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Rethinking Migraine Care: Prioritizing Patient Needs and Restoring Function

Ashley:

This is *On the Frontlines of Migraine* on ReachMD. I'm Ashley Baker, and joining me to discuss patient-centered care in migraine is Dr. Stephanie Nahas. She's a Professor of Neurology at Thomas Jefferson University and the Associate Director of the Headache Medicine Fellowship Program at the Jefferson Headache Center in Philadelphia.

Dr. Nahas, welcome to the program.

Dr. Nahas:

Thanks. Glad to be here.

Ashley:

To start us off, Dr. Nahas, why is patient-centered care so important in migraine management?

Dr. Nahas:

I'm really glad you asked that because one of the things I like to really emphasize to anybody I'm speaking to about migraine is that every case is unique. I liken migraine to snow, and individuals living with migraine, they're like beautiful little snowflakes. They all have common properties, but each one is completely unique and individualized, and therefore, we need to tailor our approach and treatment to the individual.

This is a person living with an invisible, often stigmatizing disease who is often dismissed and feeling like they're very alone. So I want to bring that locus of control back to the individual by focusing on specifically what they need. And this goes way beyond just medication. You have to provide total support for these folks in the emotional sphere, in the physical sphere, and in the spiritual sphere. Whether you yourself provide this or not, you're shepherding this patient through the process of learning how to live better with migraine.

And we like to focus on what's important to the patients themselves. A lot of patients aren't so focused on how many days per week or per month they're having headache. They get really annoyed when you focus on numbers like that. We want to pay more attention to perhaps less tangible aspects of living with the disease, like their quality of life, how their medications affect them, how they navigate the world around them, and how they have to interact with their family, their friends, their peers, their coworkers, and their bosses. And living with this unpredictable disease, which can take them out of commission at a moment's notice and at the most inopportune times instills a lot of anxiety in a lot of folks living with migraine.

So we often have to prioritize not complete relief from attack but restoring of function. If a medication gets rid of the pain but makes you too drowsy or too out of it to function, that's really not that great, and so we might be focusing more on normalizing function rather than completely eliminating symptoms. And I think this is something that, unfortunately, a lot of us lose sight of, and I constantly have to remind myself of it too, especially when we're held to specific metrics and goals that focus more on headache days and acute medication use days than on the totality of that individual's experience.

Ashley:

Now, what communication or access barriers do patients with migraine commonly face?

Dr. Nahas:

I alluded to this earlier; many patients living with migraine may feel stigmatized, and that comes both from the outside world and from within living with an invisible disease where the person you're speaking to has to trust that you're actually suffering from these symptoms. Now, that's a very lonely place to be, and so just expressing that, understanding that, and validating your patient in that way,

saying, “Hey, I get it. You’re the one who experiences this, and it may be very hard for you to articulate it. It may be very hard for others to really appreciate what you’re feeling, and so you feel dismissed and misunderstood.” And this disproportionately affects women and minorities too, and sadly, as we know, migraine disproportionately affects women to begin with.

And you may say to yourself, “Well, what can I do about all these problems? I can’t solve the world’s problems. I can’t fix everything.” And that’s true, but what you can do is you can listen, you can be kind, you can validate, and you can just be there for your patient. And I’m lucky that I was able to kind of realize this fairly early on, many years ago, because the patients we see are extraordinarily complex, and they have numerous treatment failures. We keep trying and trying again, and nothing really works, and we get to a point where the visits start to turn into just “Hey, how are you doing?” And, “I don’t really have anything new to offer you, but I really feel for you, and I want to make sure that at least what you have is working decently and not causing harm.”

There was one day many years ago where at the end of the visit, I basically sat there and just listened to the patient talk for most of the 30 minutes. Afterwards, they were so grateful; their face completely changed, and they were so thankful just to have somebody to talk to who would listen to them nonjudgmentally. And so that was a real turning point in my career. I learned that I don’t have to always push another medicine, another treatment, or another approach. Sometimes just sitting back, listening, and being kind is all that you need to do.

Ashley:

For those just joining us, this is *On the Frontlines of Migraine* on ReachMD. I’m Ashley Baker, and I’m speaking with Dr. Stephanie Nahas about how we can prioritize patient needs and preferences in migraine care.

So, Dr. Nahas, given the barriers we just discussed, how can we ensure we foster trust within our patients and fully understand their experiences?

Dr. Nahas:

It comes back to those good old communication techniques and strategies that we’re all supposed to learn in our training, and unfortunately, sometimes we ignore them early on when we’re so focused on learning facts and figures and memorizing diagnostic criteria and lists of medicines. It’s really so critically important. And sadly, some trainees really don’t get much experience or training and education in this very important aspect of the art of medicine.

