

Coalition for Headache and Migraine Patients:
**HEADACHE DISEASE
PATIENT ACCESS SURVEY**



CHAMP
Coalition for Headache and Migraine Patients

Coalition for Headache and Migraine Patients: Headache Disease Patient Access Survey

An Introduction to the Methods and Sample

Brief 1

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EXECUTIVE SUMMARY

During the winter of 2019–2020, the Coalition for Headache and Migraine Patients (CHAMP) surveyed people with various headache diseases in order to provide data for the organization's research and advocacy efforts. The web-based survey was distributed by CHAMP and its coalition participants primarily through social media and newsletters. Included topics covered headache symptoms and severity, patient–healthcare professional interactions, treatments, health insurance access, and stigma, among other constructs.

A total of 3,514 respondents initiated the survey. Of those, 3,054 were eligible adults living in the United States who had experienced at least one headache in the past year. A total of 2,037 of those eligible respondents completed the survey.

The brief is the first in a series presenting results from the CHAMP Headache Disease Patient Access Survey and is meant as a reference, providing our methodology and sample demographics. Additionally, we share our findings on the frequency of various headache types and headache characteristics. In particular, highlights from our findings include:

- The CHAMP sample is distinct in that it has a high proportion of white respondents, women, and people 50 years old or older (**Table 3**). We propose this reflected the demographics of the CHAMP coalition participants' social media followings.
- Compared to population estimates of various headache types, the CHAMP sample has a much higher proportion of people with a self-reported diagnosis of migraine, cluster headache, new daily persistent headache, and post-traumatic headache (**Table 5**).
- Over one-third of the CHAMP sample experienced headache on 25 days per month or more (**Figure 2**).
 - The *subsample with migraine* is also over-represented by those with chronic migraine, compared to population estimates (**Table 3**).
- Of those *who have migraine*, 29% reported being disabled or on disability (**Table 4**).
- Among those with *only one headache type*,
 - cluster headache was rated the most painful ($\bar{x} = 9.4$ out of 10), (**Figure 3**) and
 - the mean age of onset was youngest for migraine ($\bar{x} = 21.5$ years) (**Figure 4**).

INTRODUCTION

The Coalition for Headache and Migraine Patients (CHAMP) brings together people with migraine, cluster headache, and other headache diseases, along with organizations, medical and scientific participants, and other leaders in the field, to enhance communication, provide support, and advocate for people living with headache diseases. During the winter of 2019–2020, CHAMP fielded a survey on the needs of people with various headache diseases. The survey was meant to provide data on peoples’ lived experiences both to support the organization’s research and advocacy efforts and to give voice to the U.S. headache community. The survey sought to evaluate headache symptoms and severity, patient–healthcare professional interactions, treatment, health insurance access, and stigma, among several other constructs.

This brief is the first in a series describing the results of the CHAMP Headache Disease Patient Access Survey (HDPAS) relating to the experiences of people with migraine and other headache diseases: from diagnosis to symptoms and access barriers. In this brief, the motivations, methodology, sample description, and respondent demographics are presented. We also present data on the frequency of headache types, mean headache days per month, and mean pain level and age of onset of respondents’ most severe headache type.

BACKGROUND

Key Migraine and Headache U.S. Epidemiologic Studies

The CHAMP HDPAS adds to a growing number of studies conducted to better track and understand the burden of headache and migraine in the United States. To set the context, **Table 1** provides an overview of several well-known epidemiologic migraine studies based in the United States: the American Migraine Study I (AMS I), the American Migraine Study II (AMS II), the American Migraine Prevalence and Prevention (AMPP) Study, the Chronic Migraine Epidemiology and Outcomes (CaMEO) Study, the Migraine in America Symptoms and Treatment (MAST) Study, and the Observational Survey of the Epidemiology, Treatment and Care of Migraine (OVERCOME) Study. Each study has focused on different aspects of the migraine experience from prevalence and disability¹ and comorbidities and risks^{2–4} to differences between chronic and episodic migraine,^{5,6} lost productivity,⁷ and unmet treatment needs.⁸ The newest is OVERCOME, whose results thus far have been presented in scientific abstracts.^{9,10} Most of these studies used U.S. population-based sampling techniques. This means they matched their study populations to U.S. Census demographics to assess prevalence and other outcomes in a sample that is representative of the United States population as a whole.

In addition to the epidemiologic studies, Migraine.com has conducted an annual survey called “Migraine in America” (**Table 1**). Historically, this survey, which began in 2012, targeted people living with migraine, although in 2019, the survey began to include people with cluster headache. The Migraine in America survey samples from people who follow Migraine.com’s website and social media, making it more similar to CHAMP’s survey than the national epidemiologic studies are in terms of recruitment design. Unlike epidemiological studies, both the Migraine in America and CHAMP surveys have a bias of self-selection; people who engage in patient communities are likely more experienced with, burdened by, and thus knowledgeable of headache diseases relative to the general population.

