Diagnosing Myasthenia Gravis: The Impact of Social Media

Ashley Baker:
Welcome to *NeuroFrontiers on* ReachMD. I'm Psychiatric Nurse Practitioner Ashley Baker. And joining me to discuss the use of social media to accelerate the diagnosis of myasthenia gravis, or MG for short, are Drs. Pritikanta Paul and Vishnu Pandurangadu. Dr. Paul is an Assistant Professor of Neurology at the University of California-San Francisco, and Dr. Vishnu is a Senior Strategy Consultant at ZS Associates, a global healthcare consulting firm based out of Evanston, Illinois, in addition to an Emergency Medicine Staff Physician at Rush Oak Park Hospital in Illinois. They both contributed to a study which found that social media was effective in targeting undiagnosed patients with MG-like symptoms, and they presented this research at the 2024 American Association of Neuromuscular & Electrodiagnostic Medicine Annual Meeting.

Dr. Paul, Dr. Vishnu, it's great to have you both with us today.

Dr. Paul:
Thank you for having me, Ashley.

Dr. Vishnu:
Thank you, Ashley, for having us here.

Ashley Baker:
Starting with you, Dr. Paul, can you explain the purpose of your study and what motivated you to focus on MG specifically?

Dr. Paul:
The purpose of our study was to address the challenges around diagnosing myasthenia gravis, or MG. MG has a very heterogenous disease presentation. It can have some fluctuating symptoms. And in my career and life, I've seen how the diagnosis can be challenging and delayed. On average, patients can have delay up to a year, depending on where studies have been published from, with sometimes even more than a year wait time for patients to get diagnosed with MG.

MG is a rare disease, but it's a treatable condition, and we neurologists know the majority of the patients, if treated optimally, can return back to normal functioning, so that's the motivation to identify or expedite the diagnosis of MG. On the other hand, there has been increasing growth of social media use, and particularly with COVID, I believe we are more frequently doing telemedicine; we are becoming more tech savvy. So the idea is we can use social media and technology to expedite the diagnosis of this rare but treatable condition.

Ashley Baker:
And turning to you, Dr. Vishnu, how did you use social media to engage undiagnosed individuals? And what strategies were most effective in reaching your target audience?

Dr. Vishnu:
The thing that was probably the most effective is what we call growth hacking, which is building our social media presence, and we did this before we launched the study. We built a brand across multiple platforms and built this organic content where we posted regularly about symptom awareness and disease education. We had giveaways. We created a podcast between myself and Dr. Paul. We collaborated with influencers, created TikTok videos, and created short reels out of that content from myself, Dr. Paul, and the influencers. We just had a lot of organic content that came on board even before this study started, so we had a social media presence that allowed us to go out there and see who was engaging with our content already.

And once we had that base social presence, once the study started enrolling and engaging patients actively to come to our study, we were able to create filters—myasthenia's predominantly in young women, older men—on social media to specifically target these demographics. We also targeted our ads and tailored them so that the messaging, the imagery, and the videos fit these target demographics. So if we were targeting women, the ads were very specifically about young women struggling with activities that typically myasthenia gravis patients will struggle with.

Out of everything we did, the thing that gave us the most engagement and conversion in terms of people flowing from social media and engaging with our study was the organic posts on support groups, and this is both on Facebook and Reddit. And we spanned the entire depth of healthcare, whether it was myasthenia gravis, general wellness, or rare diseases. We tried to cover a very broad spectrum of support groups to engage people who were actively out there looking for health information to help them figure out what their diagnosis is.

Ashley Baker:
For those just tuning in, you're listening to *NeuroFrontiers* on ReachMD. I'm Psychiatric Nurse Practitioner Ashley Baker, and I'm speaking with Drs. Pritikanta Paul and Vishnu Pandurangadu about their session from the 2024 American Association of Neuromuscular & Electrodiagnostic Medicine Annual Meeting, which focused on using social media to target undiagnosed patients with myasthenia gravis-like symptoms.

So, Dr. Vishnu, what feedback have you received from participants about the self-assessment tool and the overall process of engagement through social media?

Dr. Vishnu:
In interviewing our participants, the thing that sticks out the most to me in terms of their willingness to engage with the social media is just the breadth of content that we had that spoke specifically to the symptoms that they're having, and also that we posted in places that participants trusted. Reddit was a really big source of participants for us, and the reason why they trusted Reddit so much—it's a big source of medical information for participants beyond just Google searching—is that they can stay anonymous on Reddit. And then there's also Facebook, which you can't stay anonymous on, but it's a trusted source where they're relying on other users' lived experience to help guide them through this journey, because what we're hearing is patients with myasthenia gravis swirl our healthcare system. They spend many months to years being misdiagnosed or being underdiagnosed—also going from physician to physician, not getting the right diagnosis that they need. So there is a lot of unmet need and you see that through the posts that people are putting on these support groups. So that's our social media.