So, like I said before, just take a step back, be kind, and listen in a nonjudgmental way. When you’re talking with patients, use open-ended questions, like, “Tell me how it’s going,” and just let them talk. It’s astounding. There was a study done a number of years ago looking at how long it took for a clinician to interrupt a patient when they were first taking a history, and you may be surprised to know it was about 11 seconds before an interruption. You can barely get a few words out in 11 seconds. I find it extraordinarily helpful to just sit back and let them talk until they’re done. Now, of course, within reason—if you get a patient who’s rambling, you may need to redirect them a bit, but you actually get a lot of what you need without having to go through a checklist by just sitting, listening, making eye contact, using open postures and open gestures, thoughtfully nodding, and connecting with that patient so they can actually tell you their story.

If the patient thinks you’re just asking questions off the checklist and want a bunch of numbers, they’re disengaged, and they think that you don’t really care about them; you care more about the disease. But we care about the total person, so we want to elicit that story from them. And when a patient feels like they’ve got that connection with you, they’re going to tell you their story in a way that’s meaningful, especially when you normalize the experience that they have of feeling blame, shame, and stigma and call it out and explain that you understand and you get it—and making sure that you’re not using stigmatizing blameful language.

For example, if a patient comes back to you and they haven’t exactly followed the directions that you’ve laid out for them, instead of asking them, “Why didn’t you do what I said?” or “Why didn’t you fill this medication?” or “Why didn’t you do X, Y or Z?” a better way to phrase it is, “What prevented you from doing X, Y or Z?” Again, it takes the blame off the patient, and it really just asks what’s the reality. “What kept you from doing this?” And then they’ll be much more willing to volunteer those reasons and explain the barriers. They may be internal. They may be external. Often, they’re combined. And then you can start to break down those walls and allow the patient to then progress. Maybe what you recommended wasn’t something that they were ready to undertake. Even if you had a rich and full discussion with multiple different treatment options and that’s the one they selected, maybe they didn’t really want to do it in the first place, and you just did not quite get there. So all of these—revisiting and meeting the patient where they’re at and making sure that the goals are aligned and realistic and what they’re willing to do in order to achieve those goals is mutually agreed upon by the both of you.

Ashley:

And how can we tailor communication strategies for patients from underserved populations who may face cultural, linguistic, or access-related challenges in migraine care?

Dr. Nahas:

This is another level of nuance to patient communication where we have to remember that the words and thoughts going through our minds might not be what's understood by the patient on the receiving end, especially if they have any of these potential disadvantages with respect to education, culture, etc.

So a basic ground rule is we teach all of our trainees to avoid clinical jargon, use as much plain language as possible, and speak as if you're talking to somebody with perhaps even only a seventh or eighth grade education level. They may have a much higher education level, but let me tell you, when you're in the throes of a migraine attack or living with daily, near continuous symptoms of migraine, one of those symptoms is brain fog. And while you might be a very highly intelligent, highly accomplished, or highly educated individual, if you've got brain fog, it's going to be very difficult for you to understand anything that's being said to you. So you have to speak clearly and plainly, using simple terms. Use visual tools if you can, use hand gestures, and use analogies to help explain what is going on. Even if we can't fully understand what's happening with migraine pathophysiology, there are ways that we can explain it and can make it understandable to all patients.

We also have to be sensitive to cultural beliefs about pain and the needs of an individual based on their gender, their sexual orientation, their race, their religion, and their ethnicity. All of this can actually play a critical role in how this individual lives with migraine.

Ashley:

Finally, Dr. Nahas, do you have any key takeaways you'd like to share on how we can prioritize patient preferences and needs in migraine care?

Dr. Nahas:

The best way to prioritize it is to spread the word and increase awareness. This is why beyond just our clinical societies we partner with the patient communities and advocacy societies—organizations such as the American Migraine Foundation, the National Headache Foundation, Miles for Migraine, the Coalition for Headache and Migraine patients, the Alliance for Headache Disorders Advocacy, and the Headache Alliance. All of these organizations really put a huge focus on engaging the patient community. And indeed, in the past few decades, we've seen a huge growth in patient advocacy and engagement. This has tremendously contributed to the increased awareness broadly speaking—not just the general population, but also across medicine, the pharmaceutical industry, and the scientific community.

I've seen it first hand when going to our scientific meetings in the past 20 years—the attendance has gone from a few hundred to around 2,000, and that I think really speaks volumes. But we still have a long way to go. There are 40 million Americans estimated to be living with migraine and other disabling headache. There are fewer than a thousand board certified headache specialists in this country. There's one for every, we estimate, 50,000 Americans living with this disease, half of whom aren't even properly diagnosed, let alone given adequate treatment. So we still have a long way to go, and anything that we can do to get the word out about the importance of the surge of headache disorders in this nation is of paramount importance.

Ashley:

That's a great way to round out our discussion, and I want to thank my guest, Dr. Stephanie Nahas, for joining me to discuss patient-centered migraine care.

Dr. Nahas, it was great having you on the program.

Dr. Nahas:

Thank you. It's been a pleasure.

Ashley:

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