Table 1. Headache and Migraine Surveys in the United States

Study name	Acronym	Year(s) conducted	Study type	Sampling technique	Sampling unit	Year of reported statistics	Number of respondents	Reported rate of headache or migraine	Screening criteria	Study objective
American Migraine Study I	AMSI	1989	Cross-sectional	Nationally representative ¹	Individuals ages 12+	1989	20,468	12.1% (migraine)	ICHD-1; at least 1 severe headache in the previous 12 months with unilateral or pulsating pain, and either sensitivity to light and noise or nausea or vomiting, or a visual or sensory aura before the headache	First study to describe the prevalence and socio-demographics of people with migraine
American Migraine Study II	AMS II	1999	Cross-sectional	Nationally representative ¹	Individuals ages 12+	1999	29,727	12.6% (migraine)	ICHD-1; at least 1 severe headache in the previous 12 months with unilateral or pulsating pain, and either sensitivity to light and noise or nausea or vomiting, or a visual or sensory aura before the headache	Describe prevalence, demographics, and burden of people with migraine and compare to previous wave
American Migraine Prevalence and Prevention Study	AMPP	2004–2009	Longitudinal; yearly follow-up	Nationally representative ¹	Individuals ages 12+	2004	162,576	11.7% (migraine)	ICHD-2; at least 1 severe headache in the past year but less than 15 within the past month, with unilateral or pulsating pain, and either sensitivity to light and noise or nausea or vomiting, or a visual or sensory aura before the headache	Examine differences in demographics and rates of comorbidities between those with episodic compared to chronic migraine
Chronic Migraine Epidemiology and Outcomes Study	CaMEO	2012–2013	Longitudinal; 3 month follow-ups	Nationally representative ¹	Adults 18+	2012	58,418	28.7% (migraine)	ICHD-3 beta; lifetime recall of headache or migraine with unilateral pain, pulsating pain, moderate to severe, exacerbated by normal activity and associated with nausea, light and noise sensitivity	Assess headache frequency and disability changes over a year, focusing on people with chronic migraine
Migraine in America Symptoms and Treatment Study	MAST	2017–2018	Longitudinal; 6 month follow-ups	Nationally representative ¹	Adults 18+	2017	95,821	19.2% (migraine)	ICHD-3 beta; lifetime recall of headache or migraine with unilateral pain, pulsating pain, moderate to severe, exacerbated by normal activity and associated with nausea, light and noise sensitivity	Understand the symptoms, treatment management, and unmet needs of people with migraine
Observational Survey of the Epidemiology, Treatment and Care of Migraine	OVER-COME	2018, 2019, 2020	Longitudinal; multiple cohorts and multiple waves	Nationally representative ¹	Adults 18+	2018	41,925	24.9% (migraine)	Experienced at least one headache/migraine in past year AND self-reported medical diagnosis of migraine AND/OR met the modified ICHD-3 criteria for migraine using the validated AMS/AMPP migraine diagnostic screener	Understand the burden of migraine and stigma, identify barriers to appropriate treatment, and assess how the introduction of novel treatment options may influence delivery of care and outcomes
Migraine in America survey (Migraine.com)		2012–Present	Cross-sectional; repeated annually	Purposive, self-selected from migraine community	Adults 18+	2016	3,923	100% (migraine)	Individuals currently diagnosed with migraine	Identify migraine frequency, symptoms, common triggers. Understand the challenges faced and broader impact of migraine on peoples lives. Extended to cluster headache in 2019
CHAMP Headache Disease Patient Access survey (this survey)	CHAMP HDPAS	2019–2020	Cross-sectional	Purposive, self-selected from headache and migraine community	Adults 18+	2019–2020	2,037	100% (headache, including migraine)	Survey completers who had at least one headache or migraine over the past year not due to a hangover or illness and endorsed one of 18 headache types or conditions	Examine experiences with headache-related diagnosis, healthcare professionals, and treatments, and the related barriers

¹Survey administered via panel that targets demographics intended to be representative of U.S. population. Note: See key references.^{1,6,8,11,18}

Other national surveys have been used to study headache and migraine, but are more broadly focused on general health. Some examples are the National Health Interview Survey (NHIS),¹⁹ the National Health and Nutrition Examination Survey,²⁰ the National Ambulatory Medical Care Survey, and the National Hospital Ambulatory Medical Care Survey.²¹ The latter two focus on patient records from physicians and hospitals to examine reasons for seeking care.

Table 2. CDC-funded Surveys that Collect Headache and Migraine Data

Study name	Acronym	Year(s) conducted	Study type	Sampling technique	Sampling unit	Year of reported statistics	Number of respondents	Reported rate of headache or migraine	Screening criteria	Study objective
National Health Interview Survey	NHIS	1957–Present	Yearly repeated cross-sectional	Nationally representative	Adults 18+	2015	33,672	15.3% ¹	Severe headache or migraine during past 3 months	Monitor the health status and health care access of the U.S. in order to progress towards national health objectives
National Health and Nutrition Examination Survey	NHANES	1999–Present	Yearly repeated cross-sectional	Nationally representative	Adults 20+	1999–2004	15,322	22.7%	Severe headache or migraine during past 3 months	Understand the health and nutrition of both adults and children in the U.S.
National Ambulatory Medical Care Survey	NAMCS	1973–1981, 1985, 1989–Present	Yearly repeated cross-sectional	n/a	Physicians (patient records)	2009	1822 physicians, 32,881 patient records	1.2% of visits due to “pain in head”	Headache-related reasons for visit or prescribed medication	Gather information about why and how people use ambulatory medical services in the U.S.
National Hospital Ambulatory Medical Care Survey	NHAMCS	2009–Present	Yearly repeated cross-sectional	n/a	Hospitals (patient records)	2014	283 hospitals 23,844 patient records	3.0% of visits due to “pain in head”	Headache-related reasons for visit, diagnosis, testing, or prescribed medication	Gather information about how and why people use care and services in hospital emergency and outpatient departments

