

Use of medications for migraine in Aotearoa New Zealand

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ABSTRACT

AIM: To document and assess acute and preventive medication use in people with migraine disease in Aotearoa New Zealand.

METHODS: Online survey of people with migraine in Aotearoa New Zealand (n=530), run from 22 August to 7 October 2022, including questions on current and previous acute and preventive medication use, reasons for medication discontinuation and use of new migraine medications.

RESULTS: Most respondents had used simple analgesics for acute treatment; 55% were currently using a triptan; 27% were currently using an opioid. Overall, 27% of survey respondents had over-used at least one acute medication in the last month. Half of respondents were taking at least one preventive medication but only 57% of those eligible for preventive treatment were currently taking it. In those who had previously tried preventives, side effects and lack of efficacy were common reasons for stopping. Cost, lack of knowledge and awareness were the main barriers to use of new migraine medications.

CONCLUSION: Many people with migraine in Aotearoa New Zealand are not receiving optimal treatment, which increases the burden and cost of migraine disease. More effective and tolerable acute and preventive medications are needed that are affordable and available in Aotearoa New Zealand. Greater awareness of best practice prescribing is also needed.

Despite being a common and disabling condition, with a global prevalence of 14%, migraine disease is often inappropriately or under-treated.¹ This is due to a combination of low consultation rates for headache (for reasons including cost, system barriers or not prioritising getting help for headache),² failure among health professionals to accurately diagnose migraine and poor delivery of evidence-based migraine treatment.³⁻⁵

There are two elements to migraine treatment: management of acute attacks and instigation of a preventive medication. Appropriate management of migraine attacks is important not only to ameliorate the pain and disability of the attack but also because inadequate treatment may contribute to the development of chronic migraine (headache on 15 days or more a month for at least 3 months).⁶

Over-the-counter medication such as non-steroidal anti-inflammatory drugs (NSAIDs) and prescription-only triptans are first-line treatments for migraine attacks. Triptans were developed in the 1990s specifically to treat migraine and are recommended for moderate to severe headache or when NSAIDs are ineffective.¹ Of the seven triptans used globally, two (sumatriptan and rizatriptan) are currently available in Aotearoa New Zealand. International surveys report that only between 6–23% of people with migraine

are currently using a triptan,^{3,7} and although this is higher in people with chronic migraine,⁸ it suggests that under-utilisation of triptans is widespread.³ However, NSAIDs and triptans do not work or are not suitable for all people with migraine.⁹ NSAIDs have gastrointestinal and cardiovascular side effects and triptans may be contraindicated in as many as a fifth of people.^{9,10}

Opioids (e.g., codeine, tramadol, oxycodone) are not recommended for migraine attacks because they are not as effective as first-line options, have significant side effects, a risk of addiction and are associated with an increased risk of chronic migraine and medication overuse headache (MOH).¹¹ MOH is a chronic secondary headache that develops in people with migraine (or another primary headache disorder) who have headache for 15 days or more a month and have used (for at least 3 months):

- Simple analgesics on ≥ 15 days a month (including paracetamol, NSAIDs, combination analgesics and caffeine).
- Opioids or triptans on ≥ 10 days a month.¹²

Hence, inappropriate management of migraine attacks includes not only under-use of migraine-specific triptans where indicated, but over-use of triptans and analgesics, and any use of opioids.⁹

The second element of migraine management, prevention, is recommended for those with frequent and/or disabling headache. The goals of preventive treatment are to reduce frequency and severity of attacks, reduce disability, improve response to acute treatments and prevent or treat MOH.¹³ However, preventive medications for migraine are often under-used.⁴ For example, a large United States (US) study of people with migraine calculated that 40% were eligible for preventive treatment but only 17% were currently using it.³ This is often due to the poor tolerability/adverse effects and relatively poor efficacy of these medications.^{9,14,15}

Despite affecting an estimated 642,000 people in Aotearoa New Zealand and causing significant impacts on work, life and physical and mental health,¹⁶ there are no published data on acute or preventive medication use in people with migraine in Aotearoa New Zealand, nor any published data on whether migraine management in Aotearoa New Zealand adheres to evidence-based recommendations. We undertook a survey of people with migraine to explore:

- Current and previous use of acute and preventive migraine medications.
- Under-use and misuse of medications, including risk of acute medication overuse.
- Need for new types of migraine medication, specifically the monoclonal antibodies developed to treat migraine by targeting calcitonin gene-related peptide (CGRP).

