The Conference Board of Canada

Presenting a Model of Care for Migraine in Canada

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Contents

Key findings

- Patient participants told us that people with migraine have difficulty accessing migraine care and all too often carry the full responsibility of navigating the system on their own, educating themselves on what care might work for them, and then pushing for access.
- Both patients and healthcare providers told us that the healthcare system for migraine care is inundated with misdiagnoses, inconsistencies in migraine management, and a lack of education, awareness, and resources for practitioners seeking to provide care for migraine management.
- Based on these deficiencies, we propose a person-centred model of care to provide better migraine care—relieving pain, minimizing disruption, and supporting people in doing what matters most to them.
- Implementing this model requires better system planning to ensure people get the right care at the right time and can move smoothly between primary and specialist care services. A key plank in implementation is helping people understand when and how to seek care.
- There is a gap in education on migraine. Addressing this gap in understanding involves raising awareness of migraine as a brain disorder and clarity on the care options available.
- To strengthen migraine management and increase practitioner capacity, evidence points to the value of interprofessional teams for healthcare professionals.
- Another plank is for decision-makers to highlight the full impact of migraine and the policy and funding levers that can reduce its social and economic cost.

Actionable insights

To advance the implementation of the migraine model of care, five core considerations emerged:

1. **Transfer of care between and within levels of care:** Structures and supports are needed to make transitions between levels of care possible so that patients are receiving the right care at the right time. Supports for enabling the transfer of care include having clear and aligned guidance/standards for providers (e.g., toolkits, decision supports embedded in workflows/electronic medical records [EMRs]), bolstering primary care provider capacity and comfort with delivering migraine care, identifying and operationalizing headache/migraine champions (e.g., tele-mentoring, brief consults, advisors), finding efficiencies through the referral process, and creating resources for patients to support navigation (e.g., print-outs, AI Chatbots). These supports will create smoother transitions from initial point of access to the right place in the system, from primary care to specialist care, and from specialist care back to primary care.

2. **Interaction with funding models:** Ideally, a model of care could effortlessly apply across different funding models in order to support the broad suite of migraine care. However, today there are many barriers to this kind of interprofessional model. Issues to address include current requirements for a neurologist prescription for insurance sign-off (versus from a nurse practitioner or primary care provider); penalties for patients being seen at a separate family doctor for headache to the one where they are rostered; and limited ability to shift paperwork responsibilities within a multidisciplinary team (e.g., pharmacist and nurse practitioner) to optimize time for specialist care.

3. **Medication and device coverage:** Advocates can work with insurers to update criteria, modernize medication and device coverage lists, and remove administrative steps misaligned with practice models (e.g., sign-offs from specialists for medications prescribed in primary care) so that cost is less of a barrier for people with migraine to access evidence-informed, guideline-recommended care.

4. **Patient education:** To be engaged in an active role in their healthcare team, patients need up-to-date resources that reflect the latest evidence and insights. Healthcare providers can provide support materials (e.g., a list of key questions patients should ask their providers) and have these tools integrated into practice workflows (e.g., provider adds notes about migraine in EMR and a printable resource document is provided to download or email). Emerging tools such as AI can used to summarize and re-write evidence in a style that will resonate with patients, as well as to support system navigation. Having engagement through more provincially representative patient groups/networks will deliver more relatable, health-system-specific support to patients within different regions across Canada.

5. **Healthcare provider capacity and education:** Capacity development and education for healthcare providers can include building toolkits or tip sheets that are aligned throughout the continuum of care; regionally implemented standards and quality improvement plans for more consistent, person-centered, and effective care; opportunities to utilize AI tools to support providers in guiding best medication and treatment options given a set of patient characteristics; and leveraging existing health training opportunities to include migraine.

Opportunity to develop a model of care for migraine

A model of care for migraine in Canada should emphasize the foundational components (e.g., principles, approaches, and structures) that are necessary for delivering outcome-oriented, person-centred care across the country. Canadian health systems have not had such a model on which to build programs, organize resources, structure supports, or allocate funding. The result has been a patchwork approach to migraine care and patients receiving care that does not meet their needs. The patient advocates and health practitioners we spoke to told us the current system is failing people who experience migraine.
We can do better.

The Canadian Headache Society (CHS) commissioned The Conference Board of Canada (CBoC) to establish a proposed model for migraine care delivery that could be applied broadly to Canadian health systems. Our research involved input from the literature, four dialogue sessions with a total of 20 people with migraine, and a hosted roundtable discussion with 14 healthcare professionals and leaders who have expertise in migraine care and health system delivery. (See Appendix A, Methodology.)

What is a model of care?

A model of care is an overarching design for the delivery of healthcare services. It includes core elements and principles. It is shaped by theoretical models and conceptual frameworks, evidence-based practices, and defined standards or guidelines. It can be created for application at the system, region, or practice level.[1]

[1] Davidson and others, “Beyond the rhetoric.”

