

CMA, Inc. Survey Two: Migraine Diagnosis

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 the 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 second survey asked about the diagnosis of migraine. Data were collected from November 21 through December 7, 2019. Questions asked about:

- age of first attack,
- how long it took to receive a migraine diagnosis, and
- how long it took for respondents' migraine attacks to become chronic.

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 making comparisons of the more substantive questions about the migraine experience.

Sample Demographics

A total of 319 responses were received on the second survey. Approximately 65% 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 18. A majority of the sample was 40 years old or older. About 33% were 40-49, nearly 24% were 50-59, 9% were 60 years old or older, and 2% were less than 20 years old (Table 1). The vast majority of respondents were female (96%), with only 3% male, and other categories too few to report.

Of those who answered, 20% reported a total household income of less than \$25,000 in the previous year, 22% reported \$25,000 to \$49,999, 27% reported \$50,000 to \$99,000, and 18% reported \$100,000 to \$149,999. Twelve percent reported total income of \$150,000 or greater (Table 1).

Table 1. Sample Demographics

	Count	Percentage
Migraine Frequency¹		
Episodic	111	35.0%
Chronic	206	65.0%
Age		
Less than 20 years old	6	1.9%
20-29 years old	39	12.3%
30-39 years old	66	20.8%
40-49 years old	103	32.5%
50-59 years old	75	23.7%
60 old years or older	28	8.8%
Gender		
Female	306	95.9%
Male	11	3.4%
Gender variant/non-binary	#	#
Other	#	#
Total Annual Household Income		
Less than \$25,000	52	20.4%
\$25,000 to \$49,999	56	22.0%
\$50,000 to \$99,999	69	27.1%
\$100,000 to \$149,000	48	18.8%
\$150,000 or more	30	11.8%

¹ Defined as 15 or more headache or migraine days in last month.

Too few to report.

The demographics of this sample should be considered in making generalizations to the larger population of people with migraine. Any comparisons of findings between surveys should also take into account a comparison of the demographics across surveys.¹

Migraine Diagnosis: Univariate Analysis

The most common age of first migraine attack was 11-19 years (42%) followed by 5-10 years (20%), 20-29 years (20%), and 30-39 years (8%) (Table 2). Five percent of respondents reported their first migraine attack before 4 years of age and at 40 years of age or older, respectively.

Forty percent of respondents reported a time to diagnosis of one year or less (Table 2). Approximately a quarter of respondents (23%) waited 2-5 years for a diagnosis, 23% waited more than 10 years, and 14% waited 6-10 years (Table 2).

¹ See table A1 for comparison of demographics between surveys one, two, and three.

Table 2. Migraine Diagnosis: Univariate Statistics

	Count	Percentage
Age of First Migraine Attack		
Under 4 years	16	5.0%
5-10 years	65	20.4%
11-19 years	133	41.7%
20-29 years	63	19.7%
30-39 years	25	7.8%
40 years or older	17	5.3%
Time to Diagnosis		
1 year or less	125	40.3%
2-5 years	71	22.9%
6-10 years	42	13.5%
More than 10 years	72	23.2%
Time to Becoming Chronic¹		
Within 1 year	69	22.7%
2-5 years	66	21.7%
6-10 years	63	20.7%
More than 10 years	106	34.9%

¹ Among those who have transitioned from episodic to chronic by self-report.

Within one year, 23% self-reported that they first became chronic (i.e., transitioned from episodic to chronic status), 22% first became chronic in 2-5 years, and 21% became chronic within 6-10 years (Table 2). Thirty-five percent first became chronic over a period of greater than ten years.

Migraine Diagnosis: Bivariate Analyses

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 (i.e., “chronic”) and those who reported less were analyzed. None of the differences in distributions between chronic and episodic respondents were statistically significant.

Similar patterns were observed at the age of first migraine attack, time to diagnosis, and time to becoming chronic (Table 3). Most respondents first experienced a migraine attack between 11 and 19 years of age among episodic (47%) and chronic (39%) respondents. The next most common age of first migraine attack was 5-10 years of age (episodic: 20% and chronic: 20%) and 20-29 years of age (episodic: 20% and chronic: 20%).

The most common time to diagnosis was one year or less (episodic: 36% and chronic: 42% respectively). Conversely, 25% of episodic and 22% of chronic respondents waited more than ten years for a diagnosis.

Table 3. Migraine Treatments: Bivariate Statistics by Migraine Frequency

	Migraine Frequency	
	Episodic	Chronic ¹
Age of First Migraine Attack		
Under 4 years	3.6%	5.8%
5-10 years	19.8%	20.4%
11-19 years	46.8%	38.8%
20-29 years	19.8%	19.9%
30-39 years	6.3%	8.7%
40 years or older	3.6%	6.3%
Time to Diagnosis		
1 year or less	35.9%	42.4%
2-5 years	26.2%	21.5%
6-10 years	12.6%	14.1%
More than 10 years	25.2%	22.0%
Time to Becoming Chronic²		
Within 1 year	18.2%	24.6%
2-5 years	24.2%	20.7%
6-10 years	24.2%	19.2%
More than 10 years	33.3%	35.5%

¹ Defined as 15 or more headache or migraine days in last month.