Methods

The online *Migraine in Aotearoa New Zealand Survey* ran from 22 August to 7 October 2022, via SurveyMonkey. Recruitment was through website and/or social media platforms of Migraine Foundation Aotearoa New Zealand (MFANZ), Healthify, Neurological Foundation and New Zealand Pain Society, via media articles and through personal networks of MFANZ co-founders.

The survey was piloted by six individuals, five with migraine disease. Responses were anonymous and informed consent was assumed by initiation of the survey (information about the survey was provided on the landing page). Ethical approval was granted by the University of Otago Human Ethics Committee (D23/156).

Respondents were asked about acute medications taken for migraine: paracetamol, NSAIDs, triptans, opioids, anti-emetics and caffeine, with response

options of currently use, previously used—stopped because of side effects, previously used—stopped because it didn't work, previously used—stopped for another reason, never used—would like to try, never used—don't want to try. Respondents were asked on how many days in the last month they had used paracetamol, NSAIDs, triptans or opioids and were classified as at risk of medication over-use if used 15 days or more a month (for paracetamol and NSAIDs) or 10 days or more a month (for opioids and triptans).

Respondents were also asked about use of prescribed preventive medications (same response options as above) that are listed in international guidelines on migraine treatment, including melatonin (which is often a prescription medication) and onabotulinumtoxinA (Botox™) injections. We derived the number of oral preventive medications currently or previously used through a count of all listed medications, excluding Botox™ and CGRP monoclonal antibody injections.

We determined that respondents were “eligible” for preventive treatment if they had:

- Eight or more headache days a month, and/or
- Moderate to severe disability, as measured by the Migraine Disability Assessment Scale (MIDAS), which measures the impact of migraine on daily life through questions about limitations on work/study, household work, social/family life in the last 3 months, with a score of 21 or more indicating severe disability.¹⁷

We also asked whether a GP or neurologist had been seen about migraine, with response options including seen in the last 12 months.

The survey included an open-ended question about the new CGRP monoclonal antibody medications, noting that only erenumab and galcanezumab were available in Aotearoa New Zealand. Respondents were asked about their experience with these and why they would or would not try one in the future. More details about other questions in the survey are published elsewhere¹⁶ and a copy of the questionnaire is available in the Appendix.

The final dataset included 530 respondents, after removal of duplicates (n=4) and responses completing <6% of survey questions (n=33). Only people with a positive ID-Migraine test™ (n=513), which has a sensitivity of 84% and specificity of 76%,¹⁸ or a migraine diagnosis from a health

professional (n=17) were included.

As the survey was a convenience, self-selected sample, only descriptive and unweighted statistics were calculated, using Microsoft Excel version 2403. Missing data were excluded from analyses; respondents were able to skip individual questions, so response rates for each question varied. The qualitative data from the open-ended question were coded for themes relating to reasons for or against trying the new medication. Three main themes around barriers to uptake of these medications were identified. Quotes to illustrate the themes include the gender, age group and ethnicity of the respondent.

Results

The survey sample was predominantly female (82%) and NZ European (77%) (Table 1). Over a fifth (22%) had chronic migraine, who were more likely to report severe migraine disability and poor self-rated health than those with episodic migraine.

Acute medications

Use of acute medications for migraine is detailed in Table 2. Most people had used NSAIDs or paracetamol and around half or more currently used NSAIDs, caffeine, triptans and paracetamol.

Table 1: Characteristics of survey respondent by migraine type.