Migraine in Canada

Many Canadians suffer from migraine, and migraine remains a leading cause of disability worldwide.[2] Studies have estimated the prevalence in Canada to be between 8 per cent and 26 per cent.[3] These values are likely underestimated, as many people do not seek care for their symptoms and migraine remains an underdiagnosed and undertreated disorder.

People with migraine experience recurrent disabling headache attacks with other noteworthy symptoms, such as nausea, vomiting, photophobia, and phonophobia. Some patients may also experience visual, sensory, language, and other neurological symptoms. Migraine is often categorized as episodic or chronic, depending on the frequency of headache days in a given month.

Migraine leads to personal and socioeconomic burdens, including pain, disability, and diminished quality of life.[4] Disparities are seen in migraine-related pain and disability, access to care, and quality of care among marginalized and underserved groups.[5] People with migraine often have co-morbidities, including depression, cardiovascular disease, and anxiety.[6] Approximately 90 per cent of people with migraine report moderate to severe pain, 75 per cent report impaired function, and 33 per cent require bed rest during a migraine attack.[7] Migraine poses barriers to relationships, education, careers, and many other meaningful pursuits.

The economic cost of migraine involves high health system use (e.g., visits to primary care providers, specialists, and the emergency department) and lost productivity (e.g., absenteeism and unemployment).[8] A 2025 study estimated the cost of migraine to the Ontario public payer to be $1.1 billion over two years.[9]

A six-year real-world evidence cohort study in Alberta found that over 20 per cent of people with migraine visited an emergency department for migraine over the course of the study.[10] They also found an underutilization of acute and preventive medications and an overutilization of opioids.[11] Similar patterns are likely to be found in any province across the country given the current shortcomings in how Canadians receive care for migraine.

Challenges delivering care

In Canada, effective care for people with migraine is provided through acute and preventive pharmacologic and nonpharmacologic (e.g., neuromodulation, cognitive behavioural therapy, and lifestyle modification) migraine treatments.[12] There are also highly skilled specialists and non-specialists who provide care to migraine sufferers. These include neurologists, family medicine and emergency medicine doctors, nurses and nurse practitioners, pharmacists, and allied health practitioners. Care is delivered through specialized headache clinics, non-specialized clinics and practices, pharmacies, and emergency departments. However, an inability to access the right level of care in a timely manner is a barrier faced by many people who suffer from migraine.[13]

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[2] Steiner and others, “Migraine remains second among the world’s causes of disability.”

[3] Institute for Health Metrics and Evaluation, “2021 Global Burden of Disease”; Ramage-Morin and others, “Prevalence of Migraine”; and Graves and others, “Epidemiology and treatment utilization.”

[4] Graves and others, “Epidemiology and treatment utilization.”

[5] Befus and others, “A Critical Exploration of Migraine.”

[6] Graves and others, “Migraine Treatment and Healthcare Resource Utilization.”

[7] Lipton and others, “Migraine prevalence, disease burden.”

[8] Amoozegar and others, “The Burden of Illness of Migraine”; Zhang and others, “The relationship between chronic conditions”; Graves and others, “Migraine Treatment and Healthcare Resource Utilization”; Cooke and others, “Migraine Prevalence, Treatment and Impact”; and Lay and others, “Real-World Healthcare Utilization.”

[9] Lay and others, “Real-World Healthcare Utilization.”

[10] Graves and others, “Migraine Treatment and Healthcare Resource Utilization”

[11] Graves and others.

[12] Tzankova and others, “Diagnosis and acute management”; Tzankova and others, “Pharmacologic prevention of migraine”; Medrea and others, “Updated Canadian Headache Society Migraine Prevention Guideline”; Becker and others, “Guideline for primary care management”; and Cortel-LeBlanc and others, “Managing and Preventing Migraine.”

[13] Kiarashi and others, “Factors Associated With, and Mitigation Strategies”; Lanteri-Minet and others, “Characterizing barriers to care”; and Migraine Canada, *Migraine in Canada*.

We heard from patients that people with migraine have difficulty accessing migraine care and all too often carry the full responsibility of navigating the system on their own, educating themselves on what care might work for them, and then pushing for access. Furthermore, even when people access the healthcare system for migraine care, they face misdiagnoses[14] as well as inconsistencies in migraine management.[15]

While the patient journey is difficult, healthcare providers told us they have their own challenges in knowing how best to care for people with migraine. Challenges include not having sufficient education on migraine, not knowing their role in caring for people with migraine, and not having adequate time and resources to manage patients with migraine (including co-morbidities[16] and intra-patient fluctuations and variability[17]). Having to consider out-of-pocket costs for patients, the inaccessibility of guideline-recommended treatments in each jurisdiction, and not having the authority to prescribe certain treatments are further challenges.