² Among those who have transitioned from episodic to chronic by self-report.

We asked respondents to report the time it took for their attacks to become chronic after their first migraine attack. Among those who had ever self-reported a period of chronic migraine, we examined responses by *current* self-reported migraine frequency. Twenty-five percent of *currently* chronic respondents became chronic within one year compared to 18% of *currently* episodic respondents. Thirty-three percent of *currently* episodic and 36% of *currently* chronic became chronic over a period of more than ten years.

Significant differences arose when comparing the age of first migraine attack to time to diagnosis and time to becoming chronic (Table 4). Respondents whose first attack occurred at an older age generally required less time to diagnosis compared to younger respondents ($p < 0.001$). First, the majority of respondents whose first migraine attack occurred at age 20 years or older received a diagnosis within 1 year (20-29 years: 52%, 30 years and older: 56%). However, only 23% of

respondents who experienced their first migraine attack before age 11 received a diagnosis within 1 year of their first migraine attack.

Table 4. Migraine Treatments: Bivariate Statistics by Age of First Attack

	Age of First Migraine Attack¹			
	Under 11 years	11-19 years	20-29 years	30 years or older
Time to Diagnosis***				
1 year or less	22.8%	40.6%	51.6%	56.1%
2-5 years	13.9%	25.0%	27.4%	26.8%
6-10 years	22.8%	10.9%	12.9%	4.9%
More than 10 years	40.5%	23.4%	8.1%	12.2%
Time to Becoming Chronic^{2***}				
Within 1 year	12.8%	17.2%	28.6%	48.8%
2-5 years	15.4%	20.5%	34.9%	17.1%
6-10 years	21.8%	23.0%	19.0%	14.6%
More than 10 years	50.0%	39.3%	17.5%	19.5%

¹ Age categories collapsed for chi-square analysis due to small numbers of respondents in some categories.

² Among those who have transitioned from episodic to chronic by self-report.

*** $p < 0.001$

Further, it was more common for older respondents to become chronic sooner compared to younger respondents ($p < 0.001$) (Table 4). Almost half (49%) of respondents experienced their first migraine attack at age 30 years old or older became chronic within 1 year compared to 13% who experienced their first attack before age 11, 17% whose first attack was between 11 and 19 years, and 29% who had their first migraine attack between ages 20 and 29 years. Conversely, half of respondents whose first migraine attack occurred before age 11 self-reported that they did not first become chronic for more than 10 years.

There was a significant ($p < 0.001$) relationship between the time to becoming chronic and time to diagnosis (Table 5). Among respondents who became chronic within 1 year, 56% were diagnosed with migraine within 1 year or less and about 11% were diagnosed over a period of more than 10 years. Conversely, among respondents who became chronic over a time period of more than 10 years, 42.3% respondents reported it took more than 10 years to receive a diagnosis. A relatively large proportion of these respondents were still diagnosed within 1 year, however (about 36%).

Table 5. Migraine Treatments: Bivariate Statistics by Time to Becoming Chronic

	Time to Becoming Chronic ¹			
	Within 1 year	2-5 years	6-10 years	More than 10 years
Time to Diagnosis***				
1 year or less	56.1%	41.5%	30.6%	35.6%
2-5 years	28.8%	27.7%	24.2%	13.5%
6-10 years	4.5%	23.1%	21.0%	8.7%
More than 10 years	10.6%	7.7%	24.2%	42.3%

¹ Among those who have transitioned from episodic to chronic by self report.

*** $p < 0.001$

Comparing income, one difference arose. Income was significantly associated with time to becoming chronic (Table 6). Higher income seemingly had a protective effect; 41-47% of respondents who reported more than a total household income of \$50,000 also reported more than 10 years before first becoming chronic. Further, only 7% of respondents who made \$150,000 or more became chronic within 1 year. However, among respondents with a total household income of \$25,000, 43% became chronic within 2-5 years.