Characteristic	Migraine type					
	Chronic n=118 (22.2%)		Episodic n=412 (77.7%)		Total n=530	
Age band	N	Col %	N	Col %	N	Col %
<18 years	1	0.8	1	0.2	2	0.4
18–24 years	5	4.2	15	3.6	20	3.8
25–34 years	16	13.6	64	15.5	80	15.1
35–44 years	30	25.4	93	22.6	123	23.2
45–54 years	35	29.7	120	29.1	155	29.2
55–64 years	15	12.7	55	13.3	70	13.2
65+ years	7	5.9	24	5.8	31	5.8
Missing	9	7.6	40	9.7	49	9.2
Gender						
Female	96	81.4	337	81.8	433	81.7
Male	10	8.5	31	7.5	41	7.7
Another gender	3	2.5	5	1.2	8	1.5
Missing	9	7.6	39	9.5	48	9.1
Ethnic group						
Māori	7	5.9	32	7.8	39	7.4
Pacific peoples	0	0.0	6	1.5	6	1.1
Asian	2	1.7	21	5.1	23	4.3
NZ European/Other	99	83.9	310	75.2	409	77.2
Missing	10	8.5	43	10.4	53	10.0

Table 1 (continued): Characteristics of survey respondent by migraine type.

MIDAS disability score						
0–5 (little or no)	1	0.8	74	18.0	75	14.2
6–10 (mild)	3	2.5	74	18.0	77	14.5
11–20 (moderate)	11	9.3	105	25.5	116	21.9
>21 (severe)	103	87.3	159	38.6	262	49.4
Self-rated health						
Excellent	6	5.1	39	9.5	45	8.5
Very good	24	20.3	147	35.7	171	32.3
Good	46	39.0	145	35.2	191	36.0
Fair	22	18.6	64	15.5	86	16.2
Poor	19	16.1	17	4.1	36	6.8
Missing	1	0.8		0.0	1	0.2

Table 2: Acute and preventive migraine medication use.

	Currently use		Never used		Stopped using—did not work		Stopped using—side effects		Stopped using—other reason¹		Total
	n	Row %	n	Row %	n	Row %	n	Row %	n	Row %	
Acute medications											
NSAIDs	318	60.6%	28	5.3%	106	20.2%	40	7.6%	33	6.3%	525
Caffeine	277	55.4%	138	27.6%	51	10.2%	18	3.6%	16	3.2%	500
Paracetamol	256	48.6%	16	3.0%	241	45.7%	3	0.6%	11	2.1%	527
Anti-emetic	215	41.7%	179	34.7%	35	6.8%	18	3.5%	69	13.4%	516
Sumatriptan	170	32.9%	199	38.5%	55	10.6%	44	8.5%	49	9.5%	517
Rizatriptan	166	32.1%	188	36.4%	69	13.3%	37	7.2%	57	11.0%	517
Opioids	139	27.0%	174	33.8%	70	13.6%	56	10.9%	76	14.8%	515
Preventive medications²											
Antidepressants											
Amitriptyline	52	10.8%	255	53.1%	68	14.2%	91	19.0%	14	2.9%	480
Nortriptyline	41	8.8%	306	65.4%	48	10.3%	59	12.6%	14	3.0%	468
Venlafaxine	23	5.1%	375	83.5%	13	2.9%	30	6.7%	8	1.8%	449
Fluoxetine	19	4.2%	345	77.0%	17	3.8%	34	7.6%	33	7.4%	448

Table 2 (continued): Acute and preventive migraine medication use.

Antihypertensives (including beta-blockers)											
Propranolol	24	5.1%	351	74.2%	45	9.5%	45	9.5%	8	1.7%	473
Metoprolol	20	4.4%	398	87.3%	13	2.9%	20	4.4%	5	1.1%	456
Candesartan	21	4.6%	403	88.0%	23	5.0%	7	1.5%	4	0.9%	458
Nadolol	12	2.6%	400	87.1%	22	4.8%	21	4.6%	4	0.9%	459
Verapamil	5	1.1%	433	95.2%	8	1.8%	6	1.3%	3	0.7%	455
Antiepileptics											
Topiramate	24	5.0%	329	68.4%	38	7.9%	85	17.7%	5	1.0%	481
Gabapentin	17	3.7%	401	86.8%	18	3.9%	18	3.9%	8	1.7%	462
Lamotrigine	4	0.9%	435	96.0%	6	1.3%	4	0.9%	4	0.9%	453
Sodium valproate	2	0.4%	411	89.7%	18	3.9%	23	5.0%	4	0.9%	458
Other											
Melatonin	34	7.3%	349	74.9%	50	10.7%	10	2.1%	23	4.9%	466
Botox TM	20	4.1%	424	87.6%	30	6.2%	1	0.2%	9	1.9%	484
Erenumab	15	3.2%	449	94.5%	7	1.5%	2	0.4%	2	0.4%	475
Pizotifen	7	1.5%	406	84.9%	36	7.5%	20	4.2%	9	1.9%	478

¹Stopped using for a reason other than that it did not work or had side effects (reason not specified).

