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RESEARCH SUBMISSIONS

Impact of the COVID-19 pandemic on people living with migraine: Results of the MiCOAS qualitative study

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Abstract

Background: The coronavirus disease 2019 (COVID-19) pandemic is an ongoing global health crisis that has had a range of impacts on people living with migraine.

Methods: Qualitative interviews performed as part of the Migraine Clinical Outcome Assessment System project, a multi-stage Food and Drug Administration–grant funded program to develop a patient-centered core set of outcome measures for use in migraine clinical trials, offered an opportunity to explore the experience of living with migraine during the pandemic as well as to examine whether migraine treatment priorities, symptoms, and associated disability changed due to the pandemic. Semi-structured interviews were conducted in the United States between the summer and fall of 2020 with 40 individuals with self-reported, medically diagnosed migraine who self-reported that they had not tested positive for or been diagnosed with COVID-19.

Results: Seventy percent (n = 28) of the sample reported ≥1 pandemic-related impact on their life with migraine. Fourteen participants reported both positive and negative impacts, twelve reported negative impacts only, and two reported positive impacts only. Among those reporting ≥1 pandemic-related impact, nine participants (32%) reported more frequent and five (17%) reported less frequent migraine attacks. Other negative impacts included interrupted medical care (n = 9; 32%), and greater stress (n = 13; 46%). The most frequent positive impact reported was greater access to health care (n = 8; 29%). Ictal and interictal symptoms were not noted to change due to the pandemic, but some respondents reported less disability due to increased flexibility of schedules and reduced expectations. Treatment priorities did not change due to the pandemic.

Conclusion: The global COVID-19 pandemic has resulted in both negative and positive impacts for people living with migraine. Lessons to be considered when moving into a post-pandemic world include benefits of and satisfaction with telehealth and the benefits and importance of healthy lifestyle habits and flexibility such as improved sleep, reduced stress, and fewer social expectations.

Abbreviations: CHAMP, Coalition for Headache and Migraine Patients; CM, chronic migraine; COVID-19, coronavirus disease 2019; ICHD-3, International Classification of Headache Disorders 3rd edition; MiCOAS, Migraine Clinical Outcome Assessment System; OTC, over the counter; SARS, Severe Acute Respiratory Syndrome; SR-MD, self-reporting a medical diagnosis.

KEYWORDS
coronavirus disease 2019 (COVID-19), Food and Drug Administration, impact, migraine, pandemic, qualitative

INTRODUCTION

The coronavirus disease 2019 (COVID-19) global pandemic has had significant global impact, including on people living with migraine. Severe acute respiratory syndrome coronavirus 2 emerged in December 2019 and COVID-19 was declared a global pandemic in March 2020.[1] The pandemic impacted people both directly (e.g., contracting the virus) and indirectly, particularly as mitigation and containment strategies resulted in dramatic changes in daily work and social habits, and alterations in health-care delivery.[2–4] Migraine is ideally managed with a combination of tailored pharmacologic, non-pharmacologic, and lifestyle interventions.[5,6] Access to most of these types of therapies has been impacted at various times during the pandemic. Data collected via clinician interviews, chart reviews, and web-based surveys of people living with migraine during the pandemic have documented cancellation of face-to-face medical visits and in-clinic procedures, heightened levels of psychosocial stress, social isolation, disruption of sleep and dietary habits, and financial concerns, as well as other issues thought to contribute to increased attack frequency.[4–10] Some studies have also reported perceived benefits to people with migraine including reduced frequency of migraine attacks, improved health-care access primarily via telehealth, the ability to work and attend school from home, increased and improved sleep, and reduced social pressures and expectations for some individuals.[11,12]

To our knowledge, none of the published studies used patient-centered qualitative approaches to characterize the impact of the COVID-19 pandemic on migraine. Our study addresses this gap by capturing the impact of the pandemic on people living with migraine disease through in-depth, individual, semi-structured interviews and qualitative analysis techniques. Qualitative interviews, like those conducted in this study, offer a dynamic approach to data collection, generating valuable conversation and depth of understanding that is difficult to gain from a survey or chart review.

