to mitigate, try to reduce, this huge burden that people with migraine are living with.

**Kellie Pokrifka (30:14):** And where can we learn more about your work?

**Dr. Shapiro (30:17):** So, I am on social media as @HeadacheDoc on Twitter — that's the only place I'm on social media — and my research papers are, of course, available through PubMed.

**Kellie Pokrifka (30:32):** Dr. Shapiro, thank you so much for being on the Migraine World Summit.

**Dr. Shapiro (30:36):** It's been a pleasure. Thanks so much for having me.