BURDEN OF MIGRAINE

The Impact of an Invisible Disease

Final report from a survey on the effects of migraine on quality of life.





LIVING WITH MIGRAINE: REAL WORDS. REAL IMPACT.

"My quality of life is greatly affected by my migraines. I'm not living, I'm existing."

"Nobody understands how disabling they [migraines] are. That I would give anything and do anything to make them go away. There has been no treatment so far that I have said no to. My body has gone through so much. I am so tired of pain. At times I feel like life is just passing me by. I didn't think that this would be my life."

"It is rarely acknowledged that migraine is an incurable disease that has an impact, for many of us, 24/7/365. It can control every aspect of our lives both during and between attacks. Over time, this disease burden becomes harder and harder to carry. I rarely hear this cumulative effect discussed."

"I have lost so much to this disease. If feels like I'm alone, fighting for myself so often."

"I hate my migraines. I think I could be leading a completely different life without them. I can't be ME... Every single day for me revolves around trying not to trigger a migraine. It is exhausting!"



"I just wish people knew that all we want is to be "normal" - go to work, do housework, and be an average person. I hide the pain I feel so I can fit in."

"This is an incredibly misunderstood, stigmatized disability. I feel like I spend just as much energy defending and 'proving' the fact that I'm truly ill as I do coping with the symptoms."

"I often feel very sad and disappointed in myself because of migraine. I feel like I could have a much fuller life with less migraine. I can't exercise like I should because of migraine. I'm hesitant making plans because I may have to cancel or decide to show up anyway with my game face on and fake my way through it. Ugh."

"This terrible, unforgiving illness is a living nightmare... Despite taking meds and vitamins and minerals, I know no days without pain in my head."

"I truly believe that the health care system treats women with migraines like it's a cross we have to bear. If men were the primary people that had migraines I believe we would have better options. I also feel that there is a certain amount of 'gaslighting' that goes on when women report their migraines. Like it's not as bad as we say. We aren't taken seriously."

"It's a long, frustrating journey. It's hard to get doctors to take chronic pain seriously and the treatment options are limited. I wouldn't wish this on my worst enemy."



"It's heartbreaking to see the lack of knowledge and compassion that we encounter, we have to beg and push for more treatments and medication to helps us, we are continuously being looked at like attention seeking, depressive/anxious patients, drug seeking addicts. We are not taken seriously and it takes many months or years for a diagnosis, acute treatment at home or preventatives."

"I wish it [migraine] was actually called a disease in Canada so we would be treated with respect like anyone else suffering with a labeled disease."

"It is very lonely and isolating as nobody, even medical professionals, seem to understand. You constantly feel guilty for not being able to work/help out/... and generally feel like a failure. The fact that you have to pay out of pocket for very expensive medication makes you feel like insignificant and that you should just be able to deal with it."

"I wish people would truly understand what this is like. The term migraine gets tossed around a little too lightly for my liking, and it needs to stop. I realize that there are different degrees and severities of migraine, having been a sufferer all of my life, but when you can't even stand up most of the time due to the pain - it's a different situation than taking an Advil and relaxing."

"It has changed my entire life. It has caused despair and hopelessness. It has alienated me from friends and family that do not understand."



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EXECUTIVE SUMMARY

It is estimated that approximately 12% of Canadians live with migraine, a neurological disorder characterized by recurrent attacks of head pain, sensory hypersensitivity, and gastro-intestinal disturbances, as defined by the International Classification of Headache Disorders.

Living with migraine significantly impacts the ability to function and quality of life. Migraine attacks are painful and debilitating, leaving no choice but to retreat to a dark room alone and put all plans for the day on hold. Migraine attacks steal life, one day at a time, over decades. When the frequency exceeds 15 days per month, the term "chronic migraine" is used, representing 1-2% of the population at the severe end of the spectrum.

For people with migraine, the burden is significant and the road to effective care is long. The stigma on migraine is well established and adds to the burden. Many individuals describe living with depression, anxiety, sleep disturbances and low self-confidence— psychological impacts of living with a chronic condition, searching for a diagnosis, and trying to find a medication that controls the disease.

Migraine does not discriminate. It affects children, women, and men worldwide. As you will read, this condition impacts every aspect of an individual's life, including their ability to work and maintain social and intimate relationships.

In October 2021, Migraine Canada launched its Quality-of-Life survey. By gathering the feedback of people across Canada who live with migraine, we sought to better understand their experience and the impact that both chronic and episodic migraine have on people's lives. The survey collected patient data on demographics, diagnosis, management, employment, quality of life, health and wellness. The results highlight the unique journey of each patient and validate the shared experiences across the spectrum.



KEY FINDINGS

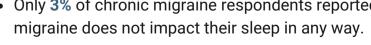
The survey found several issues with the ability of migraine patients to access specialists and information regarding their disorder. Many respondents waited years from the onset of symptoms to receive a diagnosis of migraine. Individuals suffering from migraines continue to see general practitioners or family physicians most often for treatment, which presents challenges given the lack of knowledge about migraine within this healthcare profession.

Survey responses demonstrate the harmful effects of migraine on an individual's quality of life. From sleep deprivation to deteriorating social relationships, people with migraine are shouldering an immense burden that goes unseen and under-recognized.

SLEEP

- Overall, 84% claimed migraine negatively impacted their sleep.
- 32% of chronic migraine respondents reported their sleep is disrupted for more than half of the month.
- About 40% rated their quality of sleep as poor or very poor and 37% noted it was often disrupted.
- Only 3% of chronic migraine respondents reported

"I am suffering so much, and I feel like there is no hope."



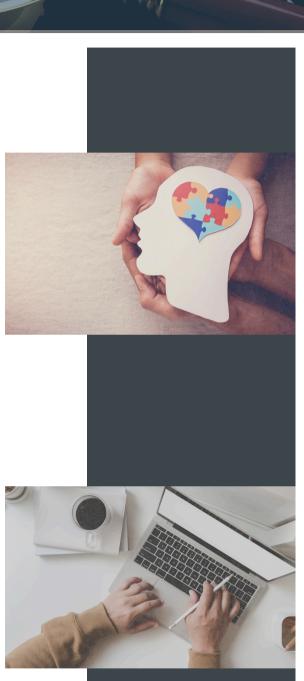


MENTAL HEALTH

- Close to 93% of respondents with chronic migraine, and 80% of those with episodic, said they believe their migraine has led them to develop symptoms of depression and/or anxiety.
- Over 60% of episodic migraine patients and 80% of chronic patients reported worrying about migraine on 6 or more days of the last month.
- **33**% of chronic migraine patients reported worrying about migraine on 25-30 days of the last month.

ABILITY TO WORK

- Half of migraine patients are worried about their family's financial stability because of migraine.
- Patients reported that migraine has had an impact on:
 - career choice (22%)
 - ability to remain in a work position (25%)
 - ability to find work (11%)
 - education (20%)
- Only 13% report it not having an impact on their career.
- Close to 25% of people with chronic migraine are on short or long term disability.





SOCIAL LIFE & RELATIONSHIPS

- 90% of patients reported avoiding interacting with other people due to migraine.
- 86% said they feel like a burden on others because of migraine.
- 91% indicated feeling a lack of control over their life because of migraine.
- Of those with children, **93**% reported missing quality time with their kids.
- **69**% report some negative impact on their relationship with their partner.



"Migraines and their life-altering effects are so hidden; loved ones don't see me when I am at my worst hiding in the dark with my head wrapped in ice or sitting up at 3 a.m. when the pain makes it unbearable to sleep. They might see me at family gatherings where they don't realize I am forcing a smile on my face and 'sucking it up' while counting the minutes until I can leave."

"It is an utterly lonely, debilitating and soul sucking disease. It takes away everything and is extremely hard to navigate and make people understand. It is not just a headache and if I just had a headache I'd be happy with that."



RECOMMENDATIONS

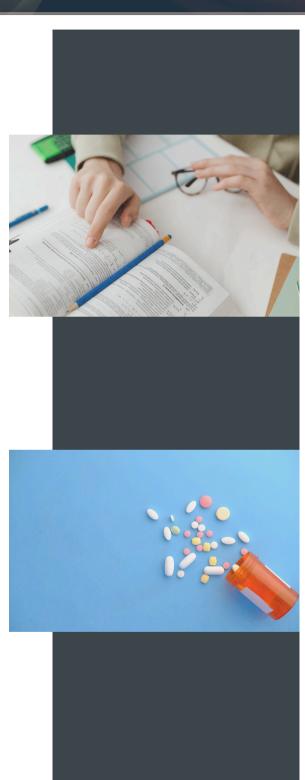
Based on the above findings, Migraine Canada proposes the following recommendations be implemented to support the community, reduce the burden of this invisible disease, and ultimately improve health outcomes.