¹Age-adjusted prevalence.
 Note: NHIS, NHANES, NAMCS, and NHAMCS are only a small sampling of nationally representative studies that collect data on headache and migraine.
 See key references.^{19–23}

Headache Prevalence by Type

Although global estimates of the prevalence of tension-type headache vary, it is consistently deemed the most common primary headache. Global, lifetime prevalence is estimated to be about 38% but ranges from 10% to 87% depending on study demographics and methodology.^{24,25} Other types of headache diseases affect fewer individuals but can be more disabling. Although the specific estimates vary slightly, multiple studies agree that migraine is quite prevalent within the U.S. population, particularly for women. The NHIS found 15.3% of the U.S. population has experienced migraine or severe headaches within the past 3 months; this breaks down to 9.7% of males and 20.7% of females.²³ The AMPP study found 11.7% of the U.S. adult population has migraine, including 17.3% of women and 5.7% of men.^{22,26} Sex differences peaked in midlife.²⁶ Although the various epidemiological studies of migraine span several decades, estimates of the prevalence of migraine remain consistent across time.²³

New daily persistent headache (NDPH) affects between 0.03% and 0.1% of the population, with higher estimates in children and adolescents.¹⁶ Although there have not been recent estimates of cluster headache within the United States, global estimates place the lifetime incidence at about 1 per 1,000 individuals.²⁷ Prevalence rates of post-traumatic headache (PTH) vary widely; some international population-based studies place lifetime estimates around 2.4% in women and 4.7% in men, while 36% of those who experienced a mild traumatic brain injury reported PTH 6 months later.²⁸

Migraine is one of the leading causes of disability globally and within the United States;²⁹ in the United States, migraine is the leading cause of years lived with disability among people under 50 years old.³⁰ A recent survey of those with cluster headache compared their cluster headache pain to other types of pain they experienced and found that cluster headache was rated the most severe by far ($x^- = 9.7$ out of 10), followed by labor pain ($x^- = 7.2$) ($p < 0.001$, all differences).³¹ In sum, previous research clearly indicates the widespread impact of headache diseases.

THIS STUDY

Many of the population studies of headache and migraine have provided valuable data on the prevalence of these diseases in the United States and some of their disabling impacts. Given its advocacy focus, CHAMP undertook the HDPAS with a slightly different focus. The intent was to field a survey to provide CHAMP and its coalition participants with data on the experiences of people with various headache diseases to inform campaigns for better treatment access. Specifically, the survey collected information on not just headache symptoms and impact, but also experiences associated with other aspects of the patient journey including diagnosis, healthcare professionals, appointments, treatments (efficacy and access), and stigma.

Methods

Survey Development

Questions were drafted and revised with the assistance of CHAMP coalition participants and expert headache researchers, Drs. Dawn Buse, PhD, and Richard Lipton, MD, using two strategies. First, the survey included validated instruments (e.g., the Migraine Disability Assessment Questionnaire (MIDAS) and the AMS/AMPP Study Migraine Diagnostic Module) that had previously been used on other large-scale headache and migraine surveys, such as those reported in **Table 1**.^{1,32,33} The survey development team also brainstormed with CHAMP participants to fill gaps and pilot draft questions. This approach was used both to ensure sensitivity of content to people with various headache diseases and to ensure that the format and wording of items were clear.

Our research design, including personnel, data collection, and data security methods, were all reviewed by an external Institutional Review Board (IRB) to ensure they met ethical standards. This included a review of our full survey instrument and informed consent document. We have maintained IRB approval throughout the project.

Sampling and Distribution

For the CHAMP survey, respondents were recruited by CHAMP and its coalition participants via social media (e.g., Facebook, Twitter, Instagram, and Google Ads) and their respective newsletters. CHAMP also shared the survey on its website. As such, the CHAMP survey used what can best be described as purposive sampling, a non-probability technique, to recruit volunteers. Although respondents have an unknown probability of selection, this design allowed us to effectively and efficiently recruit our target sample: adults with a headache disease living in the United States.

Because we used this sampling technique, we anticipated that virtually all survey respondents would have a headache disease and that some headache diseases would be over-represented. We also anticipated that within a diagnostic category, such as migraine disease, severity of illness would be greater than in more representative samples. The purpose of the CHAMP HDPAS was to characterize the lived headache experience of our community members and not to study a representative sample of the U.S. population.

CHAMP participants represent people with a range of headache disease types, which supported our broad recruitment strategy. A few screening questions ensured that those who expressed interest in the survey consented to the survey and met the defined eligibility requirements: age 18 years or older, residing in the United States or a U.S. territory, and having had at least one headache or migraine in the past year not due to hangover or illness. While the survey was open, the team monitored survey completion rates and responses to key demographics, attempting to adjust recruitment strategies where needed.

