PATIENT ACCESS
& AFFORDABILITY
PROJECT

Empowering Patient Perspective

Experiences and Unmet Needs in the Occipital Neuralgia Community

By Jim Sliney, Director of Patient Outreach for Patients Rising and
Kayla Smock, President and Founder of the Occipital Neuralgia Foundation

ABSTRACT

Occipital Neuralgia (ON) is a distinct type of headache characterized by piercing, throbbing, or electric-shock-like chronic pain in the upper neck, back of the head, and behind the ears, usually on one side of the head. Typically, the pain of occipital neuralgia begins in the neck and then spreads upward.

Patients Rising and the Occipital Neuralgia Foundation, both 501(c)3 nonprofit organizations, partnered to better understand the experiences and unmet needs in the ON patient community. Patients were asked about onset circumstances of the disease, as well as the length of time it took to get diagnosed, the types of providers seen, and the types of treatments pursued. The results from 120 respondents showed a wide variety of medical providers who diagnosed and treated ON, and while neurologists diagnosed ON in nearly 60% of cases, they provided the primary ongoing care only 45% of the time.

Data also revealed the time it took to get formally diagnosed ranged from less than one month to greater than eight years with a mean of 3.96 years to obtain diagnosis after symptoms began. Medications, therapies, and procedures varied widely within an expected field of known treatments. Respondents also reported a difficulty finding reliable medical information about ON, that providers are reluctant to treat their condition because it was "invisible," and an insufficient amount of pain management support relative to their pain levels.

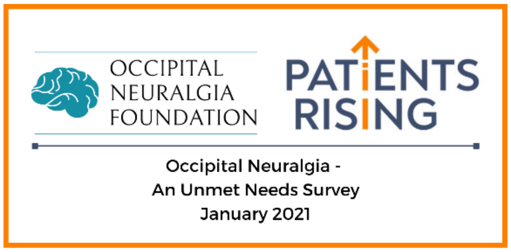
INTRODUCTION

The Occipital Neuralgia Foundation and Patients Rising partnered to conduct a survey to better understand the unmet needs within the occipital neuralgia community. This was triggered by a general dissatisfaction with healthcare in the patient community; something they found difficult to define, and likewise, something we found difficult to understand.

BUILDING & SHARING THE SURVEY

Patients Rising provides support and education to people with chronic and life-threatening illnesses. We work with patients to advocate for access to the treatments, innovations, and timely care they need. The Occipital Neuralgia Foundation (ONF) offers support to people suffering, educates the public, and fosters research into the causes and treatments of Occipital Neuralgia (ON).

We built a survey tool using Google Forms. The questions were drafted based on previous conversations with patients, then reviewed by Kayla Smock, ONF President and Founder, and Jim Sliney, Director of Patient Outreach at Patients Rising. We also consulted on wording and scope with Surabhi Dangi-Garimella, Ph.D., a pharmacist and cell biologist with experience in academic cancer research and healthcare publication and communication. The survey was presented to the occipital neuralgia community through outreach on social media and contacts from the ONF. The survey remained open to response for a prescribed 14-day period in January 2021.


OCCIPITAL NEURALGIA FOUNDATION
PATIENTS RISING
Occipital Neuralgia -
An Unmet Needs Survey
January 2021

FINDINGS

Cohort and Demographics

We received responses from a total of 120 unique individuals, all of whom self-confirmed being diagnosed with ON. Of the 120 respondents, 91.6% were female (n = 110) and 8.3% were male (n = 10). Race and ethnicity presented as primarily White (85.8%), of Hispanic, Latino or Spanish origin (6.6%), Asian (3.3%), and the rest (4.5%) were made up of American Indian or Alaskan Native, Native Hawaiian or other Pacific Islander, or were not comfortable sharing.

Insurance Status

One way we attempted to understand gaps in access was to look at the insurance status of patients. During the COVID-19 pandemic, many Americans lost their health insurance.

