



MIGRAINE WORLD SUMMIT

INTERVIEWS WITH WORLD-LEADING EXPERTS

TRANSCRIPT



**LEARNING THE FULL IMPACT OF MIGRAINE
THROUGH PATIENT VOICES**

REBECCA ERWIN WELLS, MD, MPH, FAHS



Introduction (00:05): The impact of migraine on patients' lives is pervasive, and it's profound, and it affects people in all areas of their lives and in ways in between attacks, in addition to during attacks. And it really demonstrates how important it is for patients and for researchers to understand this impact so that we can really target treatment options, start measuring this impact, and really, really find ways to be able to help those that are living with migraine.

Wendy Bohmfalk (00:38): Migraine is the second-leading cause of disability worldwide, and we have all experienced the toll it takes on our health, our time, our relationships, and resources. Dr. Rebecca Wells recently led a study to examine exactly how migraine affects multiple domains of life. You won't be surprised to hear that 90% of participants reported that migraine had a negative impact on overall life. Dr. Wells joins us to explore the personal impact of migraine and discuss why it is such a frustrating disease. Dr. Wells, welcome back to the Migraine World Summit.

Dr. Wells (01:13): Thank you so much, Wendy. It's so great to be here at the Migraine World Summit with all of you.

Wendy Bohmfalk (01:17): Oh, thank you, we're delighted to have you. I'd love to know: How did this study come about?

Dr. Wells (01:22): Yeah, so this is a really beautiful example of patient voices just coming through. So, we conducted two clinical trials in adults with migraine. Both were conducted evaluating an intervention of mindfulness. And at the end of both clinical trials, we conducted interviews to understand people's experiences with the study. And the original goal of conducting these interviews was really to understand how people experienced the clinical trial that was just conducted. But we also wanted to know how headache impacted their lives. And we began each interview by asking patients: "How does migraine impact your life?" And we were really blown away by the depth of responses to this really seemingly simple yet profoundly important question. And it was interesting because part of the goal of asking that question was to get patients warmed up and to start talking, so then they could reflect on the impact the clinical trial had on their headaches. But as we began conducting analysis of the interviews, we recognized how beautiful the participants' responses were to this question.

Dr. Wells (02:35): And when we began looking at analyzing this data, we thought this information — completely separate from the impact of the clinical trial — is so rich. And we need to share this with the world because this is really, really important information. And so, in some ways, this study evolved sort of naturally, and in some ways, serendipitously, which I think is important. But it also goes to show that often as researchers, we're not looking for the impact that migraine has on patients' lives. And so, for me as a clinician, this study really taught me a lot about how migraine is impacting patients' lives beyond what we typically ask or understand. Because it was two different clinical trials: 81 participants were involved and from two separate clinical trials that were conducted in two separate cities. So, the first study was conducted in Boston, and the second study was conducted in Winston-Salem, North Carolina. And both groups of participants in the first clinical trial, they were recruited who had an average headache frequency of four to 14 days a month; and in the second clinical trial with four to 20 migraine days a month. Most patients had more than 20 years of migraine, so most patients really had a long history of migraine. Most of these participants were having, you know, more than once-a-week migraine attacks. Most were using acute treatment medications, at least 90%, and prophylactic medication ranged anywhere from 40% to 71%. So, most were treating their headaches with migraine medications.



Wendy Bohmfalk (04:18): OK, interesting. I noticed that most of the participants in the study were white women in their 40s with private insurance and those that had completed college. Are you able to extrapolate your results for a broader population?