1. Improve Knowledge.

- Improve the education of health professionals including Primary Care Providers, allied health care providers and specialists, starting at an early stage of training.
- 2. Make headache medicine a mandatory requirement in the Neurology training objectives of the Royal College.
- 3. Ensure that every Neurology department offers academic positions for headache medicine.
- 4. Undertake public awareness campaigns to reduce stigma and increase the knowledge of the general public about migraine.
- Increase recognition that migraine can cause significant disability and that those with migraine may need appropriate accommodation in the workplace.

2. Improve Management.

- 1. Promote early migraine diagnosis.
- 2. Adopt a chronic disease management model, including therapeutic education and behavioural approaches, patient empowerment and shared decision making.
- Optimize the use of acute migraine therapies and prevent medication overuse through better patient education and long-term follow up.
- 4. Optimize the use of migraine preventive therapies.





RECOMMENDATIONS - CONTINUED

3. Improve Access to Treatment.

- 1. Improve reimbursement coverage, and criteria, on both public and private plans making access to new, safe, effective and tolerable treatments a reality.
- 2. Ensure equitable access to treatment and medication irrespective of where you live.
- 3. Remove restrictions that limit access to just six doses per month of Triptans.
- Ensure devices and injections are included as part of treatment options and coverage on provincial and private and public in drug plans.
- 5. Consider combination therapy for inclusion in drug plans.
- 6. Implement a nation-wide model of care with well-defined roles at all levels of care in an interdisciplinary vision.
- 7. Implement specialized multidisciplinary clinics for refractory patients with access to multidisciplinary teams and advanced procedural care.
- 8. Support investment in migraine research to provide better treatment options in the future.

This report aims to improve health outcomes for Canadians with migraine and provide a basis for future assessments of progress towards optimizing care and improving quality of life of Canadians with migraine.



ABOUT US

Migraine Canada is a federally registered charity. It is the only national organization in Canada solely focused on supporting all Canadians across the country who live with migraine. Migraine Canada plays an essential role in supporting people through diagnosis and disease management so they achieve their full health potential and improve their quality of life. The vision of Migraine Canada is to ensure all Canadians living with migraine and headache disorders are diagnosed, treated, and supported so their quality of life is optimized. Its mission is to improve the lives of Canadians with migraine and other headache disorders through awareness, support, education, advocacy, and research.



BACKGROUND: UNDERSTANDING THE INVISIBLE DISEASE OF MIGRAINE

Epidemiology of Migraine

Migraine is very common. A Canadian study found that **15.2**% of females and **6.1**% of males in Canada had been diagnosed with migraine by health professionals (Jette, 2007). This is likely an underestimate of how many Canadians have migraine, as often those with migraine do not seek the advice of health professionals, and when they do, they may not be diagnosed. Another Canadian study which diagnosed migraine based on a questionnaire found that **21.9**% of women and **7.4**% of men had experienced migraine attacks in the previous year. For women aged 35 to 50 almost **30**% experienced migraine attacks (O'Brien, 1994).

In women, migraine attacks often start when menstruation begins, and frequently improves after menopause; although some women and men continue to have migraine attacks into advanced old age. Migraine attacks show a relationship with hormonal factors in many women, with the most severe attacks occurring pre-menstrually, and migraine often improves during pregnancy.

Between 1% and 2% of the general population has chronic migraine, with headache on more than 14 days a month, and often every day or almost every day. Most people who develop chronic migraine have suffered from intermittent migraine attacks for years before their migraine worsens and gradually enters a phase where they have headache on "more days than not." Although the exact reasons why approximately 1 in 10 people with migraine develop chronic migraine are not known, several factors increase the risk of chronic migraine (Torres-Ferrus, 2020). These include obesity, major stress, acute migraine medication overuse, and heavy caffeine use, among others. There is the potential that the number of people who suffer from this very disabling disorder can be reduced by attention to these exacerbating factors, although it may well be that the genetic makeup of some with migraine predisposes them to the development of chronic migraine. There is some evidence that treating migraine effectively reduces the risk of developing chronic migraine.

"I had to leave my dream job and settle for something I like but it isn't what I love because of my chronic migraine. It impacts my family, social life, work life, every aspect of my life. I got sick on my wedding day. It controls my life."

Epidemiology of Migraine - Continued

Migraine is comorbid with many other diseases (Buse, 2020). Comorbidities and co-occuring conditions (hereafter referred to as comorbidities) contribute to the overall burden of migraine. Diseases are said to be co-occurring if the same person has more than one disease. Comorbidity is the greater than chance association between the two conditions in the same individual. There are many comorbidities associated with migraine including:

- cardiovascular disorders such as stroke, myocardial infarction. (Mahmoud, 2017)
- psychiatric disorders (e.g., depression, anxiety, panic disorder, bipolar disorder, personality disorders, suicide attempts) (Jette, 2007)
- neurologic diseases (e.g., epilepsy), sleep conditions (i.e., insomnia, restless leg syndrome, sleep apnea, poor sleep quality and duration) (Buse, 2019)
- inflammatory conditions (e.g., allergic rhinitis, asthma) (Martin, 2016)
- as well as chronic pain conditions (e.g., fibromyalgia) (Nuyen, 2006)
- among many others . (Wang, 2017)

Many comorbidities have been identified as risk factors for progression to chronic migraine and recent work has shown that the combination of comorbidities or "multimorbidity" is associated with medication overuse and new onset chronic migraine (D'Amico, 2018).

Migraine is a key risk factor for the development of persistent headaches after a traumatic head injury. Post-traumatic headache may occur in a person with pre-existing migraine or post-traumatic headache with migraine features may develop in people without a previous history of migraine.



The Cause of Migraine

Migraine results from an altered brain physiology and chemistry, and the ultimate cause of migraine is genetic. However, many factors over a person's lifetime affect how frequent the migraine attacks will be. Twin studies have confirmed that there is an important genetic component in migraine causation, but it is only one of the factors that determine how migraine will affect any given individual. Genetic factors account for about 50% of the risk that an individual will develop migraine attacks (Ziegler, 1998).

Changes in many different genes seem able to increase the tendency to have migraine attacks. Because different individuals with migraine have different combinations of the genetic changes that produce the migraine tendency, the manifestations of migraine can vary greatly from one person to another, as can their response to medications for migraine.

Patients with migraine are often told that "it's all their head" since imaging is usually normal. This is a harmful concept, as it suggests that psychological factors are causing the migraine symptoms and reinforces the stigma. It is essential for stakeholders to understand that migraine is a neurological disease and that research has made significant progress in understanding its causes over the last few decades.



The Cause of Migraine - continued

Elements of migraine pathophysiology demonstrated in research:

- Disorder of sensory filters: the brains of those with migraine tend to be more sensitive (hyperexcitability and lack of sensory inhibition) than is the case in those without migraine, and migraine has been described as an abnormality in the way the brain responds to sensory stimuli (Amoozegar, 2022). Sensory hypersensitivity to different stimuli is part of the migraine attack, but some degree of hypersensitivity may persist in between attacks
- Activation of brain zones during attacks: numerous studies have shown increased nerve cell activity in several parts of the brain during migraine attacks, including the hypothalamus, the trigeminal nucleus and the dorsal pons.
- Triggers related to oxidative stress and energy metabolism: many known triggers of migraine attacks are related to oxidative stress, or increased energy demands on the brain system. Triggers are known to be additive and the migraine attack is thought to occur when a certain threshold is reached.
- Cortical spreading depression: the aura is thought to be caused by a wave of intense nerve cell activity spreading over the cortex (the surface of the brain). This is well demonstrated in animal studies.
- Sensitization, peripheral and central: after repeated activation, for example by many migraine attacks, the pain neurons and brain networks can become sensitized and start reacting to smaller stimuli than normal. This phenomenon is seen in migraine and in other chronic pain disorders.
- Neurogenic inflammation and peptides: the pain from migraine is now thought to originate from the nerves in the meninges and arteries inside the skull when they are stimulated by inflammatory peptides released during the attack. The pain is felt in areas such as forehead, temples, and eyes, but also the neck, sinuses, and jaw.

Diagnosis of Migraine

There is no blood or x-ray test that doctors can use to diagnose migraine, and the physical examination in the doctor's office is usually normal. The diagnosis is made based upon the patient's symptoms. The International Headache Society has produced criteria for the diagnosis of migraine (Headache Classification Committee, 2018).

Migraine without aura is the most common type of migraine, but there are others as well. Some people with migraine have migraine with aura attacks. These are usually visual in nature and take the form of bright wavy lines or spots, although some patients experience mainly blind spots in their vision with temporary partial visual loss.