As of June 2020, and attributable to the COVID-19 pandemic, 7.7 million Americans lost their jobs and their employer-sponsored health insurance. A report by the Commonwealth Fund found that there were 6.9 million Americans listed as dependents on those insurance plans, bringing the total of newly uninsured Americans resulting from job loss during Covid-19 up to 14.6 million.

Type of insurance*	N	%
Medicare	11	9.16%
Military-related healthcare: TRICARE (CHAMPUS), VA healthcare, CHAMP-VA	7	5.83%
Medicare in conjunction with Medicaid, Medigap, Military, or other government program	4	3.3%
Medicaid	3	2.5%
Other government program	6	5.0%
State-sponsored program	1	0.83%
Private insurance (e.g. employer sponsored, marketplace, self-funded plan)	76	63.3%
Uninsured	12	10%
*Offered as an option, no one selected *Children's Health Insurance Plan* or *Indian Health Service*		

While seeing an uninsured rate of 10% was initially concerning to us, we found that it consistent with national reporting. Indeed, according to the Kaiser Family Foundation, following the passage of the Affordable Care Act, the number of uninsured nonelderly Americans declined by 20 million, dropping to a historic low in 2016. However, beginning in 2017, the number of uninsured nonelderly Americans increased for three straight years (growing from 26.7 million in 2016 to 28.9 million in 2019), and the overall uninsured rate increased from 10.0% in 2016 to 10.9% in 2019.

The Disease

We asked respondents how long they have experienced symptoms of ON.

QUESTION: How long have you had the symptoms of occipital neuralgia (example: 6 months, 4 years, born with it, etc.)?		
Duration	**N = 120**	**%**
Less than 1 year	11	9.16%
Between 1 and 2 years	22	18.3%
Between 2 and 5 years	46	36.3%
Between 5 and 10 years	22	18.3%
10 years or more	19	15.83%

The number of patients who have experienced symptoms for one or more years was greater than 90%. Considering the methods used to find participants – self-identified on social media or members of the ONF – this could suggest that patients who are more active in advocacy efforts are those who have been living with the disease longer.

The next question measured the time between onset of symptoms and formal diagnosis.

QUESTION: How long did it take for you to be formally diagnosed with Occipital Neuralgia (example: immediately, 2 weeks, 11 years, etc.)?		
Duration	**N = 117**	**%**
Less than a month	10	8.54%
1-3 months	13	11.11%
4-6 months	14	11.38%
7-12 months	18	15.51%
13-24 months	28	23.93%
25-48 months	11	9.40%
4-8 years	11	9.40%
8 or more years	12	10.25%

Time it Takes to Get Diagnosed and by Whom

The time between onset of symptoms and formal diagnosis is a time of uncertainty and concern for patients and their families. It involves seeing a variety of providers, an array of testing, and in some cases, pre-diagnostic therapies with hit-and-miss results.

Only 8.33% of respondents (N=10) were diagnosed in under one month. These diagnoses were received from a neurologist (7), a chiropractor (1), pain management doctor (1), and primary care doctor (1). Assuming it takes an average of 24 days to see a specialist, we can conclude that diagnosis was provided within one or two visits.

For 52.57% of respondents, it took more than 12 months to get diagnosed. Of those, 10.34% took eight or more years to be diagnosed – a larger percentage than those diagnosed in under a month. Furthermore, **the mean length of time between onset of symptoms and formal diagnosis was 3.96 years.**

Who is Providing the Care?

The providers who made the formal diagnosis of occipital neuralgia were contained almost exclusively amongst neurologists, pain management doctors, primary care doctors, and chiropractors or physical therapists. But the array of providers seen in an attempt to find appropriate care varied significantly.

We asked respondents which type of clinical care provider ultimately provided the ON diagnosis, as well as which type was currently providing their primary ON care.