²Preventive medications currently or previously used by five or fewer respondents are not presented (galcanezumab and lisinopril).

Other medications that respondents reported (that were not listed in the survey) included citalopram, sertraline, paroxetine, mirtazapine, duloxetine, cilazapril, quinapril, amlodipine, perindopril, lacosamide, pregabalin, clonidine, clonazepam.

Almost half had stopped using paracetamol because it did not work. Fifty-five percent were currently using one or both of the triptans, 23% had never used either of the triptans and 22% had previously used one or both of the triptans but had stopped for some reason. For each individual triptan, the most common reason for stopping was that they did not work.

Over a quarter of respondents were currently using opioids and only a third had never used them for migraine attacks (9% said they would like to try opioids). Of the 139 survey respondents who were currently using opioids for migraine, 36 had previously used a triptan but stopped, 30 had never used a triptan and the remainder were concurrently using a triptan.

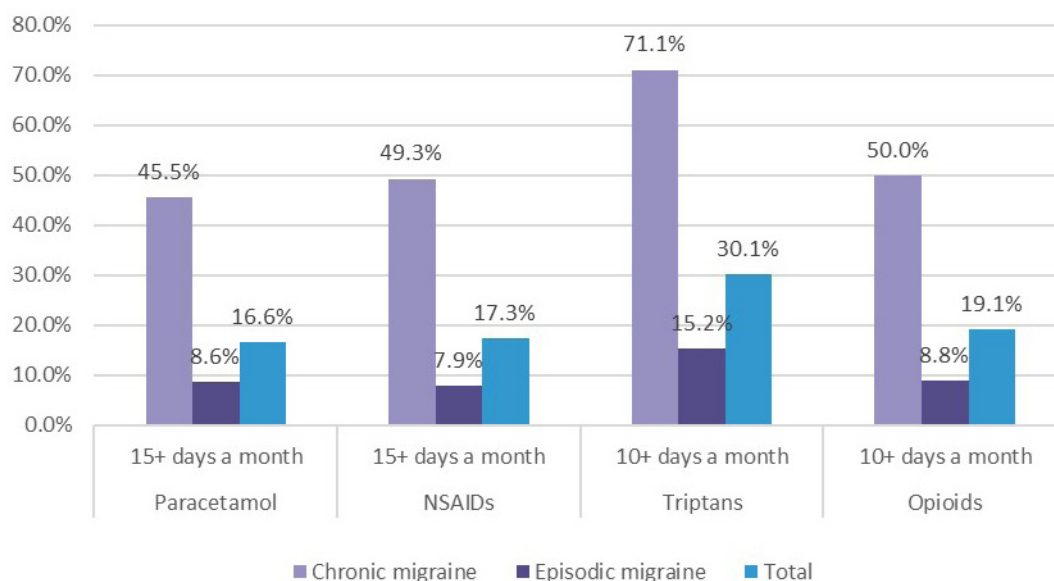
Risk of medication over-use

Overall, 27% of survey respondents had over-used at least one acute medication in the last

month (i.e., paracetamol or NSAIDs on 15 days or more, triptan or opioids on 10 days or more). This was higher in people with chronic migraine (70%) than episodic migraine (15%). By medication type, triptans were most commonly over-used, with 30% of those currently using triptans taking more than the recommended amount in the last month (Figure 1). Nearly one fifth of those currently using opioids were taking more than recommended. All the rates of over-use were much higher in those with chronic migraine than episodic migraine.