When people see a doctor for help with their headaches, they usually have migraine because migraine is so common, and the attacks are often quite severe. Nevertheless, migraine is under-diagnosed, as those with migraine do not always receive a diagnosis of migraine. To assist with migraine diagnosis, a screener has been developed. If people with headache answer "yes" to two of the three questions in Table 1 below, and have a normal neurological physical examination, the chances are very high that they have migraine (Torres-Ferrus, 2020).

Table 1: The ID Migraine Scanner

During the last three months, did you have any of the following with your headaches?

Are you nauseated or sick to your stomach when you have a headache?

Does light bother you when you have a headache?

Has headache limited your activities for a day or more in the last 3 months?

A positive response on 2 of 3 questions yields a positive predictive value of 93%



SURVEY RESULTS: IDENTIFYING THE BURDEN OF MIGRAINE

Methodology

Migraine Canada developed this Quality-of-Life survey to better understand how the lives of Canadians are impacted by their disease emotionally, physically, socially, and professionally. The criteria to participate in the survey was to have a diagnosis of migraine. The survey ran in September and October 2021 and was completed by 1,144 Canadians, who all confirmed they have a diagnosis of migraine.

The ICHD-3 classification uses monthly headache days to designate subgroups. This traditional approach distinguishes episodic migraine (14 or less days per month) from chronic migraine (15 or more days per month). This dichotomy is somewhat misleading, since this 15-day limit is arbitrary. Migraine is a spectrum of frequency and patients often vary in their monthly frequency over months and years.

Participants were asked to choose the monthly frequency that applied to them, with a 4-quartile choice: 1-7, 8-14, 15-22, 23-30 days per month on a mean. For the presentation of results, we separated the participants into two groups, episodic (1-14 days per month) and chronic (15-30 days per month).

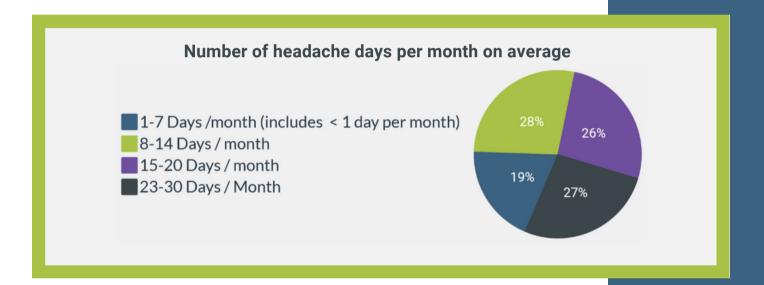
Before the survey was launched, it was reviewed and tested by patients for clarity, comprehensiveness, and to ensure the survey would capture the experience of individuals who live with chronic or episodic migraine.

Not all questions were mandatory, so the statistics included in the report are representative of the number of respondents who answered the question.



Demographics

The results revealed that 536 respondents reported experiencing episodic migraine (1-14 headache days per month) and 608 participants reported having chronic migraine (15-30 headache days per month).



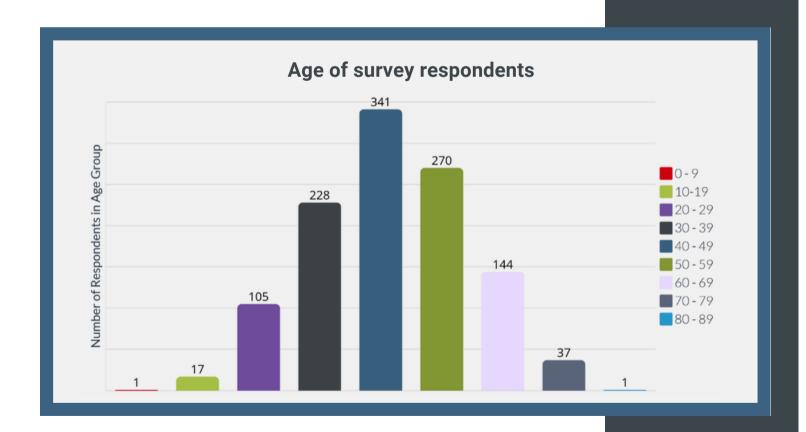
Of all survey participants, The vast majority of participants (91%) identified as female, 8% as male, and 1% as non-binary, transgender, two-spirit or other,

"I have lost family and friends because I can't get them to understand that migraine is different from a headache. I hate depending on my husband for everything. If something happens to him I worry I can't care for him."



Demographics - continued

Migraine affects all age groups, but has the greatest impact on those in their prime of work and family life. This was reflected accurately in the age distribution of survey respondents, which ranged from young children to seniors with the greatest response from adults aged 30-59 (73% for episodic migraine; 74% for chronic).





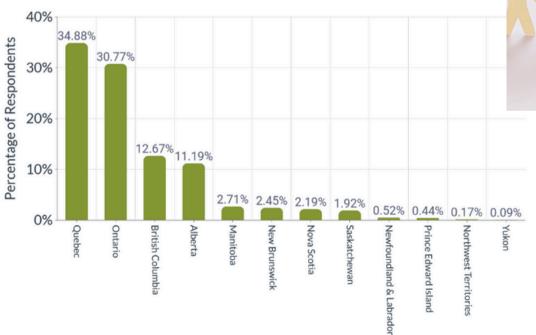
Demographics - continued

Participants reflected a number of ethnicities, identifying as Métis, Black, First Nations, Latin American, Arab, South Asian, Filipino, Chinese, West Asian, Pacific Islander, and Japanese; the majority of respondents were white.

The survey achieved national representation by respondents, with the greatest number of responses from our most populous provinces: Ontario (30%), Quebec (34%), followed by BC (12%) and Alberta (11%).



Location of respondents (by province)







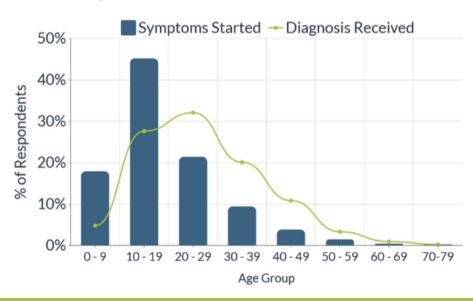
All individuals who participated in the survey (100%) reported having been diagnosed with migraine by a healthcare provider.

Diagnosis and Management

Access to effective care for migraine requires that people receive an accurate and timely diagnosis. Unfortunately, there is a significant gap between the time when people first experience migraine attacks and when they obtain a diagnosis.

Irrespective of the type of migraine (episodic or chronic), most respondents first experienced migraine symptoms between ages 10 and 19 (45%), yet less than 30% of survey participants were diagnosed before the age of 19. The majority of respondents reported that diagnosis of migraine did not occur until they were in their 20s and 30s (40%), with some waiting until into their 40s for a diagnosis (11%).

Symptoms started vs diagnosis received





"It's unfortunate that it took me so long (**20 years**) to get properly diagnosed and to get the prescription I needed!"

Diagnosis and Management -continued

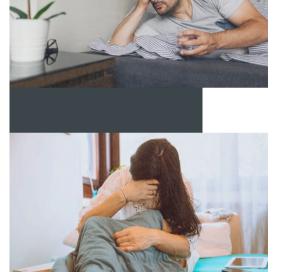
This is problematic not only for the negative impact on quality of life during the years when an individual is seeking medical support, but also due to the possible contribution that delayed diagnosis can have on disease progression. Since lifestyle factors such as stress and poor sleep and medication overuse headache can contribute to increased frequency of migraine attacks, someone experiencing episodic migraine who is not diagnosed and is ineffectively treated risks progressing to chronic migraine. Those who have suffered from migraine in the earlier years of their lives (before the age of 19) are more likely to report chronic migraine, whereas the headache characteristics of those who experience migraine attacks for the first time at age 40 or older do not experience as severe headache pain occurrences. (Katsarava 2011)

"I have lived with migraine all my life. It was horrible as a child to not be believed: when I said I had headaches, I was told I was too young to have headaches. I was forced to push through the pain, and had extreme difficulty concentrating in school and doing homework."



Diagnosis and Management -continued

A common misconception is that migraine is "just a headache". While the throbbing headache pain of migraine is debilitating, other symptoms such as extreme sensitivity to light, sounds or smells, nausea and vomiting may contribute significantly to a reduced quality of life. This is especially true for those with chronic migraine. Survey respondents with chronic migraine reported a greater number of days when they have symptoms related to migraine but no head pain than those with episodic migraine. In fact, nearly half with chronic migraine have other symptoms but no headache on 8 or more days per month. Over 20% said they have other symptoms on 23-30 days per month. This group rarely feels well.