<table>
<tr><th colspan="3">Diagnosis and Primary Provider of Care</th></tr>
<tr><th>Type of Provider</th><th>Provided Diagnosis</th><th>Primary Provider of ON Care</th></tr>
<tr><td>Neurologist</td><td>59.48%</td><td>45%</td></tr>
<tr><td>Pain Management</td><td>19.82</td><td>20%</td></tr>
<tr><td>Primary Care</td><td>4.31</td><td>20.83%</td></tr>
<tr><td>Physical Therapy</td><td>4.31</td><td>3.3%</td></tr>
<tr><td>Chiropractor</td><td>2.58%</td><td>2.5%</td></tr>
<tr><td colspan="3">Others who provided diagnosis included dentist, emergency room physician, orthopedist, otolaryngologist, and physiatrist. Others acting in the leadership role of occipital neuralgia care included physiatry, orthopedics, pediatrics, and some had difficulty identifying a single leader of their ON care.</td></tr>
</table>

The Role of Neurology

Neurologists are the primary specialists who treat and diagnose headache disorders. They are trained to treat diseases of the brain and spinal cord, peripheral nerves, and muscles. Occipital Neuralgia falls within that category. The American Migraine Foundation features an article written by Dr. Rashmi Halker-Singh, a neurologist from the Mayo Clinic. In this article, Dr. Singh describes the challenge to obtain an ON diagnosis, as well as the complex relationship between migraine and ON. The American Academy of Neurosurgeons further confirms the challenge in obtaining a proper diagnosis, as there is no one concrete test to reveal a positive or negative diagnosis, and ON often presents with similarities to migraines and other headache disorders. The difficulty in getting appropriate and effective care was also discussed.

In our survey, **59.48% of respondents received a diagnosis from a neurologist. However, only 45% remain in the care of a neurologist as primary manager of their treatment**. The rest moved on to different specialists to obtain relief. Neurologists are among the first doctors a patient sees with a complaint of head pain, yet there remain significant delays and challenges in receiving an accurate ON diagnosis and to find long term, effective care.

The Quest for Care

Of particular interest is the array of providers seen in an attempt to find appropriate care for ON. Most patients have seen multiple providers – some upwards of 10 different kinds.

While most patients saw the kinds of providers one would expect (neurology, primary care, pain management, physical therapy, chiropractor), some in their pursuit of care visited providers less associated with occipital neuralgia, such as massage therapists, acupuncturists orthopedists, otolaryngologists, and psychologists.

QUESTION: What types of clinical providers have you seen while trying to get appropriate care for your ON? (Example: Primary Care, Neurologist, Pediatrician, etc.)	
Types of Providers Seen in the Process of Seeking Appropriate Care	**Seen by % of patients**
Neurologist	80.8%
Primary Care	71.5%
Pain Management	43.33%
Physical Therapy	28.33%
Chiropractor	25.83%
Massage Therapy	10%
Acupuncture	8.33%
Orthopedist	7.5%
Otolaryngologist	6.66%
Pediatrician*	6.66%
Psychology	5%
Providers seen by fewer than 5% of patients include allergist, dentist, Emergency Room physician, immunologist, infectious disease specialist, internist, naturopath, occupational therapist, ophthalmologist, optometrist, osteopath, physiatrist, plastic surgeon, psychiatrist, radiologist, rheumatologist, sports medicine professional, and speech language pathologist.	

This diverse map of providers points at the diverse types of symptoms patients experience, and suggests that finding adequate care is not a linear process.

The Challenge of Pediatrics*

The survey revealed that of those surveyed who were 17 years of age or younger (N = 7), 85.71% **(6 out of 7) indicated that they had "minimal access to specialists because they were considered a pediatric patient."** In an effort to search for a diagnosis and proper treatment, pediatric patients are often limited to seeing "pediatric" specialists. This can significantly limit the pool of physicians and specialists to choose from, creating an additional obstacle in proper diagnosis and treatment for ON.