Preventive medications

A total of 496 respondents answered questions on migraine preventive medication. Half of these respondents (n=249) were currently taking at least one preventive. The most commonly used class of preventive was antidepressants, currently taken by 28% of survey respondents (36% previously used). Antihypertensives, including beta-blockers,

Figure 1: Acute medication over-use in the last month in those with chronic and episodic migraine.¹

¹Five missing responses for frequency of NSAID use among current users; three missing responses for opioids; two missing responses for paracetamol.

were the next most commonly used medication, currently taken by 17% of respondents (25% previously used). Only 8% of survey respondents were currently taking an antiepileptic for migraine prevention but 30% had previously taken one.

The most common currently used medications were amitriptyline, nortriptyline, melatonin, venlafaxine, propranolol and topiramate, each taken by 5% or more of respondents (Table 2). For all medications, a much higher proportion of respondents had previously tried and stopped the medication, because of lack of efficacy, side effects or another reason, than were currently using it. Side effects were most notable for amitriptyline, topiramate, fluoxetine, propranolol, nadolol, pizotifen and sodium valproate, where those who stopped due to side effects were nearly or more than double the proportion of those currently using them.

Current preventive medication use was higher in people with chronic migraine (72%) than episodic migraine (44%). Only 5% of those with chronic migraine had not previously used any preventives compared with 30% of those with episodic migraine. People with chronic migraine had previously used an average of four oral preventive medications. Of those who had previously used any preventives, 12% had tried seven or more.

Under-use of preventives

Nearly three quarters (74%, n=393) of all survey respondents were “eligible” for preventive medication, according to our stringent criteria of 8 headache days or more a month and/or presence of moderate–severe migraine disability. Of these, 369 respondents provided information about preventive medication use. Only 57% of people “eligible” for preventive treatment were currently taking it, while nearly two thirds (64%) of those **not** currently taking a preventive were “eligible” for one. Over a quarter (28%) of people with chronic migraine were not receiving preventive treatment.

Consultation with a health professional provides an opportunity for preventive treatment to be reviewed and instigated. In those who were “eligible” for preventive treatment, a higher proportion of people currently taking a preventive (compared with those not taking a preventive) had seen a neurologist (28% compared with 11%) and a GP (89% compared with 71%) about migraine in the last 12 months.

New treatments

There were 435 responses to the open-ended question about CGRP monoclonal antibodies. Many respondents reported that their migraine

attacks were so severe or poorly controlled they “would try anything” to reduce the impact of migraine attacks on their lives. The new medications represented hope for those who had found little relief from other preventives or had experienced intolerable side effects.

“I would love to try Emgality [galcanezumab]. I get horrible side effects from the propranolol... I have awful exercise tolerance due to my low blood pressure and everyday activities can be difficult. I have not reacted well or had benefit from other prevention medications so am stuck with this.”

– 18–24 years, Female, Māori

Respondents identified three main barriers to use of the new medications. The prohibitive cost (up to NZ\$325 a month for Emgality), uncertainty about effectiveness and side effects, and lack of awareness of their existence, in both patients and doctors.

All three of these barriers may need to be addressed for new medications to be accessible:

“I ... would try one in the future if I knew enough about it, if it was publicly funded and my doctor discussed it with me.” – 25–34 years, Female, Asian

Discussion

This survey of people with migraine in Aotearoa New Zealand reveals several areas where best practice in migraine prescribing was not being followed. For management of acute attacks, opioids were being inappropriately used in over a quarter of respondents. A similar proportion were at risk of MOH, through over-use of one or more acute treatments. Nearly a quarter had never used a triptan, which suggests a level of under-use, but may also include those with contraindications for triptan use. Over two fifths (43%) of those assessed as “eligible” for preventive medication were not currently taking a preventive, including 28% of those with chronic migraine, all of whom would benefit from effective preventive treatment.