"Episodic migraine was one thing. It was possible to cope with occasional attacks, as bad as they were. Chronic migraine is a completely different thing. It has affected every area of my life. I had to drop out of school, I stopped working toward the career that I care passionately about, and I even had to stop volunteering. I am in pain and utterly exhausted every day."



Support from Healthcare Providers

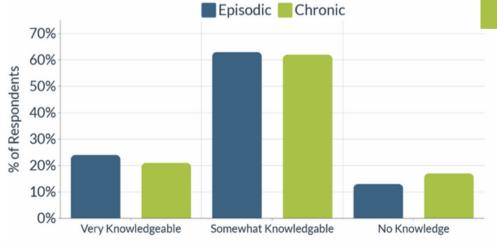
Care from a qualified and supportive healthcare provider can help migraine patients better understand their disease and feel well through effective treatment and lifestyle modifications. The challenge for patients is finding a provider who understands and is willing to treat migraine in a timely fashion.

Most survey participants reported that current treatment is provided by a general practitioner (GP): **69**% of episodic migraine patients and **63**% of chronic migraine patients. However, when asked whether their GP was knowledgeable about migraine management, nearly two-thirds of respondents felt their GP was only "somewhat" or "not" knowledgeable. This aligns with commentary from medical professionals who say that teaching and clinical exposure on headache and migraine for physicians is minimal.



Only **23**% of respondents for both types of migraine found their NP or GP to be very knowledgeable.

Knowledge level of GP or NP on migraine

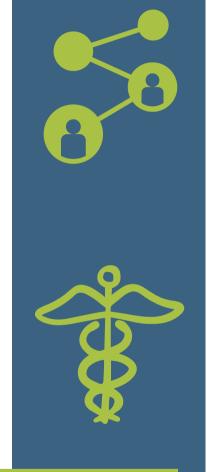




Support from Healthcare Providers - CONTINUED

If GPs are not comfortable diagnosing or managing migraine, they refer patients to neurologists or headache specialists. Not surprisingly, those with more severe disease are more likely to be treated by a specialist, with 78% of chronic patients indicating they see a neurologist or headache specialist and only 43% for episodic patients.

The survey confirmed that referrals to specialists are most often initiated by the patient's primary care provider; however, a surprisingly large number of patients indicated that the referral was made only because they requested it (34% for episodic patients, 37% for chronic patients). A referral does not guarantee improvement. The number of specialists available to treat migraine patients is low. The Canadian Medical Association reported in 2019 that only 2.9 neurologists were available per 100,000 Canadians.



"Daily headache pain makes you feel like you are in a fog. I grieve the decreased cognition, thinking, recall." Almost 10% of people with chronic migraine travel between 150km to more than 300km to see a neurologist or headache specialist.



Support from Healthcare Providers - CONTINUED

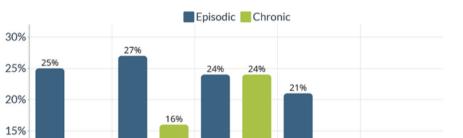
% of Respondents

10%

5%

0%

When asked about wait times to see а 23% of specialist, chronic patients waited from 12 months more than 18 months for their appointment. Once management has begun with a specialist, the frequency of visits varies.



Every 4-6 months

Frequency of visits with a specialist

Over **43**% of chronic patients see their neurologist or headache specialist every 2-3 months. Episodic patients (**25**%) are more likely than chronic patients (**12**%) to see their headache specialist less than once per year.

The lack of specialty care also means that many patients must travel great distances to access a specialist. Roughly **23**% of respondents travel 50km or more to see their neurologist or headache specialist. Almost 10% of people with chronic migraine travel 150km to more than 300km.

A referral does not guarantee effective care. Many patients see several different practitioners as they seek improvement. About **27%** of chronic migraine patients reported seeing 4 or more specialists over the course of their disease, while **19%** of episodic patients saw 4 or more specialists.

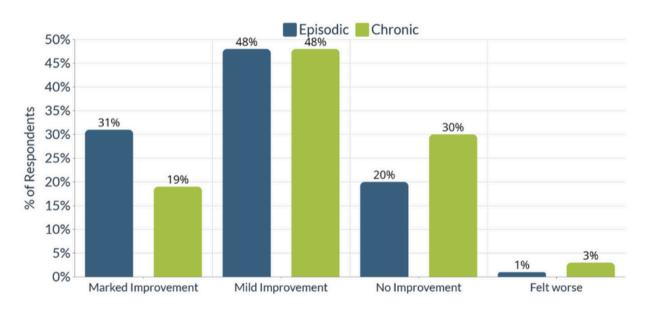


Support from Healthcare Providers - CONTINUED

When we asked participants if their medical care—whether with a specialist or not—has led to an improvement in their quality of life, the results were discouraging. About **30**% of episodic migraine patients reported a marked improvement, but less than **20**% of chronic patients did so. Just under **50**% of both episodic and chronic migraine patients reported a mild improvement. Sadly, **30**% of chronic migraine patients and **20**% of episodic patients have had no improvement from the care they've received.

Unfortunately, a significant number of migraine patients do not have the support of a healthcare professional, with 13% of episodic patients and 5% of chronic patients indicating they do not have a healthcare provider.

Improvement to quality of life due to care recieved





"Many neurologists I have seen don't specialize in migraine and therefore have no interest in helping me. We need more neurologists and headache specialists that specialize in migraine."

"Early treatment for migraine is paramount. Physicians need training in headache in all specialties to recognize and refer to a headache specialist when they see the signs of migraine and headache disorders."

"It also took me a long time to find doctors familiar and competent with migraines. I saw two neurologists who were no help at all, before someone gave me the name of a migraine expert in my area. Now I have moved, and the local migraine expert has a 5+ year waiting list."

"I never realized it would be so hard to find a doctor who is supportive, and who I can see at least within a month or two of requiring an appointment. The worst part is having to wait months to hear back after leaving a voicemail, and then have an appointment scheduled for the next year."



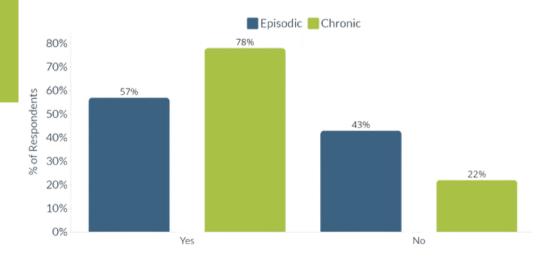
A whopping
70% have
experienced
financial
difficulties
paying for their
migraine
medication,
with 57%
deciding not to
fill a
prescription
due to cost.

Access to Treatment

Migraine is a chronic condition with no cure. Medication treatments have improved significantly with both acute treatments aimed at aborting migraine attacks and preventive medications available. However, a number of barriers exist to patients accessing the most effective treatment for their disease.

Over **70%** of patients who participated in the survey have private insurance through an employer and **14%** rely on the provincial drug programs. Although this would suggest a small portion must pay for treatment out of pocket, many migraine medications are not covered by insurance plans. When survey participants were asked if they are satisfied with how their medication is covered, **43%** said they are not.

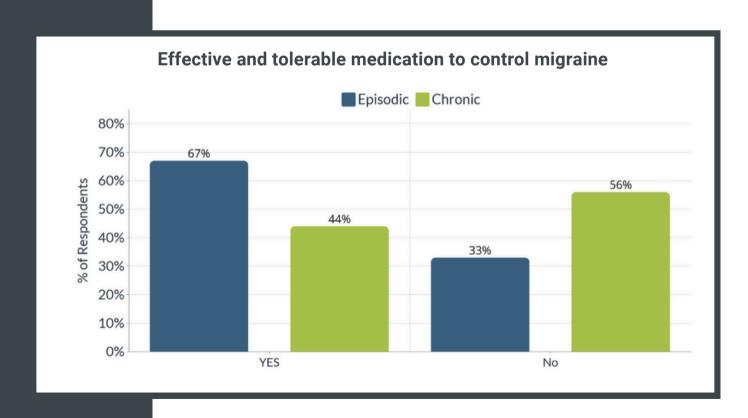
Financial difficulties paying for migraine medication



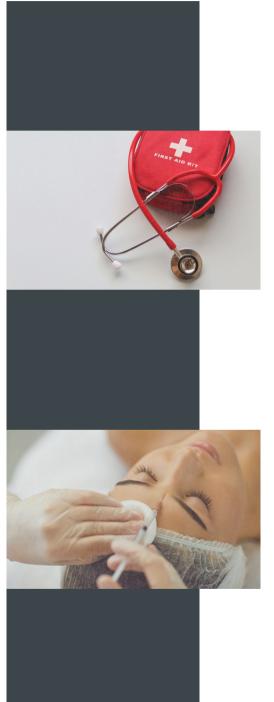


Access to Treatment - Continued

Most respondents have tried several acute treatments over the years. This may reflect the requirements of insurers that patients try and fail on "first line" treatments before coverage is provided for more modern medications. A majority of respondents (55%) have found an effective way to control most of their migraine attacks, which leaves close to half (45%) without a treatment to manage their condition. For chronic migraine patients specifically, the majority swings to the negative, with 56% saying they have not found an effective method for controlling migraine.