Dr. Wells (04:31): Most clinical trials connected to migraine have this type of patient population. And so, this clinical trial is not different from most of the other studies that we draw most of our conclusions about with clinical research. And it brings up the question of why and what can we do about this? And there is a concerted effort within the field of headache medicine to change this. So, for myself, personally, a lot of my research involves mindfulness. And so, I've partnered with someone who has spent the last 10 years finding out how we can bring mindfulness to more diverse populations. And so, with my research, this is one of my top goals in moving forward. As a field, we are really working hard to change this. There have been multiple ... recent publications within the field of headache describing how we can take action steps to change this. I'm currently the co-chair of the Diversity, Equity, and Inclusion Taskforce of the American Headache Society. And so, we are actively working to find systematic ways to ... be more diverse and inclusive and equitable both within our organization, as well as within the entire field of headache medicine. And so, I think this is a really important point, that is something that we are taking very seriously, and that we are really working hard to change because we want all patients with migraine to have their voices represented, not just a select subgroup.

Wendy Bohmfalk (05:57): Great. I'm glad to hear there'll be more diversity that we'll see in future studies. That's great.

Dr. Wells (06:02): Yes.

Wendy Bohmfalk (06:03): Why is it important to know the disease impact of migraine?

Dr. Wells (06:07): Yeah. This is such an important question. We really need to understand how migraine impacts patients' lives to be able to create and assess patient-reported outcomes for migraine studies and clinical trials. We also really need to understand the true burden of disease, you know, in order to help with resource allocation and treating migraine and in mitigating the full effect of migraine. And we also need treatment regimens that not only target the individual attack, but the full spectrum of impact that migraine has on patients' lives. And so many of our patients reported additional factors that are playing ... a role in their lives that we don't target with medications; I mean, we're not targeting stigma. Recognizing all these other factors that are playing a role in the way that migraine affects individuals' lives is so important.

Wendy Bohmfalk (07:04): Absolutely. It just seems like there — and we'll get to this — but there could be so many implications for treatment then, too. So, it's very exciting. Well, what surprised you the most about the study and the results from the study?

Dr. Wells (07:15): Yes. This is a really great question. So, the first thing that surprised us and I just want to acknowledge, was the amount of information that we gained from this study in terms of the impact it had. So, we had 81 interviews, and the participants provided over 3,300 minutes of recorded interviews. And we actually spent two years with weekly research team meetings analyzing the data because there was so much rich information and such a beautiful description of patients' experiences. And we wanted to make sure that we were doing the data justice. We wanted to make sure that the participants' voices really shined through. And so, one of the really surprising facts that we found was the magnitude and pervasiveness of these



findings, which really show the enormity of the impact. So, despite most participants using either acute or prophylactic medications, you know, 90% reported migraine had a negative impact on their life.

Dr. Wells (08:18): We did not specifically ask: "How did migraine impact your life?" Like, "What areas of your life did it impact?" And without even asking that specific question, 68% endorsed specific domains of life that were impacted, and 52% described impact on emotional life and emotional health. And then I think the other really interesting finding that we saw was that, you know, how migraine impacts patients' lives is often in ways that we don't ask about, in ways we don't measure or target in clinical practice or research — but clearly we need to. So, you know, migraine affects participants' ability to function, but it also affects relationships with colleagues at work and with family and friends. And we also found that migraine contributes to isolation, and frustration, and guilt, and avoidance behavior, and stigma. And this is something that we rarely ever address in a clinical encounter.

Dr. Wells (09:17): Migraine is something that really affects not just the person who has the disease. You know, one of the participants said, "Migraine affects my entire family. When I have a migraine, my husband has to take over. My children ... I'm not engaged with my children." And this particular participant said, "It's a disease of the entire family." I also think for many patients with migraine, they often don't have a lot of other diseases that are impacting their life. So, if they didn't have migraine, they would otherwise be very healthy. And so, it takes an individual who is healthy and active and, you know, very functional — and then, all of a sudden, an attack comes along and it is completely disabling. And so, I think it has a dramatic impact on quality of life.

Wendy Bohmfalk (10:07): We do know that migraine is often comorbid with depression, anxiety. Did that show up in the study?