Among people diagnosed with migraine, US research suggests that appropriate treatment is received by only 54–60%¹⁹ and many general practitioners (GPs) are not aware of or adhere to best practice on managing migraine.^{20,21} For example, a survey of GPs in the US found that only 28%

were familiar with the American Academy of Neurology guidelines on preventive treatment, only a third knew that opioids can cause MOH and few recommended non-pharmacological treatments, despite these being included in evidence-based guidelines.²⁰ The knowledge of GPs in managing migraine in Aotearoa New Zealand is unknown and deserves additional research to establish the role of prescribers in contributing to MOH and under-use of preventive medications. Ineffective migraine treatment increases the risk of developing chronic migraine and increases healthcare utilisation and costs.^{6,22,23} A stronger emphasis on the importance of avoiding opioids in the treatment of migraine is needed in Aotearoa New Zealand, for both health professionals, especially prescribers, and patients.

The prevalence of MOH in Aotearoa New Zealand is unknown. Estimates from international studies range from 0.5–2.6%,²⁴ with most cases associated with migraine.²⁵ As many as a third of people with episodic migraine and three quarters of people with chronic migraine may be at risk of MOH,¹⁹ which is consistent with our survey results that 15% of those with episodic and 70% of those with chronic migraine had over-used medication in the last month. MOH is avoidable with appropriate migraine management and is also treatable with effective preventive medications.²⁶ Knowledge about MOH among the public, people with migraine and health professionals is often low,^{24,25} including awareness of the risk of a person with migraine developing MOH if taking regular analgesics for another condition (e.g., back pain). Education of patients about MOH can reduce medication over-use and prevent MOH.²⁴

The high use of opioids and high rates of acute medication over-use in survey respondents also highlights the need for more options to treat migraine attacks that are safe and effective. Insufficient response to triptans can occur in around 30% of people with migraine,⁹ which could contribute to increased use of opioids as an alternative. In cases of initial triptan non-response, trying two or more different triptans is recommended.⁹ However, only two of the seven triptans on the market are available in Aotearoa New Zealand and only one is in a formulation that bypasses the stomach, which is beneficial for people with severe nausea or vomiting during a migraine attack. New, alternative treatments are available overseas (but not in Aotearoa New Zealand), including the ditan lasmiditan, which has a similar action to triptans but without the side

effect of vasoconstriction, and has demonstrated efficacy for those in whom triptans are contraindicated or ineffective.²⁷ Gepants (such as rimegepant, ubrogepant and zavegepant) are small molecule CGRP receptor antagonists taken orally or as a nasal spray that have few side effects and do not appear to induce MOH, unlike triptans.⁹

The survey also highlighted issues with the use of migraine preventive medications. These were much more likely to have been used in the past, and stopped because they were ineffective or intolerable, than to be currently used. Most people who had used preventives had tried more than one—one respondent had tried 18 different medications. International research has found that among people with migraine who have ever used preventive medication, the average number used was four for people with chronic migraine and three for people with episodic migraine,¹⁵ which was the same as in our survey. Close to half of respondents were not taking preventive medication despite frequent and disabling headaches. Many of those who were on preventive medication still had a high headache frequency, indicating that these medications were not working well. Adherence to migraine preventives has been shown to be low in many countries,¹⁴ with one study finding that only 17–20% of people continued with a preventive at 12 months.²⁸

New and more effective medications to prevent migraine attacks, that have fewer side effects, are needed to reduce migraine disability and chronification. Of the new migraine medications that target CGRP and can be used for prevention (the monoclonal antibodies and several gepants), only two monoclonal antibodies are currently available in Aotearoa New Zealand and neither are yet funded. In a recent systematic review, the CGRP medications outclassed other drugs used for migraine prevention in both safety and efficacy.²⁹ Early and effective preventive treatment has the potential to not only improve quality of life for people with migraine but also reduce healthcare and other costs and improve work and other functioning.³⁰ However, these new drugs do not work for all people with migraine, and more research into the underlying pathophysiological causes of migraine and development of additional targeted treatments is still needed.

At the time of this survey, respondents identified cost, lack of awareness about the existence of the medication and uncertainty around effectiveness and side effects as barriers to use. The latter two issues should resolve as awareness spreads across

health professionals and people with migraine, but cost remains a considerable obstacle, particularly for those who are unable to work. In December 2023, three CGRP medications (galcanezumab, erenumab and atogepant) were recommended for funding at a high priority by Pharmac's Neurological Advisory Committee, and in June 2023, these were added to Pharmac's Options for Investment list.