The Migraine Clinical Outcome Assessment System (MiCOAS) project, a multi-stage Food and Drug Administration (FDA)–funded program, is focused on developing a patient-centered core set of outcome measures/endpoints to be used in the development of migraine therapeutics. An early action of the MiCOAS project was to gather input from people living with migraine via qualitative interviews. This research was initiated in the summer of 2020, coinciding with high rates of the virus in the United States and widespread precautionary measures. Therefore, a discussion of the impacts of the COVID-19 pandemic on participants was included as well as assessing whether priorities for attributes of treatments would be affected. The objective of this report is to disseminate key findings regarding the qualitative effects of COVID-19 on people living with migraine who have not contracted COVID-19.

METHODS

Recruitment and sampling

Individuals were recruited through a study announcement disseminated by the Coalition for Headache and Migraine Patients (CHAMP), a patient advocacy organization. Eligible participants were US residents self-reporting a medical diagnosis (SR-MD) of migraine who screened positive for migraine based on the ID Migraine screener (with at least two of the following: disability due to headache ≥1 day in the past 3 months, phonophobia, and/or nausea with headache), were able to complete an interview in English, aged 18–75, and were willing to participate in a 90-minute recorded interview.[13] Exclusion criteria included: (1) patient SR-MD of multiple sclerosis, schizophrenia, bipolar disorder, cognitive impairment, Alzheimer's disease or dementia, or epilepsy; (2) screening positive for alcohol or drug abuse over the past 3 months using the CAGE questionnaire;[14] (3) self-reported diagnosis, symptoms, or hospitalization related to COVID-19.

In total, 428 individuals completed the screener and were eligible for participation. Of these, 40 participants were selected through iterative purposeful sampling including participant demographics and salient headache features designed to ensure participant diversity. The study sample size was selected to ensure concept saturation (i.e., the point during data collection when no new relevant information is identified and additional interviews are unlikely to yield novel concepts). Based on the research team's substantial experience conducting qualitative research and recent methodological research in this area, the research team determined that a sample of $N = 40$ carried a strong likelihood of achieving concept saturation.[15]

Participants completed an online informed consent process during which they read information then checked a box either agreeing or declining to participate. The study was approved by an independent institutional review board (WCG).

Data collection

A screener, sociodemographic and migraine questionnaire, and semi-structured interview guide were developed by the MiCOAS research team. Respondents were not allowed to skip any screener or sociodemographic questions but could select "prefer not to answer" as a response option for several questionnaire items.

Following consent, in the online sociodemographic and migraine questionnaire participants were asked to provide sociodemographic data including age, questions assessing sex ("What sex were you assigned at birth? [check only one]" with response options: male, female, other, prefer not to answer) and gender

("What is your gender [check only one]" with response options: woman, man, trans woman, trans man, genderqueer/gender nonbinary, other, prefer not to answer), race, ethnicity, primary language spoken at home, relationship status, number of other adults in the household, number of children in the household, highest level of education completed, current employment status, and annual household income. They were also asked questions about headache and migraine frequency over the preceding 4 weeks, acute and preventive medications and treatments for migraine and headache, migraine symptoms and criteria, and depressive and anxious symptomology.

Participants were informed during the semi-structured interview of the option to decline answering any question and that they could stop the interview at any time. None of the study participants declined answers or stopped the interview before completion. Therefore, there were no missing data attributed to this study.

Interviews were conducted virtually between July and November 2020 by trained interviewers using a semi-structured interview guide and lasted approximately 90 minutes each. The interview included sections about migraine history, symptomology, and treatment priorities as well as a section on potential impacts of the COVID-19 pandemic in relation to general migraine experience, frequency, treatment and treatment access, attack (ictal) and interictal symptomology and associated disability (daily functioning, cognitive functioning, work, school, family, emotional experiences), changes in symptoms of depression or anxiety, and an opportunity for the participant to share any information related to the impact of the pandemic on their experience with migraine. The acute and preventive medication priorities sections of the interview included a ranking exercise with a list of potential treatment benefits or outcomes such as pain freedom and fewer migraine days per month, respectively. At the end of sections assessing acute and preventive treatment value and priorities, participants were asked if, in light of the current COVID-19 pandemic, they would make any changes to their treatment benefit rankings.

Qualitative data analysis

Audio recordings of the interviews were transcribed verbatim for analysis and coded using a hybrid deductive/inductive approach informed by both a preliminary codebook constructed a priori and open codes, developed iteratively at each interview wave.

