

## **CMA, Inc. Survey One: Migraine Provider Experience**

Chronic Migraine Awareness (CMA), Inc., is conducting a series of surveys on the migraine experience. The purpose of the survey series is to inform CMA, Inc. partners and volunteers, pharmaceutical companies, and the public about various steps in the journey of people with migraine. For each survey, a link is posted across all CMA, Inc. social media platforms. Participants are recruited through these social media posts and by CMA volunteers who share the posts to their own social media outlets.

This survey asked about the experiences people have had with the health care provider who primarily treats their migraine, as well as past experiences with providers. Data were collected from October 23 to November 6, 2019. Questions asked about:

- who they first saw for treatment,
- who they now see,
- how long they have been with their current provider,
- how frequently they see their current provider,
- how many providers they have seen for migraine (total), and
- some of the reasons they might have switched providers in the past.

Each survey includes some basic demographic questions, as well as a question that aims to measure whether a person experiences chronic or episodic migraine. The latter measure simply asks on how many days the respondent had a headache or migraine attack in the last month; it is not fully aligned with the International Classification of Headache Disorders definition of migraine or chronic migraine. These questions not only provide context for comparing the sample across surveys, but also allow for comparisons of the more substantive questions about the migraine experience.

### **Sample Demographics**

A total of 228 responses were collected on the first survey. Approximately 72% of respondents reported 15 or more headache or migraine days in the previous month (i.e., chronic) (Table 1). The mean number of days reported was 20. A majority of the sample was 40 years old or older. About 35% were 40-49, nearly 24% were 50-59, and 6% were 60 years old or older (Table 1). The vast majority of respondents were female (94%), with only 4% male, and other categories too few to report (Table 1).

Of those who answered, 21% reported a total annual household income of less than \$25,000 in the previous year, 23% reported \$25,000 to \$49,999, 35% reported \$50,000 to \$99,000, and 12% reported \$100,000 to \$149,000. Nine percent reported total income of \$150,000 or greater (Table 1).

**Table 1. Sample Demographics**

	Count	Percentage
<b>Migraine Frequency<sup>1</sup></b>		
Episodic	63	27.6%
Chronic	165	72.4%
<b>Age</b>		
Less than 20 years old	5	2%
20-29 years old	31	13.6%
30-39 years old	44	19.3%
40-49 years old	80	35.1%
50-59 years old	54	23.7%
60 old years or older	14	6.1%
<b>Gender</b>		
Female	214	94.3%
Male	9	4.0%
Gender variant/non-binary	#	#
Other	#	#
<b>Total Annual Household Income</b>		
Less than \$25,000	40	21.2%
\$25,000 to \$49,999	43	22.8%
\$50,000 to \$99,999	66	34.9%
\$100,000 to \$149,000	23	12.2%
\$150,000 or more	17	9.0%

<sup>1</sup> Defined as 15 or more headache or migraine days in last month.

# Too few to report.

### Provider Experiences: Univariate

The vast majority of respondents (63%) reported that they first saw their primary care doctor (family practitioner/internal medicine provider/pediatrician) for the treatment of their migraine (Table 2). Seven percent were first seen by the emergency room/emergency department, while 16% and 10% were seen by neurologists and headache specialists, respectively (Table 2).

Perhaps not surprisingly, responses shifted when asked about the type of health care professional who currently treats their migraine. About 42% reported seeing a headache specialist, while 32% reported seeing a neurologist. Only 20% are primarily under the care of a primary care doctor (family practitioner/internal medicine provider/pediatrician) for the treatment of their migraine. About 4% see a pain management specialist (Table 2).

On average, people reported being with the health care provider (HCP) who currently treats their migraine disease for 5.5 years (not shown). Since the survey had a minor error in the item type used, it was unclear how people who were with their doctor less than one year answered. The data

was aggregated into groupings. About 26% were relatively new to their current HCP, having only been with them a year or less (0 or 1 years). Twenty-five percent reported having been with their current HCP 2 to 3 years and 4 to 7 years, respectively. About 23% of respondents reported having been seeing their current HCP for more than 7 years (Table 2).

Almost half the sample reported that they see their current HCP every 2 to 3 months. An additional 12% sees them monthly and 28% every 4 to 6 months. This may not be surprising given the fact that the sample reported a high frequency of headache and migraine day, on average (Table 2).

**Table 2. Migraine Provider Experience: Univariate Statistics**

	Count	Percentage
<b>First HCP Visited for Treatment of Migraine</b>		
Emergency room/emergency department	15	6.6%
Headache specialist	23	10.1%
Neurologist (but not a headache specialist)	37	16.3%
Primary care physician/family practitioner/internal medicine physician	144	63.4%
Other	8	3.5%
<b>Type of HCP Who Currently Treats Migraine</b>		
Headache specialist	94	41.6%
Neurologist (but not headache specialist)	72	31.9%
Pain management specialist	8	3.5%
Primary care physician/family practitioner/internal medicine physician	46	20.4%
Other	6	2.7%
<b>Number of Years with Current Provider</b>		
0-1 years	59	26.3%
2-3 years	56	25.0%
4-7 years	57	25.4%
More than 7 years	52	23.2%
<b>How Often You See HCP Who Currently Treats Migraine</b>		
At least monthly	27	12.2%
Every 2-3 months	108	48.6%
Every 4-6 months	62	27.9%
Every 7-12 months	18	8.1%
More than once per year	7	3.2%

HCP = Health care professional.

About 30% of respondents reported that they had seen 4 to 6 health care professions in total for the treatment of their migraine, 25% had seen 7 to 10, and 28% had seen more than 10. About 17% had seen 1 to 3 health care providers for the treatment of their migraine (Table 2).