It is well understood that Canada's healthcare systems struggle to meet population needs, as evidenced by many Canadians being unable to access primary care providers[18] and facing long wait times to see specialists.[19] These barriers are not distributed equally across the country, with Canadians in rural and mixed urban and rural communities less likely than those living in urban areas to see family doctors or specialists.[20] Care is also fragmented between providers, making it difficult and burdensome for both patients and providers to navigate the system.

A pan-Canadian migraine model of care can support better care for migraine.

The migraine model of care

The proposed model of care for migraine in Canada is depicted in Exhibit 1.

Pan-Canadian model of care for migraine

The model is designed around the person.

Migraine care includes three components:

- services through the healthcare system
- self-management and advocacy by the person with migraine
- supports from the broader social environment

Each component has a large role individually and collectively forms a system equipped to reduce pain and suffering, support daily functioning, and bring greater stability to the lives of people with migraine.

Several key factors are needed to enable adoption of the model of care:

- increasing patient, public and provider education on migraine;
- embedding a learning health system approach;
- embracing interprofessional collaboration.

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[14] Lipton and others, "Patterns of health care utilization."

[15] Lay and others, "Real-World Healthcare Utilization"; and Graves and others, "Migraine Treatment and Healthcare Resource Utilization."

[16] Graves and others, "Epidemiology and treatment utilization"; and Sanderson and others, "Headache-related health resource utilisation."

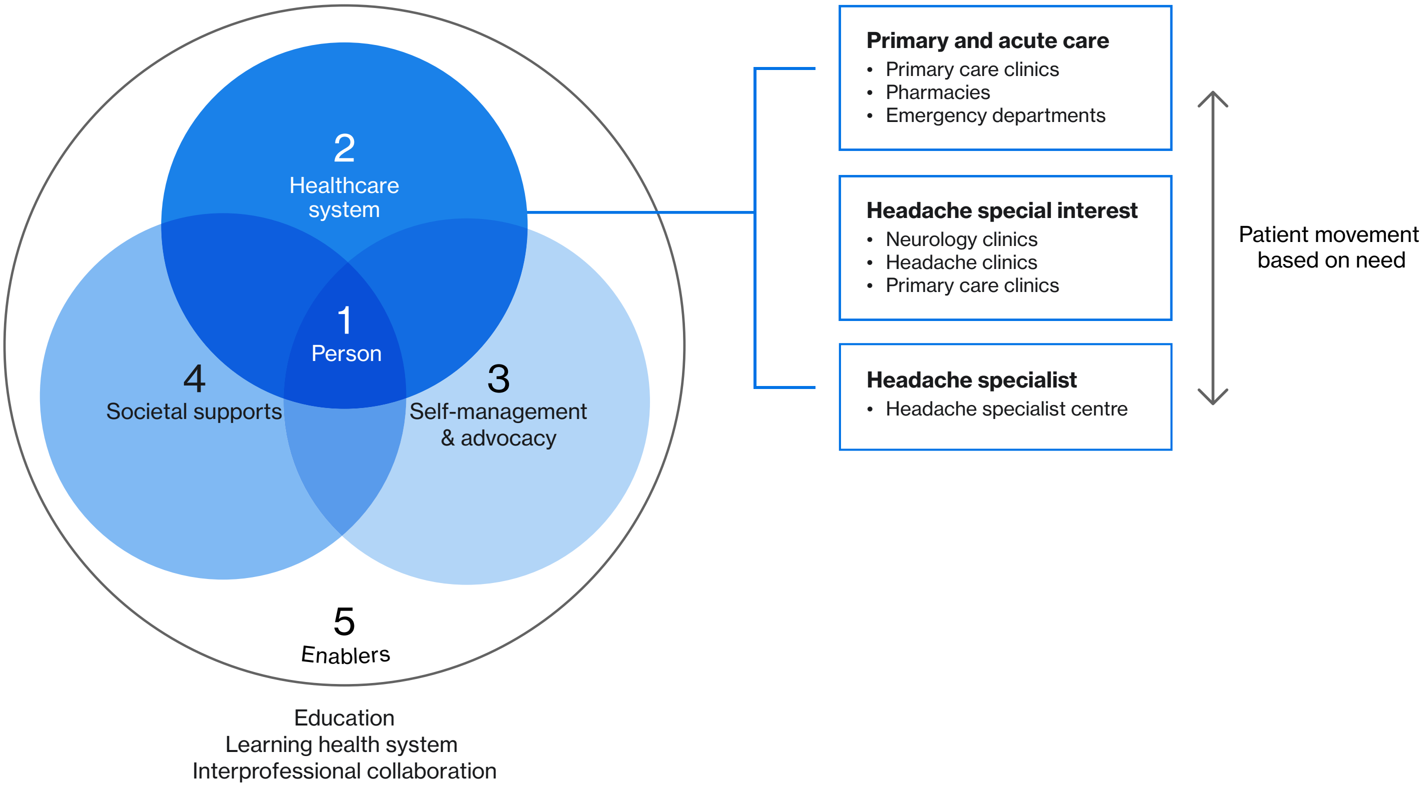
[17] Rosignoli and others, "Applying a biopsychosocial model to migraine."