Four researchers (AC, AU, MTG, NT) participated in data coding of the primary qualitative data collected. Ten percent of interviews were coded independently by two members of the research team. The passages of text tagged for coding were compared across team members. For transcripts where agreement among coders regarding code attribution (i.e., which codes to attribute to which passages of text) was less than 85%, discrepancies were reviewed and addressed through research team consensus. The research team met no less than bi-weekly throughout the study to discuss coding and address any questions or issues that may have arisen during the coding process. All coded passages were reviewed by a senior member of the research team with significant experience in coding and analysis of qualitative data (MTG, KM). All interview data were managed using Atlas.ti (v8.0) software.

Where appropriate, frequency counts were utilized to offer a high-level overview of coded content. Concept frequencies and case counts alone do not provide a full picture of the experience of individuals living with migraine as was reflected through their thoughtful insights and observations. Thus, thematic content analysis was undertaken to identify patterns within the data and to categorize coded information into recurrent themes. Concept counts, average treatment priority rankings, and thematic content analysis were used to identify key concepts and themes within multiple domains of interest. An examination of concept saturation was conducted.

Statistical analysis

The characteristics of our study sample were rendered using descriptive statistics (e.g., frequency). All statistical analysis was conducted in R software (v4.1.1).

RESULTS

Participant characteristics

Table 1 provides a demographic and descriptive summary of the participants. Participants ranged from 21 to 70 years of age (mean = 44). The sample was 78% female, 68% White, and 53% did not have a college degree. Slightly more than half of participants (55%) were employed. Participants had ≥2 monthly headache days on average. Half of participants (*N* = 20) had ≥15 and half (*N* = 20) had <15 headache days per month on average. All participants currently used acute treatment(s) and 88% currently used preventive therapy for migraine.

Concept saturation

Concepts endorsed in each interview wave were measured against previous interview waves to identify the appearance of novel concepts. This process continued for a total of eight interview waves, with each wave containing four to six interviews. Saturation grids were constructed to allow for an examination of first coding appearance by transcript and interview group and to demonstrate increasingly fewer newly cited codes in later stages of interview conduct. An examination of saturation grids demonstrated that 95% of codes related to COVID-19 impacts were identified within the first 55% (*n* = 22) of conducted interviews, suggesting that concept saturation was reached.

TABLE 1 Interview participant characteristics

Variable	Category	Total interview sample (*N* = 40)
Age, *n* (%)	18–24 years old	5 (12)
	25–44 years old	17 (43)
	45–64 years old	13 (33)
	65 years and older	5 (13)
Gender, *n* (%)	Women	31 (78)
	Men	7 (18)
	Genderqueer/gender non-binary, transgender person	2 (5)
Race[a], *n* (%)	White	27 (68)
	Black or African American	9 (23)
	American Indian or Alaskan Native	4 (10)
	Asian	3 (8)
	Native Hawaiian or Other Pacific Islander	1 (3)
	Other[b]	1 (3)
	Prefer not to answer	1 (3)
Ethnicity, *n* (%)	Hispanic	9 (23)
	Non-Hispanic	31 (78)
Relationship status, *n* (%)	Married or partnered	19 (48)
	Not married or partnered	21 (53)
# of other adults in household, *n* (%)	None	8 (20)
	1–2	27 (68)
	3–4	5 (13)
# of children in household, *n* (%)	None	12 (65)
	1	5 (13)
	2 or more	9 (23)
Education, *n* (%)	Grade 12 or GED equivalent	3 (8)
	Associates degree, technical school, or trade apprenticeship; some college (no degree awarded)	18 (45)
	College degree or advance degree	19 (48)
Employment[a], *n* (%)	Paid employment	22 (55)
	Student	8 (20)
	Homemaker	3 (8)
	Retired	6 (15)
	Unemployed	2 (5)
	Disabled (disability or leave of absence for any reason)	10 (25)
	Other	1 (3)
Household income, *n* (%)	Under $22,000	8 (20)
	$22,000 to $49,999	10 (25)
	$50,000 to $99,999	10 (25)
	$100,000 and over	8 (20)
	Prefer not to answer	4 (10)
Migraine subtype by frequency, *n* (%)	<15 headache days per month on average (episodic migraine[c])	20 (50)
	≥15 headache days per month on average (chronic migraine[c])	20 (50)
Average number of headache days per month, *n* (%)	0–1	0
	2–3	6 (15)
	4–7	8 (20)
	8–14	6 (15)
	15–23	18 (45)
	24 or more	2 (5)
OTC or prescription acute pharmacologic treatment (within past year), *n* (%)	Yes	40 (100)
Current preventive pharmacologic treatment, *n* (%)	Yes	35 (88)
	No	5 (13)

Abbreviations: ICHD-3 CM, International Classification of Headache Disorders 3rd edition, chronic migraine; OTC, over the counter.

