Migraine Meanderings and the Headache and Migraine Policy Forum recently conducted an online survey to better understand the experience people with migraine have in the emergency room and urgent care. Five-hundred responses were gathered via social media and email.

**PREVENTIVE TREATMENTS**

About 99% of respondents use treatment options to prevent migraine attacks.

- Prescription oral medication (94%)
- Prescription injectable medication (76%)
- Prescription infused medication (17%)
- Medical devices (35%)
- OTC supplements (83%)
- Nerve blocks (25%)

**ABORTIVE TREATMENTS**

About 99% of respondents use treatment options to stop an existing attack.

- OTC medications (89%)
- Prescription oral medication (93%)
- Prescription nasal spray (53%)
- Prescription injectable or infused medication (66%)
- Medical devices (33%)

**SEEKING TREATMENT AT THE EMERGENCY ROOM OR URGENT CARE**

Respondents report the following symptoms led them to seek treatment at the ER and/or urgent care:

- Pain (89%)
- Nausea, vomiting or dehydration (67%)
- Aura or other visual disturbances or changes (31%)
- Aphasia (speech disturbance) (24%)
- Stroke-like symptoms (30%)
- Status migrainosus (77%)
- Dizziness/vertigo (9%)
- Other symptoms (5%)

Since being diagnosed with migraine, respondents estimate going to the ER or urgent care:

- More than 10 times (44%)
- 6-10 times (20%)
- 1-5 times (36%)

In the PAST YEAR, respondents have gone to the ER or urgent care:

- 1-5 times (52%)
- More than 5 times (7%)
- 0 times (41%)
“Being a frequent flyer to the ER, they now know me well. Decades ago I was discriminated against for having migraine disease. Called a drug seeker. But through advocacy for myself and others I’m fortunate enough to get the treatment needed and with empathy.”

—Survey Respondent

BARRIERS TO TREATMENT

88% of respondents went to the ER or an urgent care facility due to lack of access to a healthcare professional who could treat their migraine. They report the following issues prevent them from seeing a headache specialist who could more effectively treat their migraine:

- Headache specialist not available outside of appointments (33%)
- No headache specialist available in-network for my insurance (7%)
- Copay to see a headache specialist too expensive (5%)
- No headache specialist in my geographic area (14%)
- Primary care physician/general neurologist won’t refer me to a headache specialist (6%)
- Other (16%)

28% of respondents sought treatment at the ER or urgent care due to issues getting abortive or rescue medications that their healthcare professional prescribed for them. They reported the following barriers:

- Insurance coverage/denials (19%)
- High out-of-pocket costs or copays (13%)
- Insurance required step-therapy that didn’t work (9%)
- Pharmacy didn’t have prescribed medication in stock/available (7%)
- Pharmacy didn’t want to fill a prescribed medication (3%)
- Other reasons included: doctor won’t prescribe any medications, medications don’t work, already took the max number of doses, doctors office slow to refill prescriptions

QUALITY OF TREATMENT AT THE ER OR URGENT CARE

KEY FINDINGS

- 52% of respondents found the healthcare providers at the ER or urgent care to be knowledgeable about migraine.
- 63% of respondents believed that the ER or urgent care trusted their description of symptoms.
- 44% of respondents reported that the ER or urgent care implied that they were there seeking drugs and not due to severe migraine symptoms.
- 29% of respondents said the treatment they received at the ER or urgent care did stop their migraine attack: 37% said it stopped their attack but their symptoms returned less than 24 hours later; and 27% said the treatment did not relieve their symptoms.
- 27% said the ER or urgent care prescribed an opioid for pain management.

SURVEY DEMOGRAPHICS

FREQUENCY

On average, respondents report having migraine:

- 32% 1-14 days/month
- 68% 15-30 days/month

AGE

- 3% 18-25
- 29% 26-40
- 49% 41-55
- 13% 56-64
- 6% 65+

HEALTH INSURANCE TYPE

- 63% Commercial insurance
- 36% Medicare/Medicaid
- 2% No insurance
- 8% Other
Respondents had the following to say about their experience going to the emergency room or urgent care for migraine:

“I refuse to go any more due to being treated like a drug seeker.”

“The ER staff does not seem to comprehend, or perhaps believe, the severity of pain some migraines can cause patients. They leave you sitting under fluorescent lights—a migraine trigger—for many hours!”

“The treatment for migraine in ER/UC is complicated by our overstressed medical system and the fact that there are some who seek inappropriate treatment without adequate follow up.”

“The ER should be a last resort. It is a miserable, uncomfortable place where you roll the dice as to how you are treated and whether you will receive pain relief.”

“While my symptoms might have been taken seriously or believed, I never felt comfortable in the ER and always felt like I was a bother being there. I don’t seek treatment even when advised to go to the ER by my headache specialist because I feel like there is a stigma. I work in healthcare and I know chronic pain isn’t always taken seriously, especially in the ER, so I just choose to suffer at home now.”

“The treatment for migraine in ER/UC is complicated by our overstressed medical system and the fact that there are some who seek inappropriate treatment without adequate follow up.”

“Migraine cocktail does the trick, but knocks me out. Not good when you are the caregiver for a baby. Need better prevention, and even better, to find the cause of migraines.”

“Many times ER staff are not educated on migraines enough to know that they all don’t present the same way.”

“I felt like I was shamed and not listened to by the urgent care doctor.”
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