The survey was hosted on a web-based platform called Alchemer (formerly SurveyGizmo), and a single link was used for survey data collection. The survey was anonymous, and respondents were prohibited from re-entering the survey on the same device; this measure was used to limit duplicate responses. The survey platform allowed users to save their progress and continue the survey later if they needed to stop before completion using an emailed anonymous link. The survey was open from November 23, 2019 through February 29, 2020.

The survey was incentivized. All adults were eligible to enter a raffle for one of twenty \$25 Amazon gift cards. This included people who did not consent (Group 1), who consented but were ineligible (Group 2), who consented and were eligible but failed to fully complete the survey (Group 3), and who completed the survey (Group 4). Entries were collected via separate, anonymous survey links embedded in the main survey in various ways. Groups 1 and 2 were eligible for one entry in the drawing. Group 3, partial completers, received two entries by clicking a link in a form that was emailed to them using Alchemer’s “save and continue” feature. If they completed the survey, they were counted as survey completers. Group 4, survey completers, received five entries upon completion of the survey.

Analysis

The analyses presented in this brief are descriptive statistics: means and percentages. For a few analyses, we test for statistical differences using chi-square tests and t-tests. All of our analyses use pairwise deletion; that is, we use all available data for a given analysis. The analyses are also limited to survey completers. This means that for any given analysis, data may be missing for some of the sample, and sample numbers may change even within tables, if different variables and samples are reported. For this reason, total sample counts are not reported in certain tables (**Table 3**, **Table 4**).

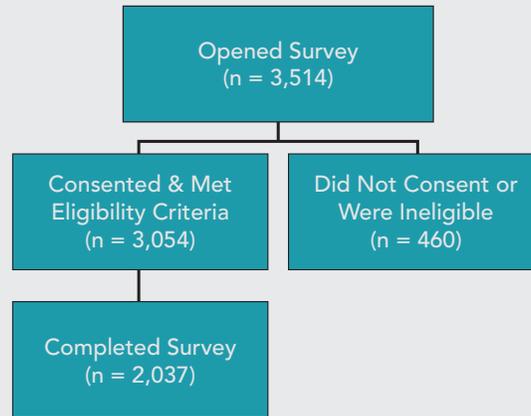
Data are missing for three reasons: 1) an item wasn’t applicable to that respondent (e.g., items that were skipped due to the branching logic of the survey), 2) an applicable item was skipped by the respondent, but the survey was continued, or 3) an item was never seen because the respondent stopped the survey before the item was reached. In most cases, we have not imputed missing or inconsistent responses. Where we have, imputation is discussed in conjunction with the relevant analysis. By limiting the analyses to completers but using all available data, we have attempted to capture a consistent sample across analyses while maximizing data on any given item.

RESULTS

Survey Sample

A total of 3,514 respondents initiated the survey by opening the link. Of those, 3,054 consented to taking the survey, were 18 years old or older, lived in the United States or a U.S. territory, and had at least one “headache in past year not due to hangover or cold/flu.” This represents the sample eligible for the survey (**Figure 1**).

Of those who were eligible, we defined survey completers as people who reached the final page of the survey and answered at least one demographic question. Under this definition, 66.7% of eligible survey respondents completed the survey (n = 2,037) (**Figure 1**).

Figure 1. Survey Sample Flowchart

Note: Survey eligibility criteria: respondents had to 1) be 18 years old or older, 2) live in the United States or a U.S. territory, and 3) have experienced at least one headache or migraine not due to illness (e.g., cold or flu) or hangover in the past year. A “completed survey” does not mean a person answered every item, only that they reached the end of the survey and responded to at least one item on that page.

Sample Demographics

This brief describes the characteristics of all respondents and serves as the foundation for a series of substantive briefs. First, we examined the demographics of our CHAMP survey sample (Table 3 and Table 4) and compared the CHAMP migraine sample to prior and current population-based studies of migraine (Table 3). The goal was to set the context for our analyses. Given the sampling technique described above, we knew that the CHAMP HDPAS sample would not be representative of the U.S. population. However, we still wanted to know how our respondents compared to participants in prior epidemiological studies. We compared our sample to those from the AMPP, CaMEO, and OVERCOME Studies. For consistency with their estimates, we compared:

1. the CHAMP sample who self-reported a migraine diagnosis with demographics from AMPP and CaMEO, and
2. the CHAMP sample whose responses to the AMS/AMPP migraine screener indicated a migraine diagnosis or who self-reported a migraine diagnosis with demographics from OVERCOME.

In all cases, chi-square tests comparing the distributions of each demographic measure indicate that the CHAMP samples are different from the migraine samples in AMPP, CaMEO, and OVERCOME. This is not surprising. However, we think some differences are worth highlighting.

First, the proportion of people with migraine who met criteria for chronic migraine is much higher in the CHAMP sample than any of the previous population surveys. In the CHAMP sample, we considered people to have chronic migraine who self-reported a migraine diagnosis or whose answers to the AMS/AMPP screener indicated migraine and whose number of headache days per month were greater than or equal to 15. Among the population studies, OVERCOME estimates are highest, with about 12% of the sample identified as having chronic migraine. However, the CHAMP estimate is closer to 60% (Table 3).