[a] Total percent exceeds 100 because participants were able to select more than one race and/or employment status category.

[b] Respondent reported races of “White, South American, and North African” and chose the label “other.”

[c] Chronic migraine was defined as an average monthly headache day frequency of ≥15 per month among people who meet criteria for migraine as per Silberstein-Lipton criteria and episodic migraine was the corollary.[25] It was not possible to assess the ICHD-3 CM criterion of ≥8 migraine days per month in this single visit study, which did not include a diary. Percentages ending in ≥0.5 were rounded up to the next whole number.

TABLE 2 Content areas and examples of the negative impacts of the COVID-19 pandemic provided by participants

Content area	Examples generated by participants	Exemplary quote
Barriers to treatment	Disruption to in-person services (e.g., unable to get onabotulinumtoxinA, nerve blocks, acute injectable treatments)	"I did try Botox. But I only had one round of those. It was one treatment. And then, three months later, COVID started, so Botox—that's the only thing. The reason we switched to Emgality was because I can't go in person to the doctor. They're not—they weren't accepting visits for Botox, so—yeah"
	Difficulty obtaining a new health-care provider as former providers retired or left their practice during the pandemic	"I'm between three clinicians, actually, because of COVID−19. So I was—my first clinician left the practice. And I was between providers, trying to see a new one. And that was scheduled to be in March, and then got transitioned to telehealth, and then that provider left the practice. So I'm now between the provider that I saw for telehealth in March and seeing the next provider, which I actually see this week"
	Delayed and/or backordered prescriptions	"But during the heat of the pandemic, my medications were delayed. Sometimes the pharmacy couldn't get their shipments in or whatever else, and so I would be delayed getting my preventative or any of my migraine-related prescriptions, which was not the best thing"
	Desire to avoid visiting urgent care centers and emergency departments	"I am not going to the hospital as much, because it's riskier than normal. So that's some of the only like big changes is that I refuse the majority—unless it's like super, super-bad, I'm not going to the hospital. I'll just tough it out and be with it or something"
Perceived reasons for increased migraine attack frequency and severity	Disrupted access to preventive treatments (e.g., onabotulinumtoxinA injections) and therapies (e.g., physical therapy)	"When it first started, we had went down to XXXX to visit our family, and then it had broke out, and we were stuck there for a little bit because they were not allowing people through certain places. And I missed my Botox by about—I think it was three weeks late, by the time I was able to come back and get in and get it done. And it, of course, was worse. I was getting them every—back to every other day again, the way I was before"
	Increased stress and anxiety	"I think going out is more anxiety provoking to me than before COVID. And as my anxiety levels come up or stay up for extended periods of time, usually I will see an increase in migraine or headache symptoms as well, so I'm trying to stay calm"
	Less opportunity to engage in preventive behaviors and therapies and challenges with telemedicine	"So I rely on massages a lot to help control the migraines, because a lot of the migraines come from the muscle knots in my neck. And during the beginning of the pandemic, physical therapy and massage therapy was out of the question. And I tried to see my neurologist via telemedicine, but the connection from his office wasn't very strong. And it didn't really work out, so I was forced to go back in … So yeah, it was really disruptive"
Perceived stressors	Mask-wearing mandates in public spaces, lockdowns, restrictions, and other public health policies related to the pandemic	"I think the frequency is greater since COVID and I think that's attributed mainly to wearing the mask. Wearing the mask is very hard for me, because I s—I tend to struggle when I have my face covered anyway, my nose or mouth. I struggle anyway, but putting the mask on me has definitely been a factor. It's increased my headaches. I go outside a lot less because of that reason"
	Closures of school dorms	"I know that sometimes high stress situations—in the same way that high brain power can bother me, high stress can. So before everything shut down, there was a lot of debate—like I don't know what's happening, the news is saying terrible things every day… it was very concerning to me, because I was still in school at the time, that school wasn't shutting down. What if school shut downs? What are they going to do? Are they going to kick me out of my dorm or where am I going to live? All of that was all happening at the same time. And at the same time, that was when I was supposed to be finally getting back to having headache management care, and that all went out the window a little bit"
	Competition for employment	"During this whole pandemic situation, I've had more headaches this year than I've experienced in a long time … I have it at work and then Coronavirus—then that made it even worse because in my state alone there were so many of us unemployed that it was ridiculous. And it's more or less we fighting for employment. And when you be fighting for employment, it makes things more stressful and you're holding your head. I know I've been holding mine. And I'm in and out the doctor''s office, I'm in and out the emergency room. My life has been miserable. Just totally miserable"