Access to Treatment - Continued

When asked about preventive therapies, close to **80**% of respondents have been prescribed preventive therapy. However, only **22**% said they are satisfied with current preventive treatments available in Canada. Do migraine patients believe there is a need for new treatment options and medications? Nearly three-quarters said "yes".

When asked about the outcomes from preventive medication that would be most valuable, migraine patients clearly indicated that a decrease in headache intensity and frequency is most important. Decreases in non-pain symptoms such as sensitivity to light and sound, nausea and brain fog are also desired.

Alarmingly, close to **15%** of both episodic and chronic migraine patients indicated they do not feel involved in the decision about which medication they are prescribed; while nearly **40%** say they are only somewhat involved. Although **65%** said they are very comfortable discussing medication and side effects with their healthcare provider, close to **40%** of respondents said their healthcare provider does not ask about side effects they may be experiencing. Only **27%** of healthcare providers provided detailed information about possible medication side effects.





Access to Treatment - Continued

Due to the chronic nature of migraine and ineffective treatments many migraine patients experience, many people seek help from a wide spectrum of other healthcare and allied professionals. This includes psychologists/therapists, massage therapists, physiotherapists, occupational therapists and others. Between 4% and 6% don't seek additional care or support from other healthcare professionals because of affordability, while 26% to 29% pay out of pocket for these services.

Only 22% are satisfied with currently available treatments in Canada

45% have not found a treatment that manages their condition.

18% often or always leave their appointments with unanswered questions.

Only **27**% of HCP discuss possible side effects.



"Being at the whim of insurance companies for treatment is frustrating. The new treatments are expensive. OHIP should cover Botox for migraine. We need the new preventatives available in the USA. When are they coming to Canada? GPs need more training in migraine. Mine was useless and gave up on me and told me to find a headache specialist on my own."

"I am exhausted, I just want some relief from the constant pain, and exhaustion. I would like to enjoy being a parent, partner, and my life."

"I wish migraine medication would be covered through ODSP, so I don't have to decide on either purchasing food or medication."

"It took a long time to get diagnosed and longer to get treatment. I had to prove to my insurance company that I had tried many options over months before they approved."



Visits to the Emergency Department

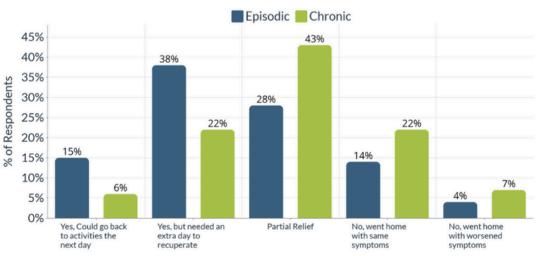
For some migraine patients, an attack can drive them to the hospital emergency department (ED) in search of relief. This may be from excruciating and long-lasting headache pain or frightening symptoms such as temporary paralysis. We asked respondents to reflect on visits to the emergency department for migraine over the past 10 years.

Close to **60%** of chronic migraine respondents were forced to go to the ED for intervention compared to **44%** of episodic migraine respondents. Of those who visited an ED, the average number of ED visits was 9 visits per patient over the last 10 years.

Emergency Department



Relief from care at ED





Visits to the Emergency Department -Continued

Only 14% of people who visited an ED were very satisfied with the care they received. Most EDs are ill-equipped to manage patients experiencing a migraine attack who often require quiet and darkened rooms to address phono- and photophobia. As well, the stigma that migraine is "just a headache" may prevent timely abortive treatment, which combined with the hectic ED environment can worsen symptoms. Unfortunately, 29% of people with chronic migraine reported leaving the ED with the same or worsened symptoms. Only 8% of people who visited the ED found relief from their migraine attack and were able to go back to normal activities the next day.

"I don't go to the emergency department anymore; they think I'm drug seeking. Different emergency rooms in different provinces same thing; they don't have much sympathy for migraine sufferers."

Diagnosis & Management Summary:

Migraine Patients Experience a Lengthy Wait for Diagnosis and Inadequate Disease Management

- 45% of respondents first experienced migraine symptoms between ages 10 and 19, yet less than 30% were diagnosed before the age of 19.
- 40% were diagnosed with migraine in their 20s and 30s, and 11% were diagnosed in their 40s.
- Only 23% of respondents found their NP or GP to be very knowledgeable about migraine.
- Almost 10% of people with chronic migraine travel between 150km to more than 300km to see a neurologist or headache specialist.
- 70% have experienced financial difficulties paying for their migraine medication.
- Due to cost, 57% of patients have chosen not to fill a prescription.



- 45% have not found a treatment that manages their condition.
- Only 27% of HCPs discuss possible side effects of treatment.
- 18% often or always leave their appointments with unanswered questions.
- Only 14% of people who visited an ED were very satisfied with the care they received.
- Only 8% of migraine patients who visited an ED obtained relief from their migraine attack and were able to go back to normal activities the next day.



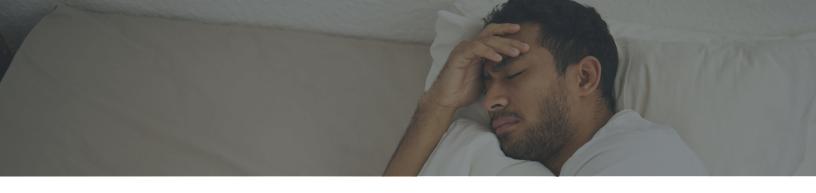
Quality of Life

Migraine impacts every aspect of people's lives. While we've examined the challenges migraine patients have with obtaining medical care and treatment for their migraine attacks, we haven't discussed how this disability shows up in daily life. The survey results demonstrate that migraine patients struggle with getting adequate sleep, experience mental health concerns and challenges with relationships, parenting, and employment—often due to a lack of understanding amongst those who do not have migraine.



"I would like to see awareness campaigns to educate the public about what a disability migraines are. I would like to see less of a challenge qualifying for disability due to migraines. It's hard living life with chronic pain. It's hard to function, it's hard to work and it's hard on relationships."

"It feels impossible to cope sometimes. Expectations of me haven't changed but my ability to meet them has. I wish there was more help."

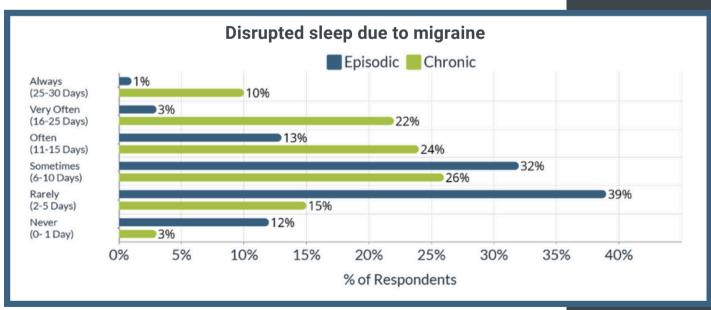


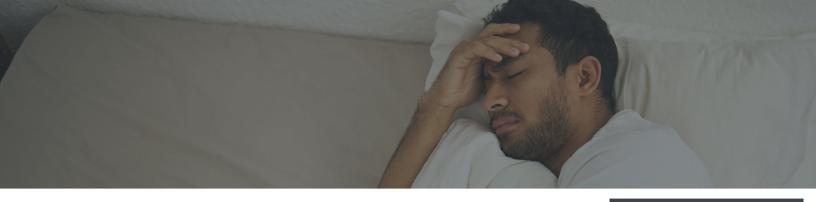
Sleep

People with migraine experience significant negative effects on their sleep. This includes the duration of their sleep and their ability to engage in slumber without interruptions. Both individuals living with chronic and episodic forms of migraine can experience these discrepancies in sleep patterns, with an increased frequency of migraines leading to a more severe impact on sleep.

People with migraine disorders report increased insomnia symptoms as a direct result of their headache disorder. Some direct impacts reported are poor sleep quality, difficulty falling and staying asleep, feeling tired after awakening, waking up too early, feeling sleepy during the day, and getting less sleep than normal (Doherty 2021). As such, there is a well-established and prominent connection between migraine and sleep disorders.