Dr. Wells (10:12): Yes. And so, what's interesting is there's a significant comorbidity of migraine and anxiety in patients with migraine. And what's interesting, we don't know from research is: sort of like, what's the chicken and the egg? Some patients will say, "Well, I wouldn't be anxious or depressed at all ... if I didn't have headaches." And we know that to be true [to] some degree, but we know that both are feeding each other and that definitely showed up in our clinical trial in terms of the impact on emotional health.

Wendy Bohmfalk (10:46): Well, let's go ahead and dive in. I want to get right into it. Let's walk through the six main themes of migraine impact that were identified in the study. So, the first one is the global negative impact on overall life. Can you talk about that one?

Dr. Wells (11:00): Yes. So, we found that most participants felt that migraine just overall controlled their life or made their life more difficult. There was disability during the attack, but then also feeling a sense of loss of control in between attacks. And many participants would describe, you know, "I tried so hard; I would push through despite the migraine." And so, in general, most of the patients describe this negative impact on their overall life, that migraine was always there. It was like, even when there wasn't an attack, the existence ... the disease itself was always there. And I think that's an important aspect: One thing we're trying to change is even the terminology we use in the field where we want to use the term "migraine." *Migraine* is a disease and individuals have attacks, but it's not: "I have *migraines*," but "I have *migraine*" because it is a disease. And so, I think that's really important.



Wendy Bohmfalk (11:54): Yeah. I'm just curious too, as we go through these: Were a lot of those responses the same across the different categories? Or was there a lot of variation within the theme and responses that you got?

Dr. Wells (12:04): Yes. There was a lot of resonance. A lot of participants reported a lot of the same themes. And it was really interesting because we saw it across both clinical trials, which I think was especially telling. You know, one study being conducted in the Northeast and one in the South across different years; you know, one study was conducted in 2011 and the other study was conducted between 2016 and 2019. And so, you know, you have two clinical trials conducted ... across different cities, you know, [over] different time periods, and ... the participants were saying the same things.

Wendy Bohmfalk (12:39): Let's talk about the second theme that you identified, and it rose up, and that is impact on emotional health. Talk to us about that one.

Dr. Wells (12:46): Yeah. So about 30% to 40% of our participants in both clinical trials reported previously having a diagnosis of depression or anxiety. So, most participants did not have a formal diagnosis of a mood disorder, but more than half of the participants reported that migraine had a negative impact on their emotional health beyond typical diagnosis of depression and anxiety. So, participants described feeling guilty for missed work or family or social activities, and often that would lead to frustration and isolation. And so, we saw the impact of emotional health beyond just depression and anxiety.

Wendy Bohmfalk (13:22): Well, the third one is impact on cognitive function.

Dr. Wells (13:26): Yes. So, I think this is an area that is ripe for more research. I mean, I wish I could give you a number. It feels as if 80% to 90% of the patients I see in clinic say, "When I'm having a migraine, I just can't think; I can't think clearly." And this came through very, very strongly in the interviews. People would describe concentration problems, like not being able to concentrate, but also communication difficulties. So, saying like, "I couldn't think of the right word," or "I couldn't talk clearly," and the impact that had [on] family, but also in work experiences. And what's interesting is sort of ... the effect of cognition and mood during an attack, I think really reveals the need for future research to better understand those factors are actually part of the expression of neural dysfunction that happens during a migraine.

Wendy Bohmfalk (14:21): I think this is fascinating. And also, because I feel, personally, like I feel the effects between attacks, too. So, it's not even just while an attack is happening, but between. Did you see that show up as well?

Dr. Wells (14:31): Yes, definitely. And often participants describe also the day of an attack or sort of what we consider the 24 hours prior to the pain beginning, the prodromal period — having cognitive dysfunction before the headache pain begins — which also really reflects, potentially, this pathophysiological change that happens during the migraine.

Wendy Bohmfalk (14:57): I think it could almost be a relief to know that it is part of the disease — these things that are happening and not just us not being able to concentrate. But it's like you said, we research this more and come up with answers. What about the fourth area, which was impact on specific domains of life? I think it was work, career, family, and social.