Note: Generally it is the practice of the authors and the journal to use generic medication names rather than trade names; however, in this case participants quotes are presented verbatim including medication trade names as they are primary data.

Abbreviation: COVID-19, coronavirus disease 2019.

Key findings

Seventy percent (*n* = 28) of the sample reported ≥1 pandemic-related impact on their experience with migraine, compared to 30% (*n* = 12) who did not. Perceived COVID-19 pandemic-related impacts included both negative (Table 2) and positive impacts (Table 3). Fourteen participants reported both positive and negative impacts, twelve participants reported negative impacts only, and two participants reported positive impacts only.

Negative pandemic-related changes

Among the 28 individuals reporting pandemic-related migraine impacts of any kind, 93% (*n* = 26) reported at least one negative pandemic-related change in their experience with migraine. Increased stress (*n* = 13; 46%), increased frequency of migraine attacks (*n* = 11; 39%), disrupted access to health care (*n* = 9; 32%), and increased attack severity (*n* = 9, 32%) represented the four most frequently reported negative impacts. Perceived negative impacts on health care included disruption of interventional treatments that required in-person contact (e.g., onabotulinumtoxinA injections and nerve blocks), concerns about losing health-care providers, reluctance to use urgent care/emergency departments, and difficulty obtaining certain medications due to shortages (Table 2). Barriers to health care, as well as pandemic-related stress, anxiety, and mask wearing were perceived to be associated with increased migraine attack frequency and severity by some.

Positive pandemic-related changes

Among the 28 individuals reporting pandemic-related migraine impacts, 57% (*n* = 16) reported ≥1 positive pandemic-related change in their experience with migraine. Easier access to health care (*n* = 8; 29%; primarily due to increased telehealth options), and decreased frequency of migraine attacks (*n* = 5; 17%) represented the two most often reported positive impacts. Additional indirect COVID-19 pandemic benefits to people with migraine included the ability to work and/or attend school from home as well as having fewer social engagements and reduced expectations. Participants benefited from these pandemic-related lifestyle changes through a reduction in missed activities and reduced guilt, along with greater perceived ability to control their environments, manage their trigger factors, and maintain healthy lifestyles (Table 3).

Generally, respondents did not note changes to ictal and interictal migraine symptoms due to the pandemic. However, *n* = 8 (20%) reported perceived reduction in associated disability and distress, both ictally and interictally, due to the pandemic. This reduction was attributed to more flexibility in work, school, and social expectations, and more control over their schedule and environment. When asked if the current pandemic caused any changes in their ranking of acute or preventive treatment priorities, all responses were negative.

DISCUSSION

Studies of the effect of the 2003 outbreak of Severe Acute Respiratory Syndrome (SARS) in China and Canada, as well as the 2014 Ebola outbreak in Africa, found that quarantine was associated with a range of negative physical and psychological effects, such as post-traumatic stress symptoms and a potential increase in suicide risk.[16–18] Therefore, it was hypothesized that lockdown and stay-at-home orders implemented to mitigate the COVID-19 pandemic could dramatically increase the burden of migraine and could lead to adverse medical and psychological outcomes.[19–21] However, results from our qualitative interviews revealed both positive and negative patient-reported impacts of the pandemic on their experience of life with migraine, including both barriers and improvements in access to health care, increases and decreases in migraine attack frequency and severity, and challenges and improvements in daily living. Negative impacts focused on interruptions to medical care, sometimes resulting in changes to migraine treatments, and increases in migraine attack frequency, barriers to non-pharmacologic and self-care strategies, and psychological stressors due to the pandemic in general and related mitigation efforts and policies. The adoption of telehealth was noted by many as a benefit of the pandemic and alleviated disruption to care, although access to therapies that required in-person delivery, such as onabotulinumtoxinA injections, was impacted. Additional perceived benefits were often attributed to having more control over one's schedule, including the ability to participate in work and/or school from home. Reductions in social pressures and expectations were also noted.