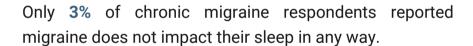






Sleep - Continued

When asked how their sleep is impacted, 32% of chronic migraine respondents reported their sleep is disrupted for more than half of the month. About 40% rated their quality of sleep as poor or very poor and 37% noted it was often disrupted. Those with a greater frequency of migraine report more sleep deprivation. Close to 50% of respondents with chronic migraine feel their migraine attacks impact their sleep. Overall, 84% claimed migraine negatively impacted their sleep.



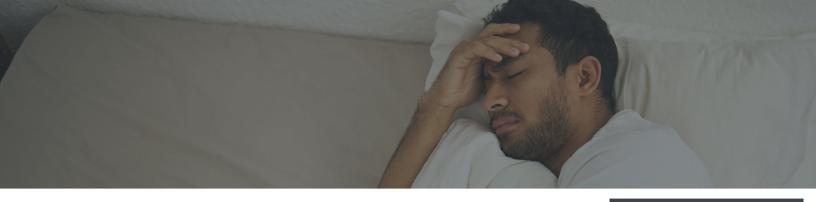
In many cases, respondents reported that their medications helped them sleep better, however, only for a short period of time. Those who take medications to help with sleep risk becoming reliant and experiencing insomnia when the medication is removed.





"Medication caused me to sleep for 12 to 14 hours for the first two weeks of taking it."

"Sleep issues create more problems and headaches."



Sleep - Continued

Improving sleep for migraine patients is often one of the first lifestyle modifications that headache specialists try to address with patients. Sufficient sleep is required to stabilize the brain and reduce attack frequency. Regular exercise can improve sleep, however, the vicious cycle of migraine limits people's ability to exercise as well. Almost three-quarters of chronic migraine respondents said a migraine limited their ability to exercise on 11 or more days over the last month. About half of those with episodic migraine had limited ability to exercise on 6 to 15 days in the last month.

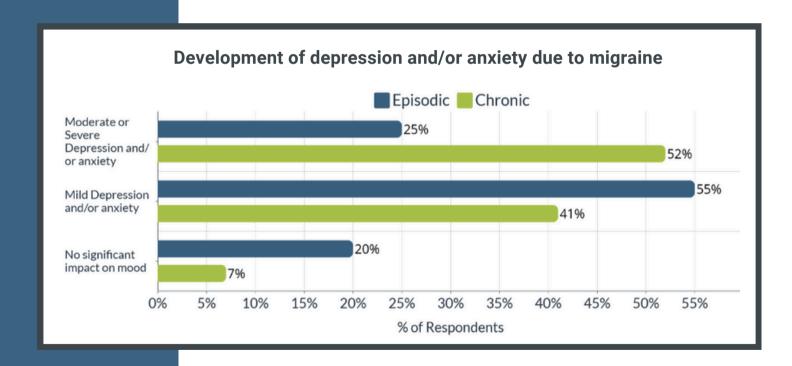
Maintaining a positive sleep routine may be further hindered by patients' needs to rest or lie down during their normal waking hours due to migraine. Nearly **56**% of those with episodic migraine reported needing to rest or lie down on 6 or more days in the last month; **87**% of those with chronic migraine experienced this.



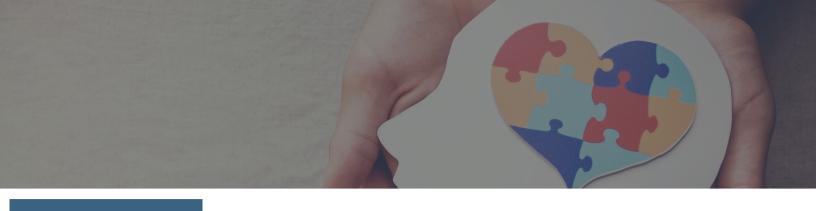


Mental Health

The debilitating effects of migraine disorder affect individuals' moods significantly, resulting in feelings of self-doubt, sadness, and dissatisfaction in their daily activities. Many migraine patients are also diagnosed with one or more mental health conditions, with depression and anxiety most commonly reported. This poses additional concerns for effective management of migraine, since mood stabilization and managing stress may reduce migraine attacks.



"Migraines have completely ruined everything ... cannot function, miserable every day and do not want to be around anyone."



Only 7% of chronic migraine patients report their migraine does not impact their mood.

Mental Health - Continued

Close to 93% of respondents with chronic migraine said they believe their migraine has led them to develop symptoms of depression and/or anxiety; 80% of those with episodic migraine reported this impact. For almost 52% of chronic migraine respondents and almost 25% of episodic respondents, the depression and/or anxiety is moderate to severe requiring counselling and/or medication to help manage their mental health. For those living with episodic migraine, almost 25% need to seek counselling and/or medication.

"I feel like a crappy parent, spouse, and employee because I can have good days and be super productive and involved. But when the bad days hit, I'm like a different, pretty much useless, person."

"Migraines are causing disruption to every aspect of my life. Along with the physical debilitation, they are now severely impacting my mental health as well."

For people with migraine, significant mental load is occupied with worrying about their condition—be it when the next attack will strike or the impact migraine is having on their life. Over **60**% of episodic migraine patients reported worrying about migraine on 6 or more days of the last month. This number increases to **80**% for those with chronic migraine. Breaking this down further, **33**% of chronic migraine patients reported worrying about migraine on 25-30 days of the last month.

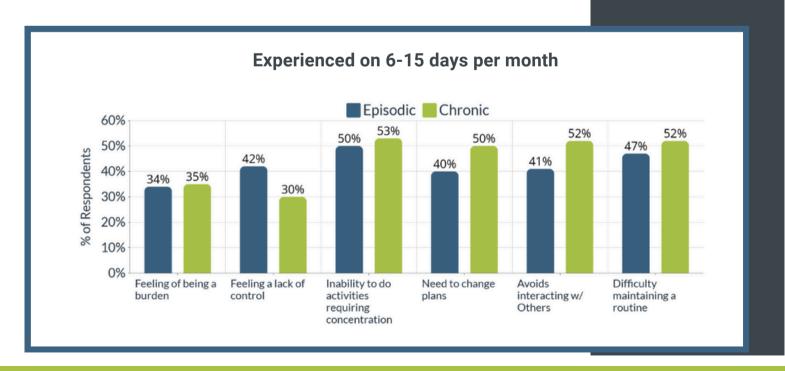


Impact on Social Life

One of the strongest indicators of quality of life could very well be how one views the quality of their social life. Numerous studies have found that social connection contributes to physical, mental, and emotional wellbeing. So, it should be alarming to learn of the negative effects on social life that people living with migraine report.

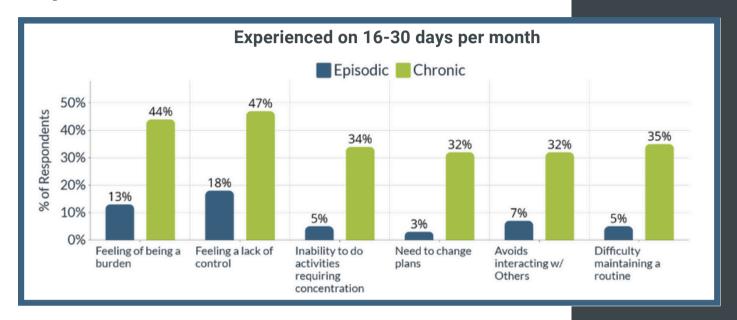
In particular, individuals living with migraine feel that they are a burden and feel a general lack of control over their lives. Many have difficulty participating in activities that require concentration and have difficulty maintaining a routine. They end up avoiding interactions with others and changing plans due to migraine attacks.







Impact on Social Life - Continued



These experiences affect an individual's ability to establish and maintain relationships, as well as their confidence in being able to engage in social interactions and activities. Feelings of loneliness and disconnection can further exacerbate mental and physical health concerns and contribute to poor quality of life.

"It causes me anxiety because my husband doesn't understand the severity of the pain when I get a migraine. I always feel guilty if I have to cancel plans so I just push through and attend even when I feel awful. It's disrupting my life."

"As a 9-year-old girl, I hate my migraines. I miss sleepovers, birthday parties, pool parties, beach days, anything with loud noises or lights. I just want to be able to be with my friends."



Impact on Family Relationships

The negative impact migraine patients experience in their social lives extends to their closest relationships—with their families. The burden of migraine affects time spent with children and connections with spouses or partners. However, members of the Migraine Canada community and healthcare providers working closely with patients are aware that many people with migraine develop ways to adapt and "push through" even when they are struggling with a migraine attack because they feel they have no choice.