The CHAMP migraine samples also have a higher proportion of female respondents than we would expect in the population with migraine (Table 3). Estimates from population studies range from 74% to 80%. In the CHAMP sample, 91–93% of respondents were women. In terms of age, race, and ethnicity, Table 3 also indicates that CHAMP survey respondents are more like those in AMPP than those in CaMEO and OVERCOME. However, CHAMP respondents’ total household income is more similar to that of those in OVERCOME than of those in AMPP or CaMEO.

Table 3. CHAMP Headache Disease Patient Access Survey Sample Demographics Compared to Three Population Surveys of Headache and Migraine

Demographic measure	American Migraine Prevalence and Prevention Study (AMPP)		Chronic Migraine Epidemiology and Outcomes Study (CaMEO)		Observational Survey of the Epidemiology, Treatment and Care of Migraine (OVERCOME) (2018 Cohort)		CHAMP Headache Disease Patient Access Survey							
							Full completer sample (all headache types)		Migraine samples					
									Met AMS/AMPP migraine screener criteria		Self-reported migraine diagnosis ¹		Either screener criteria met or self-reported diagnosis	
Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	
Migraine classification²														
Episodic	11,249	93.4	15,313	91.2	18,660	88.3	--	--	707	39.9	654	39.2	744	39.9
Chronic	794	6.6	1,476	8.8	2,483	11.7	--	--	1,065	60.1	1,016	60.8	1,119	60.1
Age														
18–29 years	1,425	11.8	4,631	27.6	5,116	24.2	149	7.3	136	7.2	121	6.8	141	7.1
30–39 years	2,408	20.0	3,793	22.6	5,166	24.4	359	17.6	335	17.8	318	18.0	353	17.9
40–49 years	3,318	27.6	3,476	20.7	3,926	18.6	614	30.1	575	30.6	543	30.7	599	30.3
50–59 years	2,987	24.8	2,867	17.1	3,590	17.0	563	27.6	525	27.9	490	27.7	547	27.7
60 years or older	1,905	15.8	2,022	12.0	3,345	15.8	352	17.3	309	16.4	298	16.8	335	17.0
Gender³														
Men	2,417	20.1	4,294	25.6	5,446	25.8	159	7.9	118	6.4	99	5.7	135	6.9
Women	9,626	79.9	12,495	74.4	15,697	74.2	1,817	90.4	1,705	92.0	1,620	92.6	1,782	91.4
Race														
White, only	10,547	87.6	14,044	83.7	16,758	79.3	1,794	90.7	1,662	91.1	1,563	90.8	1,742	90.9
Non-white	1,327	11.0	2,682	16.0	4,385	20.7	183	9.3	163	8.9	158	9.2	175	9.1
Hispanic														
	362	3.1	2,230	13.3	2,152	10.2	87	4.5	82	4.6	78	4.6	84	4.4
Total household income														
Less than \$50,000	6,700	55.6	6,732	40.1	10,278	48.6	833	47.5	782	48.0	726	47.8	812	47.7
\$50,000–\$74,999	2,255	18.7	3,774	22.5	4,155	19.7	305	17.4	281	17.2	266	17.5	293	17.2
\$75,000 or more	3,088	25.6	6,158	36.7	6,710	31.7	616	35.1	567	34.8	527	34.7	597	35.1

¹The CHAMP migraine sample labeled “self-reported migraine diagnosis” is the sample on which future migraine analyses are based (n = 1,770). We point this out for those referring back to this table from those briefs.
²AMPP and CaMEO establish a migraine diagnosis on the basis of the AMS/AMPP screener. OVERCOME (2018) establishes a migraine diagnosis based on self-reports or responses to the AMS/AMPP screener. To compare CHAMP data, we calculated various samples: met criteria for the AMS/AMPP screener only, self-diagnosis only, or either. In all cases, to meet the criteria of “chronic” respondents must have also reported 15 or more headache days per month on average in the prior 3 months. Migraine classification is not reported for the overall headache sample as it is not applicable.
³AMPP, CaMEO, and OVERCOME reported estimates for men and women only. The CHAMP data will not sum to 100% because respondents were allowed to report other identities that are not reported in this table.
 Note: See key references.^{6,13-15}

Since Migraine.com uses a similar method of recruitment for their annual Migraine in America survey, we compared our migraine sample to their demographics on several available data points. Like the CHAMP sample, the 2018 Migraine in America sample was predominantly female (93%) and nearly half self-reported having migraine on 15 or more days per month (i.e., “chronic”) (total sample n = 4,356).³⁴ This suggests that in some ways, the CHAMP sample may be more like the Migraine in America sample than the population studies of migraine.

In **Table 4**, we show additional demographics from the CHAMP HDPAS. In terms of education, 49% of the full completer (overall sample and 48% of the self-reported migraine diagnosis sample (migraine) reported obtaining an associate’s degree or less, 29% of both samples reported obtaining a bachelor’s degree, and 22% of the overall sample and 23% of the migraine sample reported obtaining an advanced degree (**Table 4**). The question of work or school status allowed respondents to select all that apply. Approximately 35% of the overall sample and 34% of the migraine sample reported full-time employment. The second most common situation, though, was being

disabled or on disability: 28% of the overall sample and 29% of the migraine sample reported this status (Table 4). Finally, although there was representation from each U.S. region, one-third of both samples were from the South (Table 4).