And in terms of our self-assessment, the tool is two parts. It's a survey of questions that asks you about things you're struggling with in your day-to-day life, and then there's a physical test that they have to perform that tries to recreate the fatigue they're experiencing because of myasthenia gravis. And the thing we've heard from participants is that the survey questions about their symptoms very much resonate with not just the symptoms that they're experiencing, but when they have gone back to their physicians, they have been asked the same questions we were asking, so in some ways we're almost mimicking the history that a physician would get. And almost the same scenario with the physical tests is that patients who are undiagnosed, yes, they have some fatigue, but they really can't pinpoint where it's coming from and what muscle is being affected, and so we've given them these very specific muscle groups to try to fatigue, such as looking up for a period of time and trying to reproduce their eyelid drooping or going from sit to stand multiple times to see if they can fatigue their leg muscles. And what we've heard is that they have never had to challenge themselves in such a physical way to then know it's this muscle, this eye muscle that's actually with my fatigue, or this leg muscle. And they're able to articulate this, and this gives them this empowerment, this confidence that these are real symptoms that they're having; they're not made up in their head, as they are often times told. And two words we've heard from multiple participants is that the study empowered them and it gave them the confidence to then go take all this information back to a physician in a very organized manner to be able to articulate exactly what's going on with their body and their symptoms, that they're suspecting myasthenia gravis, and that's coming from a credible source. It's not that they're just out there Googling and they come back with a Google search to ask their doctor questions about.

Dr. Paul:
I will add to what Vishnu said, there's some validation of their ongoing day-to-day symptoms which they're not able to see sometimes, because myasthenia can be challenging with the fluctuation in the symptoms. Some days are good days, and some days are bad days, but sometimes it can be confusing for patients, so this engagement gave them one tool to go back to their doctor or to the neurologist with and get some more proper concrete history or information for them to share with their doctor to further evaluate.

Dr. Vishnu:
Yeah. And the last thing I will add is that what happened after they did the self-assessment is that we provided them a very detailed report. It's multiple pages. There's a page that's a letter to the patient saying we have some suspicion your muscular symptoms could be

from myasthenia gravis, but you need to go see a doctor; take this report to your doctor, and here's the next steps. We give them a list of physicians in the area, particularly neuromuscular specialists in their area, if we can find them. And then the remaining page of the report is a letter to their doctor explaining what our study is. It gives them a very detailed summary of the symptoms that they explained in the survey and then a detailed summary of the physical tests that they performed that they had a challenge with and the severity of the challenge they had with each of those muscle groups. So it's more information for the patient to have in a very organized way to then go back and be able to have this very structured conversation back with their physician.

Ashley Baker:
If we look ahead, Dr. Vishnu, what next steps will you take to validate the results from the study? And how do you plan to follow up with participants over the next year?

Dr. Vishnu:
We're actively engaged in this part. So we're undergoing multiple variations of validation, so we are interviewing patients, trying to get a variety of patients who are self-reporting that they're myasthenia gravis positive or myasthenia gravis negative or that they got tested or their doctor just told them they didn't have it just to understand what happened in their journey. But our main focus is particularly to find myasthenia gravis-positive patients and understand, "What test results really told you or your doctor that it was positive?" and trying to really nail that down to give us confidence that, yes, it's self-reported, but we have some evidence.

The other way we're doing it is we took a sample of our patients and gave them access to a vendor called PicnicHealth. They're essentially a medical record aggregator. And so now patients have to exit our study and go enroll in PicnicHealth. It's a collaborative project between us and PicnicHealth. And essentially, we have a timeline view of all the things that the patient has had done in the past. We also have a year's access—one year looking forward—to the patient's record to see what's happening actively as a patient is getting diagnosed, and we're using that as a way to validate what lab tests, EMG, imaging, whatever it is that you happen to get done in this process. What those actual validated diagnostic tools were that gave us the diagnosis.

Ashley Baker:
To close out our program, I'd like to ask you a final question, Dr. Paul. What else can we do to expedite the diagnosis of MG?

Dr. Paul:
We are now living in a time where we have many options for treating MG, and that's the goal for all our neurologists and neuromuscular doctors—to get the diagnosis of MG sooner than later. And the first and most important part is increasing awareness in the community, both amongst patients and physicians. So that could be through targeted education about particularly the variable and the fluctuating symptoms of MG both in the primary care setting and emergency medicine setting, so that's for physicians and also among patients about encouraging earlier consultations. I believe we have had participants in the study who were confused or somewhat hesitant to reach out to their doctors, and I think this study tool will give them some validation or something objective to go to their doctor and talk about their symptoms and get evaluated, so that's important about increasing the awareness.

And also, the other thing is some more standardized screening protocols or checklists to understand the MG symptoms which we want physicians to think about when they're evaluating patients as a differential diagnosis. I briefly mentioned post-COVID we have been using more telemedicine, so I think one good way to actually get access to more experts, neurologists, neuromuscular experts for when there's suspicion for myasthenia-like rare conditions, more access to our patients through telemedicine.

And finally, Vishnu highlighted getting access to health records for patients and looking into these health records and analyzing. Maybe using AI models trained to identify or flag patients with symptoms or symptom patterns which can suggest MG, I think that can also expedite the process of identifying those key words or points which can predict diagnosis of MG and make it more streamlined in our clinical practice.

Ashley Baker:
With those final comments in mind, I want to thank my guests, Drs. Pritikanta Paul and Vishnu Pandurangadu, for joining me to discuss their method of utilizing social media for early myasthenia gravis diagnosis.

Dr. Paul, Dr. Vishnu, it was great having you both on the program.

Dr. Paul:
Thank you so much for having us.

Dr. Pandurangadu:
Thank you so much, Ashley, for having us.

Ashley Baker:

For ReachMD, I'm Psychiatric Nurse Practitioner Ashley Baker. To access this and other episodes in our series, visit *NeuroFrontiers* on ReachMD.com, where you can Be Part of the Knowledge. Thanks for listening.