How did you get Occipital Neuralgia?

We asked respondents, "How did your Occipital Neuralgia begin?" A significant number of patients **(41.6%) claimed not to have a clear cause of their occipital neuralgia** (idiopathic). Some of these reported that "it came on gradually", others that "it was there suddenly" and several "didn't know."

The next largest group of patients **(40.83%) connected the onset of their occipital neuralgia to some kind of trauma** like an "accident," "car accident," "whiplash," or "concussion."

The rest attributed their ON to comorbid states or underlying diseases such as Ehlers Danlos Syndrome, meningitis, and temporomandibular joint disorder, or to acute issues like onset secondary to a surgery.

Treatments and Medications Used

We've already seen that most of the patients who responded to this survey (>90%) have had ON for more than a year, and 34% have had the disease for five or more years. Over that time, many different medications and treatments were used.

When we asked respondents about the medications and treatments they used, the responses varied significantly, but several medications and treatments rose to the top. Note these are not the current or only treatment but are among the treatments tried. We list any medications or treatments used by 10% of the cohort or more.

QUESTION: Please list the medications and treatments you have used to treat or manage your Occipital Neuralgia.			
MEDICATION[1]	**% USED**	**TREATMENT[3]**	**% USED**
Gabapentin	30.83%	Nerve Block	43.96%
Muscle Relaxers[2]	29.42%	Physical therapy	24.36%
NSAIDS (over the counter)	26.89%	Chiropractor	15.12%
Botox	19.32%	Massage Therapy	14.28%
Opioids	15.12%	Radio Frequency Ablation	13.44%
Antidepressants	15.96%	Acupuncture	13.44%
Lyrica	12.6%	Heat or Ice therapy	13.44%
Tricyclic antidepressants	10.92%		

[1] Other medications included Aimovig, anti-inflammatories, anti-nausea, anti-seizure, CBD oil, cannabis, Fioricet, Flexeril, and Neurontin
[2] Muscle relaxers included cyclobenzaprine, baclofen, methocarbamol, and others
[3] Other treatments included biofeedback, craniectomy, acupressure, dry needling, neuromodulation, nerve decompression surgery, and facet joint injections

CONCLUSIONS:

Those who participated in this survey were predominantly (63.3%) covered by some kind of private health insurance. The rest were covered by Medicare (9.16%), some kind of Military insurance (5.83%), or used some combination of Medicaid or State or government program (11.63%), and 10% were uninsured.

Regarding duration of the disease, 54% of the respondents reported having symptoms for longer than two years, and almost 16% reported symptoms for 10 years or more. This allowed us to see the difference in time between symptom onset and formal diagnosis, which averaged 3.96 years.

We also incidentally learned that 6 of the 7 respondents who were 17 years old or younger reported having minimal access to specialists because they were considered pediatric patients. As for adult respondents, we learned there was a variety of providers who diagnosed people and provide their ongoing care. Of interest, nearly 60% of responders were diagnosed by a neurologist, but only 45% remain in the care of a neurologist as the primary manager of ongoing treatment.

The etiology of Occipital Neuralgia was idiopathic in 41% of respondents and connected to some kind of trauma (e.g., car accident) in another 41% of people. The rest attributed their disease to other comorbidities. The treatments pursued by responders varied widely, but nerve blocks, physical therapy, pain medication, and muscle relaxers were most common.

Respondents were predominantly female (91.6%) and White (85.8%), revealing a limitation to the scope of the project. This finding is driving new, comprehensive, diverse outreach efforts including the creation and implementation of Patients Rising's Diversity, Equity and Inclusion Council.

There is a clear need for better continuity of care for Occipital Neuralgia patients. Patients feel that reliable medical information is lacking. Also, they identified some hesitancy or obstacle in provider comfort levels treating ON because of its "invisible" nature. Finally, there needs to be better options for consistent pain support in the community.