[18] Canadian Institute of Health Information, *Access to primary care.*

[19] Liddy and others, "How long are Canadians waiting to access specialty care?"

[20] Clark and others, "Healthcare utilisation among Canadian adults."

Exhibit 1
A pan-Canadian model of care for migraine places the person at the centre of healthcare system, self-management, and societal support components



Source: The Conference Board of Canada.

Components of the model of care

1. The person at the centre

The migraine model of care delivers the outcomes that matter most to people living with migraine by placing their needs at the centre. A person-centred care approach shifts the organization and delivery of care from being disease-, provider-, or system-focused to being designed from the perspective and goals of the person with migraine.[21]

We held four dialogue sessions with 20 migraine patients. We heard that the model should:

- support the person in accessing evidence-based, effective care efficiently and consistently;
- deliver care in a way that does not compound the disruption of this disorder.

For more about the patient dialogue session methodology and themes identified through our qualitative analysis, see Appendices A and B.

> "Being well managed means working closely and in partnership with a medical provider to set objectives and then see them through. In this cooperative relationship, short-term, medium-term, and/or long-term goals would be set together. The doctor would really stick with you and work with you to meet the goals in every aspect."
> **Patient participant**

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[21] Grudniewicz and others, "Operationalizing the Chronic Care Model."

In a person-centred approach, migraine care includes the following[22]:

- **Healthcare system:** evidence-informed and guideline-driven acute and preventive care, as well as management of co-occurring physical and mental health conditions;
- **Patient self-management and advocacy:** patient self-management of behavioural and environmental factors, care navigation, and advocacy;
- **Societal supports:** societal support and recognition (e.g., workplace accommodations, insurance coverage).

2. Healthcare delivery and system organization

Identifying and diagnosing migraine

Entry into the healthcare system for migraine can occur in many different parts of the system—primary care clinic, neurology clinic, emergency department, or local pharmacy. Regardless of where a patient with migraine first presents, the patient should be able to access the right level of care. There should be a clear process and capacity in the system to make this happen.

Governing bodies can support healthcare providers to act as access points for patients and promote greater system integration by clarifying referral processes and making referral conditions more consistent across jurisdictions.

Recognizing headache and diagnosing migraine according to internationally recognized criteria[23] is a critical first step. Having the capacity to do this within the different entry points is necessary for reducing referrals for unnecessary investigations, mitigating the time and cost burden associated with finding the right care and treatment plan for the patient, and increasing the patient's quality of life.

> "Because I didn't get treatment soon enough, and even though I was referred to the headache clinic, it was a bit too late at that point."
> **Patient participant**

Increasing awareness and education about headache among patients and healthcare professionals can lead to earlier and more accurate diagnosis and more effective treatment.[24] Canadian guidelines for migraine diagnosis, acute management, and preventive care exist[25] and educational resources are available and promoted to healthcare professionals and patients through the CHS, Migraine Canada, Migraine Quebec, and the Canadian Migraine Society. However, we heard from patients that the care providers they interacted with seemed unfamiliar with these resources.

Accessing the right level of care at the right time

The migraine model of care emphasizes the importance of people accessing care at the appropriate level and having guidance and systems in place to transfer seamlessly between levels.

Headache care in Canada, like in many other countries, is organized into three levels[26]:

- **Level 1:** Primary care clinics with doctors or nurse practitioners, with some clinics having nursing, pharmacy, dietetics, and other supports; pharmacies; emergency departments.
- **Level 2:** Neurology clinics or headache clinics with a healthcare provider who has a special interest in and knowledge about headache (considered primary or secondary care).
- **Level 3:** Headache specialist centres, with a headache specialist and sometimes with multidisciplinary care offered by other healthcare professionals, such as nurses, psychologists, and physiotherapists (considered tertiary or quaternary care).

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[22] Becker and others, "Guideline for primary care management"; Medrea and others, "Updated Canadian Headache Society Migraine Prevention Guideline"; Tzankova and others, "Diagnosis and acute management"; and Tzankova and others, "Pharmacologic prevention of migraine."

[23] Headache Classification Committee of the International Headache Society, "The International Classification of Headache Disorders."

[24] Becker and others, "Migraine Prevalence, Diagnosis, and Disability."

[25] Tzankova and others, "Diagnosis and acute management."

[26] Steiner and others, "Structured headache services."

An international study based on country comparisons and expert consensus suggests that if a system has adequate resources across all levels, Level 1 could meet up to 90 per cent of patient needs, Level 2 9 per cent, and Level 3 the remaining 1 per cent.[27] However, the reality is that many Canadians do not have access to a regular primary care provider[28] and our system faces a substantial shortage of family doctors and nurse practitioners,[29] which would skew these proportions.