Table 4. Additional Demographics of CHAMP Headache Disease Patient Access Survey Sample, Overall Headache Type Frequency

Demographic measure	Full completer sample (all headache types)		Self-reported migraine diagnosis ¹	
	Number	Percent	Number	Percent
Highest level of education				
Less than high school	14	0.7	8	0.5
High school diploma or equivalent	184	9.1	160	9.1
Some college (no degree) or associate's degree	786	39.0	679	38.7
Bachelor's degree	593	29.4	510	29.1
Graduate degree	441	21.9	398	22.7
Work or school status²				
Employed full time	703	34.6	596	33.7
Employed part time	213	10.5	183	10.4
Self-employed	137	6.7	115	6.5
Homemaker	217	10.7	195	11.0
Full-time student	56	2.8	46	2.6
Part-time student	50	2.5	42	2.4
Volunteer	89	4.4	83	4.7
Retired	212	10.4	180	10.2
Medical, parental, or other short-term leave	37	1.8	33	1.9
Not employed - not disabled	104	5.1	94	5.3
Disabled or on disability	567	27.9	507	28.7
Work or school status, other	89	4.4	81	4.6
U.S. region				
Northeast	387	19.3	344	19.7
Midwest	479	23.9	417	23.9
South	673	33.6	586	33.6
West	460	23.0	392	22.5
U.S. territory	#	#	#	#

¹The CHAMP sample labeled “self-reported migraine diagnosis” is the sample on which future migraine analyses are based (n = 1,770). We point this out for those referring back to this table from those briefs.

²The work or school status question allowed respondents to “check all that apply.” Totals will sum to more than sample (n) and 100%.

Too few cases to report.

Note: People with missing data or who responded “prefer not to answer” are not reported.

The survey opened with a key question about headache types. Acknowledging there are many we could have asked about, the survey included five specific headache types: migraine (any type), tension-type headache, cluster headache, NDPH, and PTH. We also provided an “other headache type” option where people could write in their headache type. The research team coded these write-in responses to determine if they fit one of the five headache types.

For each headache type, including other, we asked respondents whether they “had” that headache type, “had been diagnosed by a healthcare professional” with that headache type, or “were under treatment by a healthcare professional” for that headache type. Across headache types and conditions, respondents could select all that apply.

Some data imputation was done on these items. When respondents indicated they “were under treatment” for a headache type but not that they “had been diagnosed” with or “had” that same headache type, we recoded the latter two items affirmatively. Likewise, when respondents indicated they “had been diagnosed” with a headache type but not that they “had” that same headache type, the latter item was recoded affirmatively. The number and percentage of affected cases is reported in Table A.1. in the appendix.

Table 5 shows the resulting distribution of the frequency of headache types for the full CHAMP sample. Migraine was the most commonly reported headache type. Almost 93% of the completer sample reported having migraine, 87% self-reported a migraine diagnosis, and 75% were under treatment by a healthcare professional for migraine (**Table 5**).

The next most common was tension-type headache, with about 30% reporting a diagnosis (**Table 5**). Those with a cluster headache diagnosis (23%) and NDPH diagnosis (24%) followed (**Table 5**).

Table 5. Relative Frequency of Headache Types

Headache type	Number	Percent
Migraine, any type		
I have this headache type	1,889	92.7
I have been diagnosed by a healthcare professional with this headache type	1,770	86.9
I am currently under treatment by a healthcare professional for this headache type	1,524	74.8
Tension-type headache		
I have this headache type	1,118	54.9
I have been diagnosed by a healthcare professional with this headache type	609	29.9
I am currently under treatment by a healthcare professional for this headache type	364	17.9
Cluster headache		
I have this headache type	675	33.1
I have been diagnosed by a healthcare professional with this headache type	468	23.0
I am currently under treatment by a healthcare professional for this headache type	311	15.3
New daily persistent headache		
I have this headache type	756	37.1
I have been diagnosed by a healthcare professional with this headache type	492	24.2
I am currently under treatment by a healthcare professional for this headache type	382	18.8
Post-traumatic headache		
I have this headache type	302	14.8
I have been diagnosed by a healthcare professional with this headache type	219	10.8
I am currently under treatment by a healthcare professional for this headache type	118	5.8
Other headache type¹		
I have this headache type	584	28.7
I have been diagnosed by a healthcare professional with this headache type	431	21.2
I am currently under treatment by a healthcare professional for this headache type	364	17.9

¹People who wrote in an “other” headache type that could be categorized as one of the existing five headache types are included in the appropriate row above and were removed from these “other” rows.

Notes: Of 2,037 survey completers, all responded to at least one of these 18 items. Respondents could select multiple headache types, so values may sum to more than 2,037 or 100%. Some responses to “have” and “have been diagnosed” were imputed (i.e., changed from “no” to “yes”) when respondents indicated they were “under treatment” for a headache type but did not indicate that they “had” or “had been diagnosed” with that headache type. Additionally, some responses to “have” were imputed when respondents indicated they had been diagnosed with that headache type.

