A thematic analysis of 1119 Canadians living with migraine: advice and key messages for young people with migraine, health care providers, and policy makers

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Introduction

- Migraine negatively impacts all aspects of life, from the personal, to the social, and the work spheres.[1]
- A recent Greek study has used a Delphi and focus group approach to investigate burden of disease diagnosis, treatment and unmet needs.[2]
- The burden of migraine in Canada is significant and costs have been quantified.[3]

- Patient organizations have experienced substantial growth and influence over recent years.
- Strategic planning should align closely with the evolving priorities of the patient community.
- Gathering input directly from patients helps disease advocates and clinicians representing their views.

- Open-ended responses can provide valuable, unfiltered insights.
- Thematic analysis helps distill core messages from large volumes of patient feedback[4].
- We asked patients to tell us directly what they would say to three different types of stakeholders.

To a young person with migraine starting the journey

Q1	% of respondents who provided qualitative responses: 70.4% answered	
1	Seek a health care professional	39.7
2	Encouragement and fight stigma	39.5
3	Empower yourself (Self Advocate, Self Educate)	26.4
4	Self-care (diary, avoid triggers, alternate therapies)	25.0
5	Optimize Treatment (take as prescribed, take prevention, learn about newest drugs)	24.1

Follow the the Migraine Canada FB and website. Attend the webinars. Join the Migraine World Summit for latest information and multi disciplinary approaches.
Talk to your HCP and keep a diary and take it with you. And get a good preventative… being mindful of triggers…but live your life…they are manageable…you have to be patient though.

Methodology

- An online survey including 106 questions assessing different aspects of life with migraine was distributed to the networks of Migraine Canada and Migraine Quebec (English and French language) and through Canadian headache clinics from September 16th 2021 to October 31st 2021.

- Three open-ended questions were included to probe participants on the advice they would give different target groups:
  - A young person starting their migraine journey (Q1)
  - Health care providers (Q2)
  - Health Care Minister (Q3).
- Two researchers (KF and RB) reviewed the surveys and engaged in open coding, identifying meaningful units of text and assigning preliminary codes
- Codes were then reviewed with researchers EL and DB.
- Discrepant codings were resolved by consensus.
- The final themes were organized into groups by KF, RB, DB and EL.
- In total, 1119 respondents completed the survey.

To a doctor / health care provider

Q2	% of respondents who provided qualitative responses: 70.7% answered	
1	Treat migraine patients with compassion and respect	64.6 (highest %)
2	Optimize treatment and propose all options, keep trying	39.3
3	Migraine is a real disability/disease and accommodations and support are needed (anti-stigma)	18.6

Please listen to your patients concerns, take the time to explain things, let them know that what they are experiencing is normal and why.

Don't leave them feeling more helpless after their appointment and don't push them to take medications that cause really bad side effects when they tell you they are affecting every aspect of their life.

Results

Sex	
Female	93.5%
Male	6.4%
Prefer not to answer	0.1%
Ethnicity	
Caucasian	94.4%
Non-caucasian	5.6%

Age	
0-29	10.8%
30-39	20.2%
40-49	30.0%
50-59	23.3%
60-89	15.6%

Province	
Northwest*	12.8%
Alberta	10.7%
Saskatchewan, Manitoba	4.6%
Quebec	35.3%
Ontario	31.1%
Maritimes**	5.5%

*: British Columbia, Yukon, Northwest Territories
** New Brunswick, Newfoundland and Labrador, Nova Scotia, Prince Edward Island.

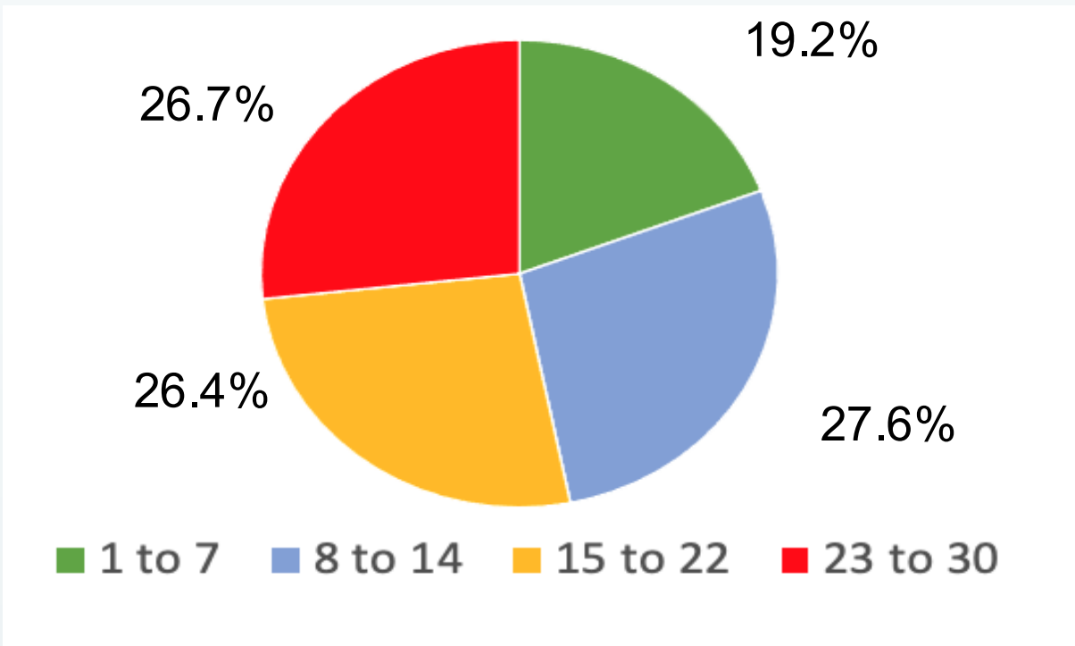

Figure 1: Participants were divided in four categories of Monthly Headache Days Frequency (MHDF)

53 000 words were analyzed.

To a Health Care Minister

Q3	% of respondents who provided qualitative responses: 66.8% answered	
1	Increase funding/ access to treatments	53.2
2	Migraine is a real and disabling, decrease stigma, provide support	31.6
3	Increase funding for research/HCP training	25.0
4	Improve access to health care providers	18.7
5	Disability benefits and workplace accommodations	12.0

Cover migraine specific treatments for ALL. Acquire more headache specialists as the wait times and options are limited.
Train and inform hospital emergency room staff how to treat chronic pain patients with compassion and not make us out to be drug seekers when the pain we're in is agonizing enough on its own.
Invisible illnesses are real and deserve the same level of attention as a visible illness.

Conclusion

To our knowledge, this is the first study using this methodology on a large number of patients to study these themes.

Different overlapping themes emerged from our survey

- Stigma, empowerment, access to care, try and optimize

These themes support our current strategic plan

- Raising awareness on migraine with different stakeholders
- Promoting more education on migraine in medical curricula (partnership with the Canadian Headache Society)
- Improving access to care for migraine in Canada

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One sentence summary

Herein we share a qualitative analysis of data from 1119 Canadians living with migraine who shared key messages and advice they would direct to three sets of stakeholders: young people beginning their migraine journey, healthcare professionals who care for people living with migraine and to policy makers via an online survey.