

## Background & Objectives

- The Migraine Clinical Outcome Assessment System (MiCOAS) is a multi-stage NIH-FDA grant focused on integrating patient input into the development of clinical trial outcomes and endpoints.
- An early action was to gather input from people living with migraine via qualitative interviews, including the effects of the COVID-19 pandemic on the lived experience of people with migraine who had not had COVID-19.
- We examined the perceptions of the impact of the COVID-19 pandemic on a sample of people living with migraine during the summer and fall of 2020.

## Methods

- Individuals with self-reported, medically-diagnosed migraine were recruited through a voluntary organization, the Coalition for Headache and Migraine Patients (CHAMP) for participation in qualitative interviews.
- Exclusion criteria included symptoms of and/or hospitalization for COVID-19 or a positive test.
- N=428 individuals responded to the study screener and were determined eligible, of whom 40 were selected through iterative purposeful sampling to meet predetermined quotas for headache days per month and participant diversity.
- Selection for participant diversity entailed consideration of a number of variables, such as age, race, gender, employment status, and household composition to ensure a wide selection of lived experiences were represented in the qualitative data.
- Interviews were conducted virtually between July- November 2020 using semi-structured interview guides. Potential impacts of the COVID-19 pandemic were assessed with open ended questions and probes.
- Interviews were transcribed verbatim and coded using a hybrid deductive/inductive approach.
- Thematic content analysis was applied to identify key concepts and themes.

## Results

- Participant ages ranged from 21-70 (mean=44). The sample was 77.5% female, 67.5% white, and 55.0% employed.
- 100% of participants currently used acute treatment(s) and 87.5% used preventive therapy for migraine.
- Perceived COVID-19 pandemic related impacts included both positive and negative changes to care access and treatments, frequency and severity of migraine attacks, daily life, and emotional functioning (see Tables 1 and 2).

## Results (continued)

- Generally, migraine symptom profiles, disease impacts, and treatment priorities did not change due to the pandemic.
- Perceived impacts on care included both disruption to interventional treatments which must be performed in person as well as expanded access and convenience of healthcare via telehealth. There were also concerns with losing providers, a desire to avoid urgent care/emergency departments, and difficulty obtaining certain medications due to backlogs (Table 1).
- It was perceived that several variables lead to increased migraine attack frequency and severity, such as barriers to access as well as increased stress and anxiety (Table 1).
- Conversely, participants reported some perceived benefits secondary to the pandemic, including the ability to work and attend school from home and having fewer social engagements and expectations leading to reduced missed activity, reduced guilt, and an improved sense of control over one's life (Table 2).

**Table 1. Content areas and examples of the negative impacts of the COVID-19 pandemic provided by participants with migraine**

Content thematic area	Examples given by participants
Perceived barriers to migraine treatment due to the pandemic	Disruption to in person services (e.g., unable to get OnabotulinumtoxinA, nerve blocks, acute injectable treatments)
	Difficulty obtaining a new healthcare provider as former providers retired or left their practice during the pandemic
	Delayed and/or backordered prescriptions Desire to avoid visiting urgent care centers and emergency departments
Perceived reasons for increased migraine attack frequency and severity due to the pandemic	Disrupted access to preventive treatments (e.g., onabotulinumtoxinA injections) and therapies (e.g., physical therapy)
	Increased stress and anxiety Less opportunity to engage in preventive behaviors and therapies
Perceived stressors due to the pandemic	Mask-wearing mandates in public spaces, lockdowns, restrictions and other public health policies related to the pandemic
	Closures of school dorms
	Competition for employment

**Table 2. Content areas and examples of the positive impacts of the COVID-19 pandemic provided by participants with migraine**

Content thematic area	Examples given by participants
Benefits of telehealth due to the pandemic	Improved access to care via telehealth
	Reduced travel
	Reduced exposure to triggers
	Coordination of at-home treatments leading to quicker pain and symptom relief Better communication with providers
Positive general life impacts due to the pandemic	Fewer concerns about the need to engage in activities outside the home (e.g., remote work and school, errands, appointments)
	Reduced guilt over canceling social events with friends or family
	Greater access to online services (e.g., delivery services, telehealth)

## Conclusions

- Participants reported a range of positive and negative effects of the COVID-19 pandemic and local stay-at-home orders on access to care, changes to treatment, changes in migraine severity and frequency, and as well as challenges and improvements in daily living.
- Migraine symptom profiles, disease impacts, and treatment priorities were not reported to be affected by the pandemic.

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