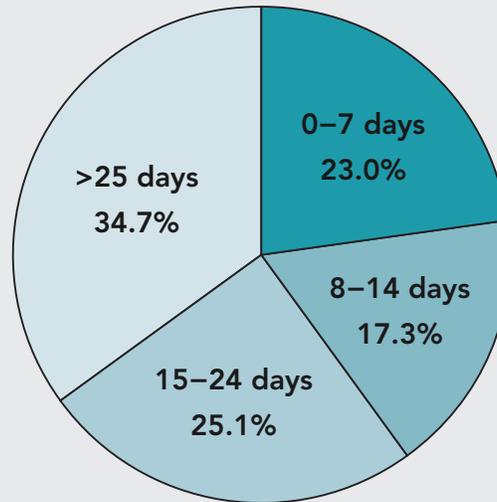
Also shown in **Table 5**, 11% of respondents reported a PTH and 21% an “other” headache type diagnosis. These other headache types are exclusive of write-ins recoded as the five main headache types and include sinus headache, headaches attributed to cerebrospinal fluid leaks or high cerebrospinal fluid pressure, neuralgias, etc.

As a proportion of those who reported having a headache type, those with migraine were the most likely to report also being under treatment (1,524/1,889 or 81%) compared to tension-type headache (only 33%), PTH (39%), cluster headache (46%), and NDPH (51%; calculations from **Table 5**).

Mean Headache Days per Month

In this analysis, we look at the full sample (all headache types together) and consider only the average number of headache days per month over the past 3 months. By this measure, the distribution is still skewed toward those with a high frequency of headache (Figure 2). About 40% of the sample is “episodic” and 60% “chronic,” the latter experiencing headache on more days than not.*

Figure 2. Number of Headache Days per Month



Note: n = 1,924. Number of headache days per month was calculated as the mean number of headache days per month over the past 3 months.

The mean number of headache days per month for the overall sample was 17.4 (Table 6). Table 6 reports the mean number of headache days for those with various headache diagnoses. However, it should be noted that people can report more than one type of headache. The mean for NDPH is the highest ($\bar{x} = 22.7$), followed by PTH ($\bar{x} = 21.1$), other headache ($\bar{x} = 20.9$), tension-type headache ($\bar{x} = 18.2$), migraine ($\bar{x} = 17.6$), and cluster headache ($\bar{x} = 17.5$) (Table 6).

Table 6. Distribution of Headache Days per Month Over Past 3 Months, Overall and by Headache Type Diagnosis

Headache type diagnosis	Number	Mean	Median	Std. Dev.	Min.	Max.
Overall	1,924	17.4	17.0	9.94	0.0	30
Headache type diagnosis						
Migraine, any type	1,670	17.6	17.7	9.73	0.0	30
Tension-type headache	577	18.2	20.0	9.27	0.7	30
Cluster headache	438	17.5	18.3	9.71	0.0	30
New daily persistent headache	453	22.7	26.7	8.32	0.7	30
Post-traumatic headache	205	21.1	23.3	9.01	1.0	30
Other headache type	423	20.9	23.3	9.16	1.0	30

Note: Respondents could select multiple headache types. Total (n) of headache type rows will sum to more than 1,924. Numbers by headache type diagnosis will not match table 5 due to some respondents' missing data on number of headache days over past 3 months.

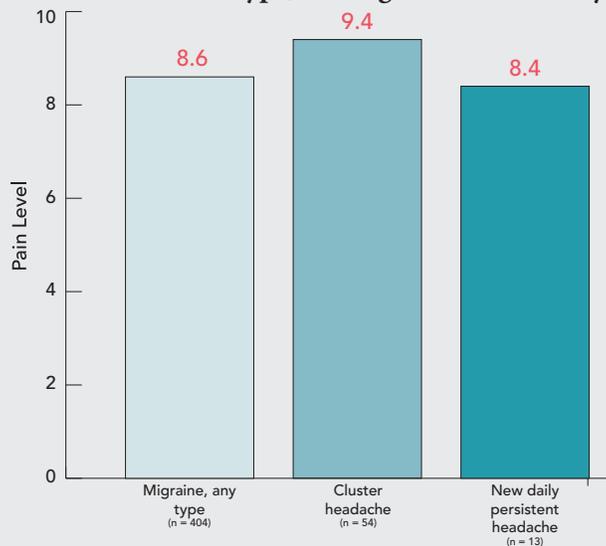
Headache Severity and Age of Onset

We also examined the mean severity and age of onset of respondents' most severe headache type. Knowing that most people reported multiple headache types, we restricted this analysis to those who only reported one headache type. With this restriction, there are too few people with only tension-type headache or PTH to report, and the sample sizes are also quite small in cluster headache and

* Just over one-third (35%) of respondents with any headache diagnosis reported daily headache attacks; defined as headache on 25 days or more, on average, over the prior 3 months. This estimate, and those for each headache type, can be found in a supplemental table (Table S.1.1) on the survey section of the CHAMP website <https://headachemigraine.org/survey-briefs/supplemental-tables/>.

NDPH. However, those with cluster headache report significantly higher mean pain levels ($\bar{x} = 9.4$) than those with migraine ($\bar{x} = 8.6$, $p < 0.001$) or NDPH ($\bar{x} = 8.4$, $p < 0.01$) (Figure 3).