No participants reported that the current pandemic changed their perspective on their priorities for acute or preventive treatments. To our knowledge, this is the first time these concepts have been assessed and reported. Respondents also did not report changes in ictal or interictal migraine attack symptoms, but they shared narratives suggesting a reduction in disability of attacks, often related to greater control over one's schedule, fewer expectations, and the ability to work and/or attend school from home.

Perceived challenges and benefits generated from participants in the MiCOAS qualitative interviews generally aligned with reports from other published studies of the indirect impacts of the pandemic on people living with migraine from countries including China, Lebanon, Italy, and the United States, with some differences.[7–11] A survey of 1018 people with migraine recruited from a headache clinic registry and via social media from July 15 through July 30, 2020, in Kuwait generally found more negative impacts of the pandemic.[7] They found that 59.6% reported increase in migraine frequency, 10.3% reported that they had developed chronic migraine, and only 16.0% reported a decrease in frequency. Unlike our findings, 61.5% of their respondents reported not communicating with their neurologist, which may be a sign of limited or no telehealth opportunities. In addition, 58.7% reported an overuse of analgesics and 66.1% reported negative perceived impacts specific from cancellation of onabotulinumtoxinA injections. Our study participants

TABLE 3 Content areas and examples of the positive impacts of the COVID-19 pandemic provided by participants

Content area	Examples generated by participants	Sample quote
Positive general life impacts	Fewer concerns about the need to engage in activities outside the home (e.g., remote work and school, errands, appointments)	"Just that the world kind of has to live the way I have now. Has to stay inside, and things are more accessible to me"
	Reduced guilt over cancelling social events with friends or family	"Because I can't really do much, because I can't go out with friends or go do anything at a theater or like a festival or a concert or something. I guess I am able to just stay home in between and not have to worry about breaking plans as much. But in a way, it's kind of a relief, I suppose"
	Greater access to online services (e.g., delivery services, telehealth)	"There's a lot more online that I couldn't access and I'm afraid will be gone again. But actually, the world's like a better place for me…"
	The ability to work from home and feeling more in control	"You know what, I feel really bad saying this, but in any way, I think the silver lining of pandemic is getting to do everything from home. So I can, to the best of my abilities, control my own environment. So in an office or in a classroom, I can't do my work sprawled on the bed in the dark with an ice hat, but I can do that. So now—so it—again, it sounds so terrible to take something good out of this, but that part has been a little bit easier"
Benefits of telehealth	Improved access to care	"Before coronavirus, I had to go to an emergency room every time that I needed care_that I needed medications to break it. So now that I have it at home, I don't have to do that and I don't have to coordinate with somebody else to drive me and hang out with me for a couple hours and then drive me later. Now I can just be at home, and I don't have to do anything. And I know I'm going to feel better in 15 minutes. And I can just go back to living my life."
	Reduced need for travel to work, medical appointments, etc	"Now, benefits of COVID is (a) I don't have to get in my car in the sun and drive to my doctor"
	Reduced exposure to potential migraine triggers	"I'm like now, I won't have people up on my back with their nasty-smelling perfume. And you know, I—they limit the number of people in the stores. See, this was all perfect for people with migraines, because we_these are things—we're like, I wish people would just stay off my back. I can't—back up, you know? So this helps us greatly. And then they're only allowing a certain amount of people in an area, and this is perfect for people like us"
	Coordination of at-home treatments leading to quicker pain and symptom relief	"So now—so coronavirus actually helped me be able to get the treatment to be—to do it at home, because my doctors didn't want me to be going to emergency rooms"
	Better communication, accessibility, and less travel to health-care professionals	"Again, an improvement. I had asked my doctor to—for phone calls, and now I'm able to not have to travel to see my doctors, which is amazing. And if I need to, I can. But yeah, it's been actually really for the better"

Abbreviation: COVID-19, coronavirus disease 2019.

also shared concerns and negative impacts from cancellations of preventive injective therapies. Seventy-eight percent (78.1%) of the respondents from Kuwait also reported negative impacts on sleep and 79.5% experienced symptoms of depression and/or anxiety. These impacts were mentioned by some of our participants but were not among the most common impacts mentioned. Four percent of participants in the Kuwait study had COVID-19, while we excluded people who had contracted the virus.