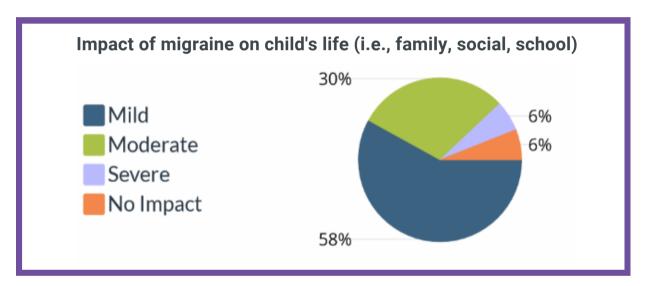
Of survey respondents, **34%** reported having children under the age of 18 years old. Of those, about **2%** of people claimed their partner had to take over parenting activities due to their migraine on 25 to 30 days of the last month. For the majority of people (**53%**), parenting duties needed to be assumed by their partner on 6 to 15 days of the last month. An additional question that should have been asked was, "how often do you push through even when you are experiencing a migraine attack?".

Over the last month, **65%** of respondents reported missing an occasion to spend quality time with their children due to their migraine between 2 and 10 days, while **13%** missed quality time with their kids between 16 and 30 days. Family meals are also missed at times. The frequency is greater for chronic migraine patients, of which **49%** miss a family meal between 6 and 25 days per month. Whereas **19%** of episodic migraine patients missed a family meal between 6 and 25 days per month, and **51%** between 2 and 5 days. Overall **58%** of respondents feel they would be a better parent without migraine.



Children with Migraine

As genetic factors account for about **50%** of the risk of developing migraine, the survey asked if respondents have a child living with migraine and one-quarter of respondents said they did. Of those, **50%** of these children are not receiving active medical care for their migraine, **10%** are seeing a neurologist or headache specialist, and the remainder are receiving care from a pediatrician or family physician.



At the present time, **58**% of respondents said the impact of migraine on their child's life (family, social, school) is mild, **30**% said moderate, **6**% said severe, and **6**% said there was no impact.

One issue that children with migraine face is a challenge accessing medication for migraine attacks when at school. The Migraine Canada community has shared this concern, noting that because most medications that are prescribed for children to abort an attack are usually not indicated for migraine and/or for use by children, school administrators are often uncomfortable playing a role in the child's medical treatment even when a doctor's note is provided. Abortive medications are most effective when used at early onset of migraine symptoms. Survey respondents were asked whether their child with migraine can easily access medication when needed at school: 54% said yes, 46% said no.

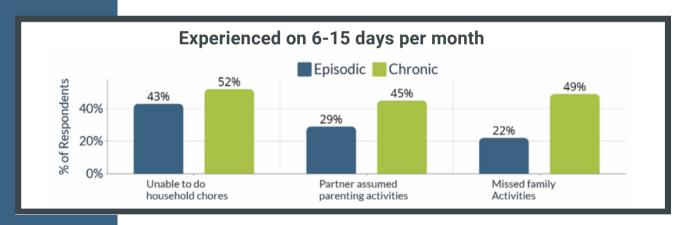


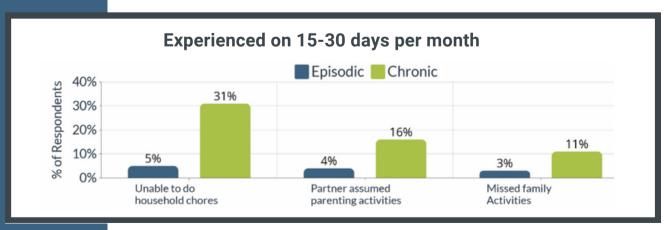
60% of chronic migraine patients feel their partner does NOT understand their condition

Impact on Family Relationships-Continued

Only **35**% of chronic migraine patients believe their partner understands migraine and even fewer episodic patients (**12**%) feel their partner understands their condition.

Over half of respondents worry about their family's financial stability due to their condition and more than half also feel their condition has a negative impact on their relationship with their partner.







45% of chronic respondents believe they would be a better parent without migraine.

Impact on Family Relationships -Continued

Over 18% of women living with chronic migraine and 13% living with episodic migraine have chosen not to have children because of their condition. Some commented that their migraine attacks are so painful and debilitating they would not take the chance of handing it down to a child. Others shared concerns for their quality of life and ability to take care of others while also managing migraine.

"I don't have a life. Nothing active and social. I stay home all the time while my family continues their lives. My husband and I are still intimate but maybe not as often as he would like."

"I know it stresses my child when she sees me lying down due to a migraine. My migraine condition also played a role in our decision to just have one child because I couldn't imagine functioning without migraine drugs for 9 months."

"Because of my migraine, my husband has had to take on more the role of taking care of the kids, cooking and cleaning. It's hard to spend quality time with the kids when I always have symptoms, and hard to spend alone time with my partner when I just want to go to bed."

Quality of Life Summary:Migraine Patients Struggle to Enjoy Life's Pleasures and Maintain a High Quality of Life

- Overall, 84% claimed migraine negatively impacted their sleep.
- 32% of chronic migraine respondents reported their sleep is disrupted for more than half of the month.
- About 40% rated their quality of sleep as poor or very poor and 37% noted it was often disrupted.
- Close to 93% of respondents with chronic migraine, and 80% of those with episodic, said they believe their migraine has led them to develop symptoms of depression and/or anxiety.
- Over 60% of episodic migraine patients and 80% of chronic patients reported worrying about migraine on 6 or more days of the last month.
- 33% of chronic migraine patients reported worrying about migraine on 25-30 days of the last month.
- 65% of respondents reported missing an occasion to spend quality time with their children due to their migraine on 2 to 10 days, while 13% missed quality time with their kids on 16 to 30 days. 49% of chronic migraine patients and 19% of episodic patients miss a family meal on 6 to 25 days per month.



- Overall 58% of respondents feel they would be a better parent without migraine.
- More than half feel their condition has a negative impact on their relationship with their partner. Only 35% of chronic migraine patients and 12% of episodic patients believe their partner understands migraine.
- Over 18% of women living with chronic migraine and 13% living with episodic migraine have chosen not to have children because of their condition.

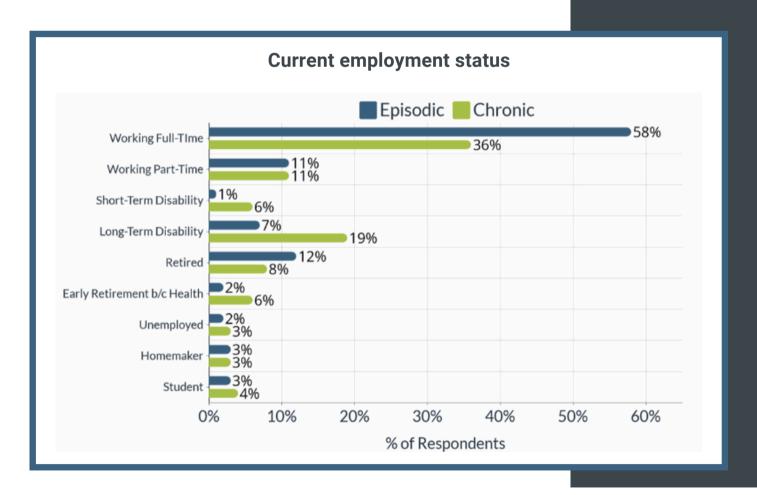


JEMPLOYMEN'S

Employment

Just as migraine takes time away from social and family engagements, the disease affects patients' ability to choose satisfying employment and feel like productive and contributing members of society. Many respondents shared comments about abandoning career goals to manage their migraine, while others wrote of challenges obtaining accommodations from employers.







"I hate being sick. I hate the constant loss that this illness brings to your life. As a child I was taught to dream and work hard and I would achieve my goals. I've been a Registered Nurse for 10 years and I've been off sick for 6 of them... now I can't work at all. Migraine has robbed me of my career. Migraine bankrupted us. We live extremely low income and I cannot afford my medications."

"It's hard to live with chronic pain. We have to push through and try to ignore the pain to get through our daily lives. And it's disheartening when others (public, friends, coworker, management) dismiss our chronic pain because we are so good at hiding it."

"I just want my life back. I want meds that work. I want to be able to work again."

"Migraine has greatly affected my ability to enjoy life fully. I never know if I will be hit with a migraine while travelling or working. [...] It can really take the joy out of life on the bad days. I don't like missing out on life because I'm sick with a migraine."

"I constantly worry about how I'm going to get through this and how will we get through without bringing in an income and hemorrhaging money because migraine is a big disability that is not recognized as such. I'm treated like a healthy person when I most certainly am not."



Employment - Continued

Only **36**% of chronic patients are working full time compared to **58**% of episodic migraine patients. Approximately **17**% of respondents reported to be on long-term or short-term disability due to their migraine attacks. Of those, close to **70**% have been on disability for more than 18 months.