Dr. Wells (15:16): Yes. So, we saw the impact on all these different areas, and specifically there was, in terms of work and career, there was ... people felt guilty. There was change of job status, so some people either lost their job or quit their job or retired early. We talk about, you know, when people can't be at work, but there's also something called "presenteeism" — where individuals are at work, but they're less functional and they're not able to concentrate or be as productive as normal — as well as the financial impact. Many participants reported that their careers did not take off as well, and they felt the financial impact on their careers because of migraine. And then there were some participants in our study who were in school, and they talked about the impact it had on their ability to study and their academic function. And then in terms of family impact: There was definitely a sense of frustration, a sense of guilt that they either weren't able to participate, but also the burden that then was placed on other members of the family when a migraine attack would occur, and then also frustration of the disrupted time. And then in terms of the social impact, often it led to, you know, altered plans, not being able to be reliable with friends or family, and, really, difficulty with, sort of, the social aspect of communication. And when individuals had an attack, they felt like, you know, if they were having a conversation, all of a sudden they couldn't effectively converse with other people.

Wendy Bohmfalk (16:51): Absolutely. I think so many people relate to this area, in particular. You know, going back where we talked about work and career, especially in presenteeism, I think there's also that that desire to hide, you know, and try to hide your condition. I don't know if that showed up, too, where you're trying to minimize, or you even just sometimes call it just "a headache," you know, just to make people think it's not such a serious thing. Did you see that, as well?

Dr. Wells (17:12): Yes. And I think, you know, when we are thinking about how to interpret this data, it's kind of fascinating that some of the things that people with migraine do to be able to push through and to function, to still function despite it, is also sometimes some of the very things that end up leading to some of the stigma or the misunderstanding of it. You know, some of the participants said, "I try so hard to push through, but then people think that I'm fine, and I'm not fine." And some people say, "Well, I have migraine and people will tell me, 'Oh yeah, I get headaches, too.' And you're like, 'No, no, no. Migraine is not just a headache.' " I mean, there's even a hashtag: #notjustaheadache. So, I think that is one of the challenges with the stigma, that in order to survive and function and continue to try to live the best life that you can despite migraine, it sometimes reinforces the belief that: Oh, you're fine; you pushed through yesterday, you can push through today. And that's ... it's challenging.

Wendy Bohmfalk (18:21): Well, that is one of the areas: internalized and externalized stigma. If you want to say anything else about that — I'd love for you to extrapolate further.

Dr. Wells (18:29): Yes. So "internalized stigma" is where individuals have a changed perception of who they are, whereas "externalized stigma" is where other people have a changed perception. And I think both [of] the stigmas really shone through, which really underscores the need for societal change of migraine awareness and perception. And it's interesting: I've really been thinking about this a lot in terms of like, for example with the guilt — the guilt and the stigma — and I thought about it in terms of the triggers. So, anyone who has migraine triggers will often tell friends or family, "Oh, I can't drink red wine, it sets off a headache," or, "Oh, I can't ... eat that ..." (whatever that particular [thing] happens to be) " ... because it will set off a headache." Well, in informing other people about triggers and how triggers can affect the likelihood of having an individual attack, what then happens is when somebody has an attack, the first thing that friends or family will say [is]: "Well, what did you eat?" or, "What did you



drink?" which then implies that: I'm guilty; like, I did this to myself; I must have done something. And so, whether it's friends or family, or even participants themselves, like when an attack happens, the first thing that's often running through the head is like, "What did I do? Why did this happen? Why did I cause this?" which then creates an entire stream of guilt. And I try so hard when I'm seeing patients in clinic to say, you know, "Migraine we think of as a genetic condition, and you are going to have attacks no matter what you do. And our goal is to decrease the likelihood that those attacks happen, but sometimes they're just going to happen." And trying to take away that guilt and that shame and that frustration, and just become sort of aware that sometimes they just happen.