A lack of primary care capacity (including limitations in knowledge as well as numbers of providers) not only prevents patients from receiving appropriate primary care, but creates a barrier for patients to return to Level 1 after seeing specialists, where their care would be more appropriately managed. Patients discharged from speciality care but without access to primary care can become orphaned. This means they can no longer receive higher levels of care but are not able to access support from lower levels to help them manage migraine.

Transitioning between levels of care can also create a disconnect in information sharing between specialists and primary care doctors. Clear discharge instructions are often missing for patients who no longer require speciality care. Finally, inappropriate or multiple referrals to higher levels creates longer waits for those requiring advanced care.

Developing processes and adhering to guidelines can support the seamless transfer of patients between levels. The referral process is a key area for improvement. Potential solutions include implementing digital referral platforms and having centralized referral or triage systems.

3. Self-management and advocacy

Migraine is a variable, dynamic, and complex condition. Frequency, duration, and severity of migraine differs between patients, as do the symptoms and impact on their ability to function.[30] Patients have different medical histories and co-morbidities, individual responses and preferences to treatments, and unique goals and life circumstances. People with migraine are expected to be responsible for self-managing aspects of their condition after diagnosis and are the primary navigators and coordinators of their own care.

People who are well-informed and empowered are better able to manage their migraine on a day-to-day basis and in the longer term, be better advocates for their care, and participate more fully in their care plan.

Well-informed patients know the different phases of migraine headaches, understand the benefits of abortive and preventive therapies, and are aware of and understand how lifestyle changes may be beneficial. Empowered patients have improved self-efficacy, are able to advocate for their care, and can apply knowledge, skills, and supports to manage their condition. Effective education and empowerment improves the provider–patient relationship, gives patients a greater sense of autonomy and control, increases patient adherence to care plans, and ultimately improves quality of life.[31]

> "So even with the best care, I really still had to push. And once I did, though, I feel like [my provider] really came through for me and they've been really helpful over the years."
> **Patient participant**

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27 Steiner and others, "Recommendations for headache service organisation."

28 Canadian Institute of Health Information, *Access to primary care*.

29 Health Canada, "Caring for Canadians."

30 Lipton and others, "Risk factors for migraine disease progression."

31 Pescador Ruschel and others, "Migraine Headache."

4. Societal supports

Societal supports are core elements of migraine care.[32] Patients who were asked about their support network identified family and friends, patient advocacy groups, and workplaces as important elements. However, although they said these three elements are very important, they said that migraine affects their ability to maintain these relationships or engage these networks in meaningful ways.

Family and friends are an important support network for people living with migraine. They support lifestyle changes, step in to help seek aid, or take on life responsibilities.[33] They also promote healthy behaviours, reduce loneliness, and even increase compliance with treatment.[34] However, the role of family and friends as supports can be challenging to navigate.[35]

This is where patient, advocacy, and professional groups, such as the Canadian Headache Society, Migraine Canada, Migraine Quebec, and the Canadian Migraine Society, can help. They have resources that people with migraine and providers may find useful,[36] such as evidence-informed and experience-driven information and peer networks, run awareness campaigns, advocate for care, and support research. Examples of resources include patient education resource kits for migraine management,[37] activity programming,[38] and online support groups.[39]

Workplaces offer meaningful supports through medical benefits that cover treatments and care, flexible schedules that allow people with migraine to adjust their workhours, work environment accommodations that consider migraine-sensitive spaces, and supportive colleagues who can help ensure people with migraine have networks and resources to manage their responsibilities.[40]

These supports are important given migraine's impact on professional lives and productivity.[41] Without adequate supports, people find they need to leave their jobs, change careers, or reduce hours. This has personal, financial (take-home pay and health benefit coverage), and emotional consequences.[42]

> "And like I lost my 10-year career because of migraine, and I lost my benefits, and then I lost access to all the medications that I could have had before."
>
> **Patient participant**

Along with absences, productivity loss occurs through presenteeism. People with migraine try to work but are less effective due to pain, other symptoms, unpredictability of attacks, co-morbidities, emotional impact, undertreatment and underdiagnosis, and stigma.[43] The patient participants felt that a lack of broader public understanding of migraine makes it challenging to request accommodations (e.g., low lighting in workplaces) that would help them function better.

Stigma around migraine is a barrier to social support. It hampers a person's ability to seek help and further isolates them from the people and programs that could better support them.[44] Stigma is rooted in a lack of awareness about migraine and leads to people with migraine internalizing the stigma, which gives rise to feelings of shame, guilt, and isolation. Stigma causes discrimination in workplaces, healthcare, and personal relationships.[45] It also impacts social structures, such as policies and funding.[46] For example, despite its high prevalence and socioeconomic impact, we heard from healthcare professionals that there is only a limited amount of clinical education dedicated to migraine care.