Data from 163,176 adult users of the "Migraine Buddy" smartphone application diary between January and May 2020, were analyzed to examine whether changes in stress were associated with changes in migraine frequency.[10] They defined a "stress-related migraine" as one in which stress or anxiety was reported as a trigger or symptom. They found a peak in the proportion of stress-related migraine attacks in mid-March 2020, with 53% of attacks fitting this description. These data are aligned with comments from our qualitative interview participants such as, “I think going out is more anxiety provoking to me than before COVID. And as my anxiety levels come up or stay up for extended periods of time, usually I will see an increase in migraine or headache symptoms as well, so I'm trying to stay calm.” Migraine Buddy also sent a questionnaire on the impact of COVID-19 on migraine experience and management from April to May 2020. This questionnaire was completed by 923 app users. When asked what caused increased stress, some of the responses aligned with our findings. Specifically, access to essentials (food, medication, etc.; 18.7%), and financial concerns (17.8%) were causes identified by Migraine Buddy users, and in our study unemployment and competition for employment was mentioned (which are likely linked to financial concerns). In contrast, the two other most-often mentioned causes of increased stress according to Migraine Buddy respondents (social isolation [22.6%] and information overdose [21.2%]), were not mentioned by our study participants. Rather, our study participants mentioned mask-wearing mandates and other containment measures, such as shelter-in-place orders and closures of school dorms, as sources of additional stress.

In contrast to the aforementioned findings from the Kuwait and Migraine Buddy studies, a review of data from a headache clinic in Genova, Italy found primarily positive outcomes during quarantine. Forty-nine subjects with migraine participated in a phone interview and were asked about their migraine experience from March 10 to May 3, 2021 (during a time of lockdown), compared to their experience the prior 2 months before quarantine began.[10] Migraine experience was measured using a global assessment of migraine severity (GAMS) and a visual analogue scale (VAS). The Italian researchers found significant improvements in both the GAMS and the VAS for migraine during quarantine and a trend toward a reduction of number of triptans used per week. They also found a time-by-depression interaction, which suggested that patients with migraine with lower levels of depression had a better course of migraine during quarantine and people with higher levels of depression had a worse course of migraine during quarantine. While all these studies collected data from roughly the same time period, they varied greatly in methodology, study samples, geography, and focus on topics and variables collected.

One of the most frequently reported benefits in our study related to the use of telehealth. This is consistent with other research findings. For example, more than a thousand ($N = 1098$) people living with migraine completed an American Migraine Foundation survey designed to assess the patient experience of telemedicine for headache care from March to September 2020.[22] More than half had used telemedicine for headache care during that period and almost all respondents (93.8%) were established headache patients. Just over sixty percent (62.1%) rated their experiences as “very good” and 20.7% as “good,” compared to 3.6% who rated their experience as “poor.” The overwhelming majority (89.8%) endorsed that they would like to continue to use telehealth for their headache care. To complement those findings, 225 American Headache Society physicians and advance practice provider members responded to a survey about their experience of using telehealth to treat people with migraine and other headache during the pandemic in the fall of 2020.[23] Participants had ≥2 months of telehealth experience and/or completed ≥50 telehealth visits. Most respondents endorsed that they were “comfortable/very comfortable” treating new patients with headache, follow-up patients with migraine, and follow-up patients with secondary headache via telehealth options. Respondents noted many benefits to patients, including cost reduction, convenience, comfort, and no need to travel. Health-care providers noted some concerns and barriers to telehealth, such as not being able to perform procedures or conduct parts of the neurologic exam, lack of vital sign data, and socioeconomic/technologic barriers, but just over half (55.3%) felt that no-show rates were reduced and 78.7% believed that visit duration remained the same.

This study has limitations. Recruitment through CHAMP's network likely yielded a severely impacted, health literate, and aggressively treated sample of people with migraine as demonstrated by survey research conducted using similar sampling methods.[24] It is possible that their experience and perspectives may vary from those with less frequent and/or less severe migraine. However, the current MiCOAS qualitative respondents are likely to be similar to those who completed the American Migraine Foundation survey, as well as patients seeking headache care in tertiary settings. The interview sample was stratified for episodic and chronic migraine, migraine with and without aura, and socioeconomic variables, but subsample sizes were insufficient to robustly detail differences across groups. US public policies regarding closures, gathering limitations, and mask mandates varied by date and geographic location. Thus, participants who resided in different geographic areas and/or were interviewed at different time points may have experienced different impacts. Finally, these results are from people with migraine who had not contracted the virus; they do not address the experience of the pandemic on people who reported being infected.