Wendy Bohmfalk (20:31): The last category or theme is fear and avoidance.

Dr. Wells (20:35): Yes. So, what was interesting was we found that factors outside of actual migraine attacks, like anticipatory anxiety, or fear of the next attack, and avoidance behaviors lead to life restrictions, which really can then contribute to poor quality of life. So, it's not just during the attack that individuals are affected, but in between the attacks some people sort of live on edge — like, constantly worried about what to do, where to go, trying to avoid any possible trigger to set off a headache. And that, in itself, is a completely changed life than what we wish for anyone.

Wendy Bohmfalk (21:17): Absolutely. So, did any of these themes stand out to you as being particularly disruptive to life?

Dr. Wells (21:24): Yeah. Well, I think what was interesting was how all of them individually and then combined — like if you had any one of these themes, you would think: Wow, that's a pretty dramatic impact. But what's interesting is, for so many participants, they have all of these themes. And our research could almost ... it's possible that there was almost an underreporting of themes because our goal was not ... When we were asking these questions, we didn't set out to actually understand headache impacts, so we weren't asking specific questions — people were just spontaneously telling us this information. And so, if we went back and created another interview with the asking [of] all these questions, we might find ... how prevalent even more of these themes are.

Wendy Bohmfalk (22:16): What about then with the individual responses? Did any really stand out to you?

Dr. Wells (22:20): Yes. There were definitely some that were very powerful, and I will tell you them. And every time I read them, I often get goosebumps or teary-eyed. There was one patient who said: "When I get migraines, I put a lot of blame on myself. And I get frustrated that I had a migraine, and I get angry at myself that I couldn't get rid of it. I blame myself because I have a rotten brain. Why do I have a defective brain? I just blame myself. It's my brain, so it's my fault."

Wendy Bohmfalk (22:56): Oh.

Dr. Wells (22:58): So, every time I read that I get goosebumps, thinking of somebody visually imagining a rotten brain inside of their head. And I just ... that one's shocking. And then there was another — sometimes participants would tell us stories, and sometimes stories are so powerfully effective at understanding the depth of what an individual goes through — and so I'm going to tell you one of the stories that one of the participants described. This participant said: "It has affected my family. It puts a lot of stress on my husband and myself. Things have



gotten better, but there was a lot of stress with the relationships with my children, particularly with one daughter who was a lot like my husband and simply did not want to be inconvenienced by me and what I was having to deal with. So, some family members were taking a trip to Alaska to go deep sea fishing. And after a while of planning, I decided I wanted to go. I really wanted to go and figured I could deal with it. I told my oldest daughter, the one who had a lot of trouble with it, that I had planned on going. And she was quiet until a few days later, she called back and said, 'Mom, I was really excited about going on this trip until you told me that you were going. I don't wanna deal with you eating on a regular schedule, and what if you get sick and we have to turn the boat around. I don't wanna have to deal with it. I'm going on vacation.' So, I stayed home. She's come a long way since then. It's hard for people; they want to go out and live their life and they don't wanna deal with someone who's pulling them back." And that story says so much.

Wendy Bohmfalk (24:40): Guilt seems to play an outsized role in our reaction to our migraine disease, and we do try to make things better for other people around us. You mentioned raising awareness and understanding, and how can we do this? What are your suggestions for that?

Dr. Wells (24:55): Yeah. Well, I think number one is patients themselves feeling more confident in understanding their disease. Talking to their doctors, online educational opportunities like Migraine World Summit — learning more. When each individual feels more empowered in understanding their disease, I think it's really, really helpful. I also think there's a multitude of advocacy organizations, so patients can get connected with other people. I think that was one of the interesting things about our clinical trial, was that our clinical interventions were set up in groups design, and many of the participants reported how profoundly helpful it was to hear about other people experiencing migraine because so many patients are isolated because of their migraines. You know, when you get sensitive to light and noise and you get nauseous, it tends to make you stay at home. And so that isolation can often lead to feeling like you're the only one in the whole world that's dealing with what you're dealing with. And so connecting with other people, I think, who experience similar problems can really, really be profoundly helpful.