Table 6. Migraine Treatments: Bivariate Statistics by Current Total Income

	Income				
	Less than \$25,000	\$25,000-\$49,999	\$50,000-\$99,999	\$100,000-\$149,999	\$150,000 or more
Age of First Migraine Attack					
Under 11 years	30.8%	23.2%	29.0%	27.1%	23.3%
11-19 years	44.2%	39.3%	36.2%	39.6%	46.7%
20-29 years	21.2%	21.4%	24.6%	14.6%	23.3%
30 years or older	3.8%	16.1%	10.1%	18.8%	6.7%
Time to Diagnosis					
1 year or less	34.0%	35.2%	42.4%	41.7%	51.7%
2-5 years	28.0%	29.6%	16.7%	14.6%	17.2%
6-10 years	20.0%	11.1%	16.7%	22.9%	10.3%
More than 10 years	18.0%	24.1%	24.2%	20.8%	20.7%
Time to Becoming Chronic^{1**}					
Within 1 year	27.5%	24.5%	21.2%	20.9%	6.9%
2-5 years	43.1%	18.9%	12.1%	14.0%	31.0%
6-10 years	15.7%	22.6%	19.7%	20.9%	20.7%
More than 10 years	13.7%	34.0%	47.0%	44.2%	41.4%

¹ Among those who have transitioned from episodic to chronic by self report.

** $p < 0.01$

A limitation of utilizing current total income is this does not necessarily measure the total income at age of first migraine attack, time to diagnosis, and time during the transition from episodic to chronic. However, this measure of income is our best proxy for socioeconomic status and access to healthcare resources.

Conclusions

The sample of respondents in the second survey was overwhelmingly female, over 30 years old, and a majority of people with “chronic” migraine. The sample demographic characteristics generally align with the sample in the first survey (Appendix A). This is important to keep in mind as we consider the findings across surveys.

Most respondents had their first migraine attack at 11-19 years (40%), 5-10 years (20%), and 20-29 years (20%). A smaller percentage of respondents reported their first migraine attack after 30 years (13%) and under 4 years of age (5%).

It is encouraging to see 40% received a diagnosis of migraine within 1 year. The following subgroups were more likely to receive a diagnosis within one year: respondents who had their first migraine attack when they were 20 years of age and older, respondents who became chronic within 5 years, and respondents who reported a higher total household income.

Conversely, populations that may wait more than 10 years for a diagnosis include: respondents who experienced their first migraine attack before age 11, respondents who first became chronic after 10 years, and respondents who reported a lower total household income. These populations may require additional research and interventions to reduce suffering and healthcare resource utilization due to a lack of diagnosis.

Though our measure has limitations, higher income appears to have a protective effect on the transition to chronic migraine. Almost half of respondents who made more than \$50,000 reported more than 10 years before first transitioning to chronic migraine status. This is consistent with prior research.¹ However, it was more common for older respondents to report first becoming chronic sooner compared to younger respondents. Almost half (49%) of respondents who experienced their first attack at age 30 years and older became chronic within 1 year compared to 13–29% of respondents whose first migraine attack came before age 30.

Acknowledgements

These reports are a team effort. Chronic Migraine Awareness, Inc., would like to thank Director of Data Analysis, Beth Morton, PhD, for leading the survey design, data analysis, and reporting. She is assisted by Nikki S., who provided feedback during the survey design, and was instrumental in analysis and report writing. Many thanks also to Lindsay, who read each report and was a valuable editor. From CMA, Inc, Catherine Charrett-Dykes (CEO), Nancy Harris Bonk (COO), and Jennette Rotondi (Executive Director) have provided their invaluable content knowledge to the survey development process.

References

1. Xu J, Kong F, Buse DC. Predictors of episodic migraine transformation to chronic migraine: A systematic review and meta-analysis of observational cohort studies. *Cephalalgia*. 2020; 40(5): 503-516. doi:10.1177/0333102419883355

Appendix A.

Recall, survey one examined respondents’ experiences with health care providers. Though this second survey sample was also a majority “chronic,” the distribution shifted slightly toward episodic compared to the first survey ($p < 0.10$). The mean of survey one was 20 days and survey two 18 days. The distributions of age, gender, and income were all similar (all $p > 0.10$).

Table A1. Comparison of Survey Demographics in Survey One and Survey Two

	Survey 1	Survey 2
Migraine Frequency*		
Episodic	27.6%	35.0%
Chronic ¹	72.4%	65.0%
Age		
Less than 20 years old	2.2%	1.9%
20-29 years old	13.6%	12.3%
30-39 years old	19.3%	20.8%
40-49 years old	35.1%	32.5%
50-59 years old	23.7%	23.7%
60 years old or older	6.1%	8.8%
Gender		
Female	94.3%	95.9%
Male	4.0%	3.4%
Gender variant/non-binary	1.3%	0.3%
Other	0.4%	0.3%
Total Annual Household Income		
Less than \$25,000	21.2%	20.4%
\$25,000 to \$49,999	22.8%	22.0%
\$50,000 to \$99,999	34.9%	27.1%
\$100,000 to \$149,000	12.2%	18.8%
\$150,000 or more	9.0%	11.8%

* $p < 0.10$

¹ Defined as 15 or more headache or migraine days in last month.

Figure A1. Comparison of Demographics in Survey One and Survey Two