Study strengths include the novel methodologic approach. To our knowledge, this is the first qualitative examination of the impact of the pandemic on people living with migraine. This semi-structured data collection methodology allowed for a patient-centered approach to the generation of new information and the capture of data that reflect the pandemic-related barriers and challenges that are most relevant to the lives of people living with migraine disease. We also attempted to include respondents representing a broad range of sociodemographic and headache characteristic variables. Finally, we asked participants some questions that, to our knowledge, have not been reported in other studies of the impact of the pandemic on people with migraine. The results of these questions may provide insights for interpreting related data collected during the pandemic.

CONCLUSION

The MiCOAS qualitative interviews found that the COVID-19 pandemic has had both perceived negative and positive impacts for people living with migraine. Our findings align with some previously collected data and differ from others. There were reports of increased migraine attack frequency, often attributed to stress and interruption to medical care. There were also reported positive impacts including expanded availability and use of telehealth as well as improvements in healthy lifestyle routines and the benefits of increased flexibility offered by remote work/school arrangements. Additionally, reduced social pressures and expectations had a perceived positive impact as well. The positive impacts reported provide important insights for healthcare professionals and people living with migraine alike into what changes were perceived as valuable. It is wise to consider how these benefits may be carried forward into a post-pandemic world.

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CONFLICT OF INTEREST

Dawn C. Buse is a part-time employee of Vector Psychometric Group LLC, which in turn received funds from the FDA to conduct the research detailed in the manuscript. In addition, she receives research funding from the National Headache Foundation and Amgen. She has been a consultant to Allergan/Abbvie, Amgen, Lilly, Lundbeck, and Teva Pharmaceuticals. Maya T. Gerstein was a full-time employee of Pharmerit/OPEN Health, which in turn received funds from Vector Psychometric Group LLC and the FDA to conduct the research detailed in the manuscript. Carrie R. Houts is a full-time employee of Vector Psychometric Group LLC, which in turn received funds from the FDA to conduct the research detailed in the manuscript. James S. McGinley is a full-time employee of Vector Psychometric Group LLC, which in turn received funds from the FDA to conduct the research detailed in the manuscript. JSM has received honoraria/payment/reimbursement from the journal Cephalalgia (biostatistics editor). JSM has also received research grants/support from Amgen, Inc. and the National Headache Foundation. Alyssa A. Uzumcu was a full-time employee of Pharmerit/OPEN Health, which in turn received funds from Vector Psychometric Group LLC and the FDA to conduct the research detailed in the manuscript. Kelly P. McCarrier is a full-time employee of Pharmerit/OPEN Health, which in turn received funds from Vector Psychometric Group LLC and the FDA to conduct the research detailed in the manuscript. Alexis Cooke was a full-time employee of Pharmerit/OPEN Health, which in turn received funds from Vector Psychometric Group LLC and the FDA to conduct the research detailed in the manuscript. Nancy M. Touba is a full-time employee of Pharmerit/OPEN Health, which in turn received funds from Vector Psychometric Group LLC and the FDA to conduct the research detailed in the manuscript. Tracy K. Nishida is a full-time employee of Vector Psychometric Group LLC, which in turn received funds from the FDA to conduct the research detailed in the manuscript. R. J. Wirth is a full-time employee of Vector Psychometric Group LLC, which in turn received funds from the FDA to conduct the research detailed in the manuscript. Richard B. Lipton received research support from the FDA on the MiCOAS project. In addition, he receives research funding from the NIH, the National Headache Foundation, and the Marx Foundation. He also receives research support from Allergan/Abbvie, Amgen, Biohaven, Eli Lilly, and Electrocore. He receives personal fees as a consultant or advisor from Allergan/Abbvie, Amgen, Biohaven Holdings, Dr. Reddy's, GlaxoSmithKline, Grifols, Eli Lilly, Lundbeck, Merck, Novartis, and Teva Pharmaceuticals. He holds stock or options in Biohaven Holdings and CtrlM Health. In addition, he receives royalties for *Wolff's Headache*, 7th and 8th editions.

AUTHOR CONTRIBUTIONS

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