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[32] D'Amico and others, "Are Depressive Symptomatology, Self-Efficacy, and Perceived Social Support?"
[33] Migraine Canada, "Migraine & Relationships."
[34] D'Amico and others, "Are Depressive Symptomatology, Self-Efficacy, and Perceived Social Support?"
[35] Leonardi and others, "Chapter 2 - Societal and Personal Impact of Migraine"; and Buse and others, "Life With Migraine."
[36] Migraine Canada, "Migraine & Relationships"; and Canadian Migraine Society, "A Chronic Migraine Primer."
[37] Migraine Canada, "Patient Education Resource Kit."
[38] Migraine Québec, "Programmation d'activités."
[39] Canadian Migraine Society, "Find Support."
[40] Begasse de Dhaem and others, "Migraine in the workplace."
[41] Leonardi and others, "Chapter 2 - Societal and Personal Impact of Migraine"; and Buse and others, "Life With Migraine."
[42] Begasse de Dhaem and others, "Migraine in the workplace."
[43] Begasse de Dhaem and Sakai.
[44] Parikh and others, "Migraine."
[45] Tana and others, "Health equity, care access and quality in headache."
[46] Parikh and others, "Migraine."

5. Enablers: Factors that support a model of care

Education

Education is a cross-cutting enabler needed to deliver improved patient outcomes.[47] We heard that a lack of migraine knowledge undermines the ability of our healthcare system to effectively deliver migraine care.

Further education is required for healthcare providers, for patients and their support networks, for decision-makers, in society as a whole:

- Improving education on migraine among healthcare providers would increase the capacity of healthcare systems to meet patient demand and deliver consistent, high-quality care.
- Identifying and disseminating reputable and evidence-based educational resources would empower people with migraine to educate themselves about their condition and potential treatments or lifestyle changes, so they can participate meaningfully in care decisions.
- By collecting and sharing better information about the true extent of people with migraine at a population level, policy-makers and healthcare system decision-makers will be better positioned to accurately assess and meet the demands for accessing migraine care.
- Increased public understanding of headache disorders would reduce the stigma of migraine and encourage more people with migraine to seek care or help.

"I think what creates good care is really good education."
Patient participant

The learning health system

The migraine model of care includes a learning health system component that will enable it to evolve and support migraine care delivery, and maximize its utility. A learning health system approach combines research and quality improvement with healthcare operations for rapid generation, synthesis, uptake, and refinement of evidence to improve care.[48]

"The research is moving forward, but the communication of the research is still way behind."
Patient participant

There are many areas to explore for quality improvement and research work, which would feedback into improving the model of care, its uptake, and its impact. Some examples are:

- knowing how caseloads are currently split between levels of care, which would help measure the impact of changes in policy, practice, and clinical guidelines;
- understanding the risks and benefits, tools, and safety measures necessary to make more migraine medications (e.g., triptans) available as over-the-counter medications;
- bolstering knowledge mobilization strategies to combat rapidly evolving misinformation;
- measuring the return on investment of workplace programs to support migraine.

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[47] Smith and others, "Migraine Education Improves Quality of Life"; and Lagman-Bartolome and others, "Headache Education Active-Waiting Directive."

[48] "Ontario SPOR SUPPORT Unit, "Learning Health System."

Interprofessional collaboration

The effectiveness of migraine care can be greatly improved through structured (e.g., multidisciplinary teams) or unstructured interprofessional collaboration.[49]

Many migraine patients receive care from several healthcare providers (e.g., neurologists, primary care doctors, nurses, dietitians, pharmacists, physiotherapists, acupuncturists). The patient participants said they have many different providers as part of their care team, but emphasized that the care being provided is often uncoordinated or sequential, which causes delays and introduces the potential for conflicting care pathways.

Interprofessional collaboration enables, for example, primary care providers to seek the expertise of neurologists or headache specialists. Nurses and psychologists can provide patient education and mental health support, and guide medication use. Pharmacists can offer patient education, help identify migraine, provide care management, verify dosing, and identify drug interactions. The key is for healthcare providers to establish mechanisms for communication, shared goal-setting, and informed decision-making.

Collaboration between professions in the development and distribution of tools and guidance, education materials, and resources bolsters their validity and usefulness, employs practical principles to enable multidisciplinary teams to work collaboratively, and aligns language and practice.

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[49] Wallasch and others, “Multidisciplinary integrated headache care”; McCutcheon and others, “Impact of interprofessional primary care practice”; and Bosch and others, “Interprofessional collaboration in health care.”

Implementation considerations

To advance the implementation of the migraine model of care, five core considerations emerged:

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The key organizations positioned to implement elements of the model include those mandated to raise awareness and advocate for migraine care, responsible for training healthcare providers, involved in developing and disseminating practice standards and care pathways, and responsible for funding and policy decisions. Key individual stakeholders for model implementation include patients, healthcare providers (e.g., primary care doctors, nurse practitioners, pharmacists, neurologists), and decision-makers.