Migraine results in absenteeism, affecting the number of days that people miss work. Presenteeism is also an issue as people living with migraine report feeling that the quality of their work is impacted when they are working.

Some people have to work part time to accommodate their migraine: **10%** of episodic respondents and **12%** of chronic respondents. About **10%** of all respondents have chosen to retire early due to migraine. Several people commented they were extremely sad to leave jobs they loved in the prime of their lives because they haven't found an effective treatment.

When asked if respondents had disclosed their migraine diagnosis to their employer, approximately **63%** had. The majority of those disclosed their illness because of the impact their migraine attacks had on their work. A troubling finding was that close to **50%** of those who have not disclosed their migraine condition said they did not disclose for concern about consequences even though migraine is negatively impacting their work.

Only 1% of people working full time said they have no limitations to working.

22% had their request for workplace accommodation denied.

JEMPLOYMEN'S

Employment - Continued

For those who have disclosed their condition, only 32% have asked for an accommodation at their workplace. While close to half (47%) had their request accepted without needing a medical note, over 30% needed to get a medical note from their clinician. Unfortunately, 22% of those who requested an accommodation had their request denied. The most common accommodation requests were schedule flexibility, lighting changes, screen and workstation adaptations.

Fewer than one-quarter of survey respondents feel their co-workers understand migraine, which further compounds feelings of isolation and the challenges of managing their condition. Many respondents commented that their colleagues will tell them to take an over-the-counter pain reliever or try to drink more water and to feel better.

"It is extremely debilitating and yet you are supposed to just power through. I have lots of shame regarding the limitations it has imposed on my life. It has isolated me and changed my entire career and economic status."

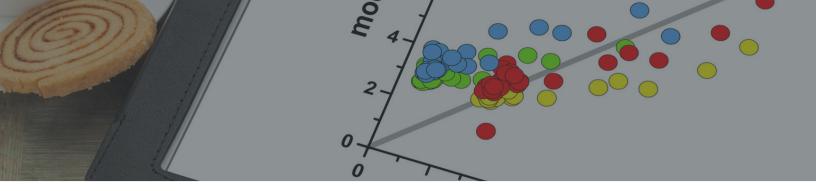
"It has really affected my ability to earn money and it did affect my pension because of the amount of time lost."

"The most disabling thing about chronic migraine is the unpredictability of when they will occur. I often have to cancel plans and I avoid making commitments that I may not be able to keep. Migraines have stolen my career from me."

JEMPLOYMEN'S

Quality of Life Summary:Migraine Patients Struggle with Employment

- Some people have to work part time to accommodate their migraines: 10% of episodic respondents and 12% of chronic respondents.
- About 10% of all respondents have chosen to retire early due to migraine.
- Approximately 16% of respondents reported to be on longterm or short-term disability due to their migraine attacks.
- Close to 50% of respondents who chose not to disclose their condition was because they feared the consequences of disclosing.
- Approximately 22% of people who requested an accommodation to their employer were denied.
- Only 1% of people working full time said they have no limitations to working.



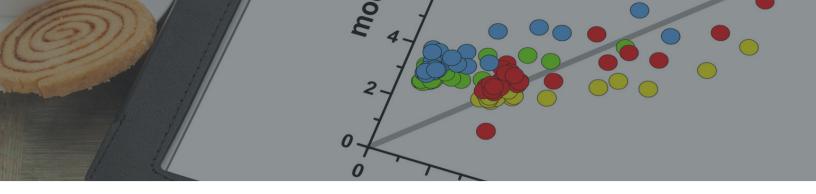
Observations & Recommendations

The survey results have made it very clear: living with migraine has a significant impact on quality of life. For most participants, every aspect of their life has been touched by migraine. The consequences of migraine include sleep disruption, avoidance of social activities, deteriorating relationships, an inability to pursue career goals and precarious employment. Overall wellness and feelings of satisfaction with life are hindered by the vicious cycle that migraine sets in motion.

Lives are filled with isolation and hopelessness due to loss of close relationships and a lack of understanding about migraine by loved ones. Many participants indicated that their friends and family have difficulty comprehending chronic pain and illness. Many report feeling like a burden because their condition causes a lot of worry for their loved ones and they aren't able to carry out daily activities.

Migraine is a burden causing people to constantly assess their situation, worry about what tomorrow may bring and adjust each day. The unpredictability of the disorder impacts activities that are important to leading a healthy life as patients are hesitant to make plans because they aren't confident they will feel well enough to participate. When they do attend social events, they are often not able to contribute as they'd like due to headache pain and other symptoms. Many survey respondents expressed they can no longer engage in their favourite hobbies.

Even those who are undergoing successful treatment have worries about the future. The cost of medications and the financial burden that living with migraine brings to a family unit is a constant stressor for participants. This concern is heightened by workplaces that are unsupportive of necessary accommodations for migraine patients, and many respondents have made the choice to work only part time or to retire early in order to manage their disease.

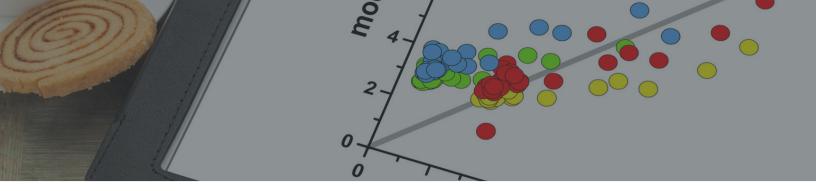


Observations & Recommendations - Continued

When it comes to migraine management and treatment, obtaining support from knowledgeable and qualified healthcare specialists is difficult. Many migraine patients wait years from the onset of symptoms for a diagnosis and then face numerous hurdles to receive effective treatment—a lack of headache specialists, little to no coverage of medication by insurers, and delays in approvals of modern treatments.

In the absence of a cure for migraine, action must be taken to improve the quality of life of the 4.3 million Canadians diagnosed with migraine. Migraine Canada proposes the following recommendations be implemented to support the community, reduce the burden of this invisible disease, and ultimately improve health outcomes.





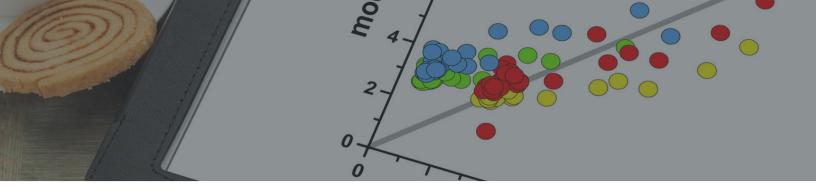
Observations & Recommendations - Continued

Improve Knowledge.

- 1. Improve the education of health professionals including Primary Care Providers, allied health care providers and specialists, starting at an early stage of training.
- 2. Make headache medicine a mandatory requirement in the Neurology training objectives of the Royal College.
- 3. Ensure that every Neurology department offers academic positions for headache medicine.
- 4. Undertake public awareness campaigns to reduce stigma and increase the knowledge of the general public about migraine.
- Increase recognition that migraine can cause significant disability and that those with migraine may need appropriate accommodation in the workplace.

Improve Management.

- 1. Promote early migraine diagnosis.
- 2. Adopt a chronic disease management model, including therapeutic education and behavioural approaches, patient empowerment and shared decision making.
- 3. Optimize the use of acute migraine therapies and prevent medication overuse through better patient education and long-term follow up.
- 4. Optimize the use of migraine preventive therapies.



Observations & Recommendations - Continued

Improve Access to Treatment.

- 1. Improve reimbursement coverage, and criteria, on both public and private plans making access to new, safe, effective and tolerable treatments a reality.
- 2. Ensure equitable access to treatment and medication irrespective of where you live.
- 3. Remove restrictions that limit access to just six doses per month of Triptans.
- 4. Ensure devices and injections are included as part of treatment options and coverage on provincial and private and public in drug plans.
- 5. Consider combination therapy for inclusion in drug plans.
- 6. Implement a nation-wide model of care with well-defined roles at all levels of care in an interdisciplinary vision.
- 7. Implement specialized multidisciplinary clinics for refractory patients with access to multidisciplinary teams and advanced procedural care.
- 8. Support investment in migraine research to provide better treatment options in the future.

WE HOPE THIS REPORT WILL LAY
THE GROUNDWORK FOR IMPROVING
HEALTH OUTCOMES FOR CANADIANS
CURRENTLY FACING THE BURDEN OF
MIGRAINE. THE DATA COLLECTED
THROUGH THIS SURVEY WILL ALSO
PROVIDE A FOUNDATION FOR
FUTURE ASSESSMENT OF PROGRESS
TOWARDS THE GOAL OF OPTIMIZING
CARE AND IMPROVING THE QUALITY
OF LIFE OF CANADIANS WITH
MIGRAINE.

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