When respondents were asked why they had switched HCPs who had treated their migraine, only 8% indicated they had never switched providers. Of the remaining 210 respondents, the most common reason selected was that their treatment was unsatisfactory (62%). More than half reported they switched after being told there was nothing more that could be done for them (51%). About 40% reported switching from a health care provider who lacked compassion and 36% switched from one who lacked expertise. Additionally, 37% indicated switching because a provider was not a good fit, while distance was reported by 23%. An additional 7% indicated moving as a reason – most often, the respondent moved (Table 2).

**Table 2. Migraine Provider Experience: Univariate Statistics, Continued**

	Count	Percentage
<b>Number of HCPs Seen for Migraine Total</b>		
1-3	38	16.9%
4-6	68	30.2%
7-10	56	24.9%
More than 10	63	28.4%
<b>Reasons for Switching HCP<sup>1</sup></b>		
Treatment unsatisfactory	130	61.9%
Insurance coverage	49	23.3%
Distance	65	31.0%
Not good fit	77	36.7%
HCP lacked expertise	76	36.2%
HCP lacked compassion	85	40.5%
Not enough time spent	49	23.3%
Nothing more HCP could do	108	51.4%
Other		
HCP retired/died/moved/left practice	12	5.7%
Moved (most answers implied respondent moved)	14	6.7%
Switched/referred elsewhere/aged out	11	5.2%

HCP = Health care professional.

<sup>1</sup> Could report multiple reasons. Will sum to > 100%. 210/228 people indicated at least one reason for switching.

### **Provider Experiences: Bivariate**

For each of the survey items, the distribution of responses for those who reported 15 or more headache or migraine days in the previous month (“chronic”) and those who reported less were analyzed.

**Table 3. Migraine Provider Experience: Bivariate Statistics**

	Migraine Frequency	
	Episodic	Chronic <sup>1</sup>
<b>First HCP Visited for Treatment of Migraine</b>		
Emergency room/emergency department	4.8%	7.3%
Headache specialist	6.3%	11.6%
Neurologist (but not a headache specialist)	14.3%	17.1%
Primary care physician/family practitioner/internal medicine physician	71.4%	60.4%
Other	3.2%	3.7%
<b>Type of HCP Who Currently Treats Migraine**</b>		
Headache specialist	25.8%	47.6%
Neurologist (but not headache specialist)	35.5%	30.5%
Pain management specialist	0.0%	4.9%
Primary care physician/family practitioner/internal medicine physician	33.9%	15.2%
Other	4.8%	1.8%
<b>Number of Years with Current Provider*</b>		
0-1 years	19.7%	28.8%
2-3 years	24.6%	25.2%
4-7 years	21.3%	27.0%
More than 7 years	34.4%	19.0%
<b>How Often You See HCP Who Currently Treats Migraine</b>		
At least monthly	8.5%	13.5%
Every 2-3 months	42.4%	50.9%
Every 4-6 months	30.5%	27.0%
Every 7-12 months	15.3%	5.5%
More than once per year	3.4%	3.1%
<b>Number of HCPs Seen for Migraine Total</b>		
1-3	24.2%	14.1%
4-6	32.3%	29.4%
7-10	24.2%	25.2%
More than 10	19.4%	31.3%

<sup>1</sup> Defined as 15 or more headache or migraine days in last month.

HCP = Health care professional.

\*  $p < 0.10$

\*\*  $p < 0.01$

Comparing the two groups, a few differences arose. First, those survey respondents who were categorized as “chronic” were also more likely to report a headache specialist as the current health care professional (HCP) primarily responsible for treating their migraine than their “episodic” counterparts: 48% versus 26%, respectively. Conversely, those who were “episodic” were more

likely to report their current HCP was a primary care physician (or family medicine practitioner/internal medicine provider) than their “chronic” counterparts: 34% versus 15% ( $p < 0.05$ ) (Table 3).

Additionally, respondents with “episodic” migraine generally reported more years with their current HCP, though there was some inconsistency in the pattern: 34% of “episodic” versus 19% of “chronic” migraine respondents reported having been with their current HCP for more than 7 years. Among those who had been with their current HCP 1 year or less, 20% were “episodic” and 29% were “chronic” (Table 3) ( $p < 0.10$ ).

The distributions of other survey items by respondents’ migraine status (“episodic” versus “chronic”) as well as their current migraine HCP type were explored, however, no additional statistically significant differences were found or the data did not meet the assumptions required for the chi-square test.

## **Conclusions**

The sample of respondents in this first survey was overwhelmingly female, over 30 years old, with a majority incidence of “chronic” migraine. This is important to keep in mind as we consider the findings. Compared to national estimates, this survey has a higher proportion of women and people with chronic migraine,<sup>1</sup> likely owing to recruitment and CMA, Inc., audience.

For these reasons, it isn’t surprising – and is encouraging – that while most first saw a primary care doctor for the treatment of their migraine symptoms, the majority currently see a neurologist or headache specialist. In comparing, episodic and chronic respondents, those who were chronic were even more likely to report currently seeing a headache specialist.

Additionally, that the majority of respondents first saw a primary care physician of some type suggests there is an opportunity for those physicians to both receive greater training on migraine disease and be an important first line of treatment for people with migraine.

Given the high percentage of respondents who reported that the current HCP treating their migraine is specialist (headache, neurologist, pain management), it might be surprising how frequently respondents are seeing them; especially given what we know about the shortage of some of these types of doctors and the wait times to see them.

When asked about reasons they had switched, some of the most common reasons given by respondents were concerning: unsatisfactory treatment, being told by a HCP there was no more they could do, and a lack of HCP compassion. Unlike factors such as distance or moving, these

and many of the other factors reported by respondents are ones that the migraine community – researchers, educators, advocates – can address.

### **Acknowledgements**

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### **References**

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