Appendix A

Methodology

About the research

To develop the model of care, The Conference Board of Canada sought to answer the following questions:

1. Patient outcomes: What are the outcomes that matter to people living with migraine?
2. Integrated models: What are the components of a model of care for migraine?
3. Alignment: How should the components be structured to address the outcomes that matter to patients?
4. Implementation: What are the barriers and facilitators that must be considered when implementing the model of care?

We reviewed grey and academic literature, conducted patient dialogue sessions, and held a roundtable discussion with healthcare providers, system leaders, and industry representatives.

Detailed methods

Patient dialogue sessions

We conducted patient focus groups in the first phase of the project to understand the outcomes that matter to people living with migraine. We followed the Experience Group Methodology developed by the Value Institute for Health and Care at The University of Texas at Austin. The methodology is based on a grounded theory approach that uses inductive methods to generate insights, brings together small groups of people with shared medical experiences to discuss their lived experience, and applies a light moderation technique to facilitate the discussion. Our approach was reviewed and approved through Veritas IRB (2024-3626-19415-1).

We facilitated four dialogue sessions with 20 patient participants in December 2024 and January 2025. They were recruited from British Columbia, Ontario, Quebec, and Nova Scotia. The project's Research Advisory Board (RAB) members shared information about the study and eligibility criteria with their patient networks. Potential participants then reached out to the lead researcher, who answered questions and distributed the informed consent form. Once potential participants confirmed their consent, the lead researcher scheduled the participant into one of four sessions. All participants were diagnosed with chronic migraine; however, two participants also shared experiences from when their migraine was episodic.

The sessions were recorded in Microsoft Teams, transcribed through Teams (180 pages), and managed in NVivo. The lead researcher coded the transcripts using open and closed coding. The codes selected *a priori* were based on the dimensions of meaningful patient outcomes described by Liu, Bozic, and Teisberg (2017): i. comfort – relief from physical and/or emotional suffering; ii. capability – ability to function and do the things that define them as individuals; and iii. calm – ability to live without disruption from their condition or its treatment.[1]

We used the qualitative framework method to describe themes according to categories of patient outcomes (i.e., comfort, capability, and calm). We also identified themes that supported the formation of the components included in the migraine model of care (e.g., patient-centred care, care team relationship, education).

The qualitative findings, which are presented in the report, helped us develop the model of care. We also included direct quotes to support and illustrate the content. A description of the qualitative findings is presented in Appendix B.

Literature reviews

In the second phase of the project, we wanted to understand the potential components of a model of care for migraine. This involved focused reviews of grey and academic literature. We searched Google and Google Scholar for websites, reports, presentations, and figures describing examples of models of care, their components, and principles for migraine and other chronic conditions. We looked to the academic literature to understand the theoretical and conceptual concepts underpinning models of care for migraine (e.g., chronic care model). We extracted information on model components (e.g., core components, context, inputs, principles), system transformation or implementation, and the patient perspective or experience. This information was used to design and describe the model of care components.

We also conducted focused reviews to gather background information on migraine epidemiology, health resource use, and current challenges in delivering care. These findings were used to provide context.

Findings were reviewed by RAB members for their relevance and importance. RAB members also shared additional references for us to consider.

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[1] Liu and others, "Value-based Healthcare."

Roundtable discussion

In the third phase of the project, CBoC set out to provide insights for implementing the model of care. We hosted and facilitated a 2.5-hour virtual roundtable discussion in Microsoft Teams in December 2024. Fourteen leaders with expertise in industry, migraine care, patient and provider advocacy, and system transformation were invited. Twelve of these participants were members of the project's steering committee and RAB. We also invited two additional guests from industry and system transformation.

Attendees were given an overview of the model of care components. We used prepared prompts for participants to discuss who the change-makers are and what is needed, what is available, and what barriers exist in the system for:

- delivering evidence-informed care (access, delivery, learning systems);
- optimizing use of healthcare professionals (appropriate levels of care, transitioning between levels, access);
- supporting integrated care (organizational, functional, structural, service, and clinical structures/processes);
- embedding a patient-centred approach (patients, providers, system);
- harnessing synergies (connectivity between components, levers) and mitigating frictions (objectives, professions, system/provider/patient).

CBoC recorded and transcribed the roundtable discussion in Teams. From the discussion, we then developed considerations for implementing the model of care, actionable insights, and examples.

Appendix B

Patient dialogue session themes

Relief from pain and suffering

The patient participants want access to care that alleviates the physical, mental, and emotional suffering caused by migraine. They spoke about having to push themselves past pain, push through symptoms, and push their healthcare providers for help to find a management plan that addresses not only their pain but other symptoms and co-morbidities.