Wendy Bohmfalk (26:01): Just in summary, can you please just talk about what the results of the study were at a high level and what they suggest?

Dr. Wells (26:07): Yeah. So, I think in summary, this clinical study showed that the impact of migraine on patients' lives is pervasive, and it's profound, and it affects people in all areas of their lives and in ways in between attacks, in addition to during attacks. And it really demonstrates how important it is for patients and for researchers to understand this impact so that we can really target treatment options, start measuring this impact, and really, really find ways to be able to help those that are living with migraine.

Wendy Bohmfalk (26:47): Well, now that we have research to prove how difficult migraine is, what can we do about it? Do we take this to our providers? Like, what would you recommend?

Dr. Wells (26:56): Yes. Great question. So, for anyone with migraine, I think it's really important when you're talking to your doctor to just describe the impact it has on your life, whether they ask you specifically or not. When people are saying, "Tell me about your headaches," I think telling about the characteristics and the features of individual attacks is really important to make sure the diagnosis is accurate. And then also talking about the impact.



Wendy Bohmfalk (27:19): Well, what final thoughts would you like to leave with our audience today?

Dr. Wells (27:22): Yeah. Well, I just want to say ... So, I have been caring for patients with headache for over 15 years. And there was one day that I was working on this paper, and I, literally, in editing the paper — we had the manuscript written, we had all the tables written — and I went through and read every single comment. And then that day — I had gotten up early that morning to work on this — and that day I had a full day of clinic caring for patients with headache. And it was really like I heard their voices; I heard what they had to say with different ears. Like I was just so aware, like things that people have said to me for a long time — all of a sudden it was put in context. And so, I highly encourage you, if you have not already, take time to read the tables. We have ... so many quotations from participants. One of the things we found with this clinical trial is, sometimes participants said it felt so good to talk to other people. And then sometimes people said, "Wow, it felt so good to hear their stories because I realized mine aren't that bad," and so it often can also give perspective. But I'm hoping that this research will empower you to feel, as a patient, to feel that you understand your own disease better, to know that you're not alone, and to recognize that there are so many of us who are really working to hear your voice and to make things better for you.

Wendy Bohmfalk (28:53): Well, now you've given me goosebumps, so thank you. I know there's going to be a lot of people that are going to want to learn more about you and the work that you're doing and to follow your work. How can they do that?

Dr. Wells (29:03): Thanks. So, I'm on Twitter. My Twitter handle is @rebeccawells, R-E-B-E-C-C-A W-E-L-L-S M-D; Rebecca Wells, MD. And hopefully ... I work at Wake Forest Baptist, and I founded and direct our comprehensive headache program; and I should say, I work at Atrium Health Wake Forest Baptist — we just merged with Atrium Health — and at the Wake Forest School of Medicine. And [I'm] hoping soon ... I'm working with our online web team to develop something so that if you're interested in participating in any of our research studies, you can just go to our website and click a button and say: I'm interested in participating. And I think that's one other thing I can encourage is: Clinical research happens with patients. And so being actively involved is one way that you can improve the lives of all of those living with migraine, is by engaging in clinical research. And I'm hoping to soon have more studies to follow up on these results and other results, as well. So, I encourage you to feel empowered that you can make a difference in all of those living with migraine.

Wendy Bohmfalk (30:13): What a great way to wrap things up today. And I just want to thank you again for this amazing study, for really listening to our voices, and for joining us today on the Migraine World Summit.

Dr. Wells (30:22): Well, thank you so much. It's really an honor to be here today, and I've really enjoyed a chance to connect with you about this research that I find so important for us all to be aware of.