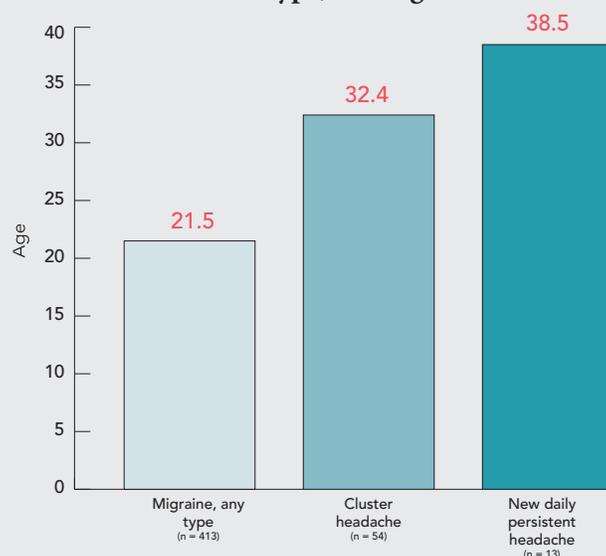
Figure 3. Mean Pain Level of Most Severe Headache Type, Among Those With Only One Type



Note: There were too few cases to report data for tension-type headache and post-traumatic headache. T-tests: migraine vs. cluster headache $p < 0.001$; cluster headache vs. NDPH $p < 0.01$.

The mean age of onset is also significantly younger for migraine ($\bar{x} = 21$ years) than for both cluster headache ($\bar{x} = 32$ years, $p < 0.001$) and NDPH ($\bar{x} = 39$ years, $p < 0.01$) (Figure 4).

Figure 4. Mean Age of Onset of Most Severe Headache Type, Among Those With Only One Type



Note: There were too few cases to report data for tension-type headache and post-traumatic headache. T-tests: migraine vs. cluster headache $p < 0.001$; migraine vs. NDPH $p < 0.01$.

DISCUSSION

The CHAMP survey provides a unique sample and opportunity to investigate the headache disease patient journey. Compared to population estimates of various headache types, the CHAMP sample has a much higher proportion of people with a diagnosis of migraine, cluster headache, NDPH, and PTH, while likely under-representing those with tension-type headache.[†]

Notably, the CHAMP survey is also over-represented by those with both chronic headache and chronic migraine. This provides a unique opportunity to understand the needs and experiences of those with severe and disabling headache diseases. Although chronic headache diseases are not as common as episodic ones, people with chronic headache diseases have many unmet needs and face distinct barriers that are worth investigating.

Our sample is also distinct in that we have a large number of respondents older than 50 years. It has been largely established in headache and migraine literature, in particular, that the prevalence of migraine declines with age, particularly among women. This is generally attributed to the hormonal changes associated with menopause.^{35,36} As such, the CHAMP sample, comprised of large numbers of older women, offers an opportunity to investigate the burden of migraine among those who are typically assumed to have decreased needs as patients.

All these differences represent under-explored avenues in headache disease research. Although certain headache diseases are quite rare, through this CHAMP survey, we have identified a sizable group of people who live with them and are eager to share their experiences. Because we also have a larger proportion of headache types other than migraine and tension-type headache than would be normally expected, we can use this opportunity to develop new understandings of the differences between headache diseases across many dimensions.

We recognize that there are limitations to our study, as with all studies. By targeting members of the CHAMP community and CHAMP coalition participants' communities, we attracted a group that not only has more disabling symptoms of their respective headache diseases, but also may be more motivated and educated about headache diseases than average. Our survey may also be susceptible to recall bias since respondents must recollect past events and social desirability bias since they must share sensitive health information.

Overall, we think the CHAMP sample is special and presents a unique opportunity to understand the lives of those with severe headache burden, but its limitations should be kept in mind when viewing our briefs and attempting to apply the results to broader audiences.

[†] Other survey responses indicated at least some portion of those who reported NDPH may not have understood this as a distinct headache type, but meant something like chronic or daily tension headache.

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APPENDIX

Table A.1. Number of Cases for which Responses Indicating Whether Someone Had or Had Been Diagnosed with Various Headache Types were Changed Based on Other Data¹

Headache type	Number	Percent of total responses
Migraine, any type		
I have this headache type	554	27.2
I have been diagnosed by a healthcare professional with this headache type	401	19.7
Tension-type headache		
I have this headache type	232	11.4
I have been diagnosed by a healthcare professional with this headache type	107	5.3
Cluster headache		
I have this headache type	192	9.4
I have been diagnosed by a healthcare professional with this headache type	96	4.7
New daily persistent headache		
I have this headache type	183	9.0
I have been diagnosed by a healthcare professional with this headache type	129	6.3
Post-traumatic headache		
I have this headache type	90	4.4
I have been diagnosed by a healthcare professional with this headache type	33	1.6
Other headache type¹		
I have this headache type	173	8.5
I have been diagnosed by a healthcare professional with this headache type	123	6.0

¹Some responses to “have” and “have been diagnosed” were imputed (i.e., changed from “no” to “yes”) when respondents indicated they were under treatment for a headache type but did not indicate that they “had” or “had been diagnosed” with that headache type. Additionally, some responses to “have” were imputed when respondents indicated they had been diagnosed with that headache type.

Notes: Total sample (n) = 2,037.