> "I think that's one of the reasons why migraine disease is so challenging because it can be more debilitating with less pain or less debilitating with more pain."
> **Patient participant**

While they understand that treatments can vary between individuals and that an intervention takes time to become effective, they have experienced unnecessary delays in receiving care or having a healthcare provider identify the right treatment. This adds stress and anxiety and the wrong treatment can worsen a migraine. Participants also said there is a lack of awareness among healthcare providers, who may also lack capacity to deliver the latest guideline-recommended treatments. They also admitted that patients themselves can fail to understand the importance of adhering to a certain protocol and may find it challenging to follow the recommendations of a healthcare provider, especially when they do not know why certain decisions are being made. The patient participants also said they cannot afford the out-of-pocket costs for some medications, treatments, or interventions. These also vary from province to province.

Functioning

Patient participants are frustrated and concerned that their migraine symptoms and side effects from the treatments are causing a lot of dysfunction in their lives. They don't expect to always be able to carry on as normal, but they do want a model of care that mitigates dysfunction from migraine and supports a better quality of life. They want to be able to do more and to be more consistent in what they can do.

> "It was under control at one point and now it's totally out of control. I'm so worried about losing my life and getting that state where I can't function and I can't push through. It feels sometimes like sand slipping through your fingers, like you've got something under control and then something changes."
> **Patient participant**

> “I have two teenage boys. So an ideal day for me is just to be able to show up and be present and not just be in survival mode, like cooking dinner and doing laundry. I’d love to get back to work, but I’m not there. I’m sorry. It’s emotional.”
> **Patient participant**

The patient participants described migraine as an invisible disease, and everyone’s experience differs. They felt they had to work hard to be heard by healthcare providers about how much they are struggling. Once providers understood just how much migraine was impacting them, they were only then taken seriously and received a care plan that addresses their personal migraine-management goals. Moreover, a lack of broader public understanding of migraine means that most workplaces are not aware of accommodations that could be offered to support employees (e.g., low lighting).

Disruption

Migraine and its treatment and management can be extremely disruptive to patients’ lives – on their ability to live well and to maintain work, interests, and relationships. The patient participants said they feel in control when their symptoms are well managed.

> “My ideal version of what it looks like to be well managed is where I can make plans, not worry and think about my attacks all the time. And then when I do get an attack, being able to take a pill and know it is going to help me and then I’m not going to be debilitated or have to cancel plans.”
> **Patient participant**

Migraine diagnosis is often delayed, and that the delay means that people live with untreated pain and other symptoms for too long. The patient participants said that the public and healthcare providers should be more aware about migraine and its debilitating effects. There should also be access to primary care doctors who can make a diagnosis, develop a care plan, or make a referral.

> “And my GP never diagnosed me, and I never had a preventive treatment for all these years where I had like a migraine or two a month. But then when the frequency started to be alarming, I could not see my GP. Over six months, I went from one or two a month to 30 a month and being completely disabled.”
> **Patient participant**

Securing access to the right level of care is a challenge for patients. This challenge may be the result of not having a primary care provider, not being able to secure a referral to a specialist, or having to wait for long periods of time for visits. For some, this means they are not able to access the right treatments or form a care plan in a timely way.

> “It took two years for my GP to actually fill out the paperwork properly, and then I actually ended up having to fill it out myself and then have the GP send it in for me.”
> **Patient participant**

When patients do interact with the healthcare system and are receiving care for migraine, they said they have experienced inconsistencies in the care being provided and in the process used to be referred to a specialist. Once they saw a specialist, participants said they felt like they were treated as temporary patients – tossed around among providers. This inconsistency and instability can make a patient feel unsupported, disappointed, and fatigued by the healthcare system.

> “It’s just impossible to get appointments. I think within this country, it’s hard to get to see somebody that is able to treat you on a regular enough basis to make a difference. It’s the system itself.”
> **Patient participant**

Rather than starting with a new healthcare provider, patient participants want a model that makes it possible for patients, when appropriate, to form care plan goals (short-term, medium-term, and long-term goals) and to enter into a partnership with their providers.

Recognizing the limitations of how long a specialist can spend with a patient, the patient participants felt there was a lot of value in having access to interprofessional teams where another provider could spend time answering questions, hybrid appointments could be arranged with a headache specialist and an allied healthcare provider, or technologies like AI or virtual visits could be used to balance efficiency with patient dialogue.

Greater emphasis should be placed on preventive care and healthcare providers who provide preventive care should be adequately compensated. The patient participants felt that having greater opportunities, tools, and resources to speak to healthcare providers about self-management options and preventive care could mitigate the disruptiveness of migraine.

Time spent managing migraine, time missed at work or other meaningful activities, and time spent accessing care also cause disruption in the lives of people with migraine. Managing migraine care, especially for patients with chronic migraine, takes a lot of time and effort. One patient participant estimated it took them 15 to 20 hours a week managing their migraine. Also missing work due to migraine can lead to a loss in full-time employment and the benefits that pay for migraine care. Patient participants from rural and remote communities shared the benefits of virtual appointments given the distance required for in-person visits.

Appendix C

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