Strengths and limitations

This was the first survey of people with migraine undertaken in Aotearoa New Zealand and provides a snapshot of medication use in this sample. However, it was a non-representative survey, delivered online, and cannot be used to estimate prevalences at a population level. Responses from Māori and Pacific peoples were low, and more research is needed to explore potential ethnic inequities in migraine management.

We asked about medication use in the last month to minimise error from recall bias and reduce respondent burden from multiple questions. Since the diagnosis of MOH requires 3 months of medication over-use, our results only identify people at risk of MOH and will likely over-estimate the true risk. We provided names of commonly used medications but recall of previous medications may have led to an under-count of these.

Our estimate of eligibility for preventive medication was based on headache frequency and migraine disability, but is a conservative estimate because prevention is often appropriate for people with fewer than 8 headache days a month (e.g., if disability is high, if acute medications are ineffective or not well tolerated, or for specific types of migraine). Hence, our results will under-estimate the true number of “eligible” people and the proportion of those who are “eligible” but not using preventive medication.

Many non-prescription and non-medication approaches to migraine management (e.g., supplements, biofeedback, neurostimulation, acupuncture, lifestyle changes) are recommended for use, often in conjunction with medication.⁹ These were not included in this analysis but merit further research.

Conclusions

Many people with migraine in Aotearoa New Zealand are not receiving best practice prescribing of acute and preventive migraine medications. More awareness is needed among health professionals

and patients about the risk of MOH with acute treatments, especially opioids and triptans. There is a clear need for more effective acute and preventive medications, with fewer side effects. The lack of availability and affordability of new migraine-specific medications in Aotearoa New

Zealand means that people with migraine in Aotearoa New Zealand are likely to experience higher migraine disability and lower quality of life than those in countries with a broader range of treatment options.

COMPETING INTERESTS

Nil.

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Appendix 1: Migraine in Aotearoa New Zealand survey

Migraine in Aotearoa New Zealand

Survey information

This survey is to understand the burden and impact of migraine in Aotearoa New Zealand. It includes questions about treatments you've tried, health services you've used and any issues or challenges living with migraine has on your professional and personal life.

We are seeking participants who currently live in New Zealand who have been diagnosed with migraine or have symptoms that are consistent with migraine disease. These include:

- pain on one side of the head
- pain that lasts 4 hours to 3 days if not treated
- throbbing or pulsing pain, usually moderate to severe and often worse with routine activity such as walking or climbing stairs
- sensitivity to light, sound and/or smell
- nausea and vomiting.

This survey is being run by Migraine Foundation Aotearoa New Zealand. Migraine Foundation Aotearoa New Zealand is the only registered charity in New Zealand supporting people living with migraine. Our mission is to raise awareness of the impact of migraine disease and support people living with migraine in Aotearoa New Zealand.

All responses are anonymous and remain confidential.

The survey will take around 20 minutes to complete.

Migraine identification

Do you have migraine?

These questions help identify people who have migraine disease.

1. Have you had a headache in the last 3 months?
 - Yes
 - No
 - Don't know
2. Has a headache limited your activities for a day or more in the last 3 months? (Activities includes work, study, play or other things you need to do in the day.)
 - Yes
 - No
 - Don't know
3. Are you nauseated or sick to your stomach when you have a headache?
 - Yes
 - No
 - Don't know
4. Does light bother you when you have a headache?
 - Yes
 - No
 - Don't know

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

Please answer the following questions about ALL of the headaches you have had over the last 3 months. Select zero if you did not have the activity in the last 3 months.

It can be hard to remember what happened in the last 3 months, so your best guess is fine.

10. On how many days in the last 3 months did you miss work or school because of your headaches?
11. On how many days in the last 3 months did you not do household work (such as housework, home repairs and maintenance, shopping, caring for children and relatives) because of your headaches?
12. How many days in the last 3 months was your productivity in household work reduced by half or more because of your headaches? (Do not include days you counted in question 3 where you did not do household work.)
13. On how many days in the last 3 months did you miss family, social or leisure activities because of your headaches?

The total MIDAS score can be used to define four grades of migraine-related disability with grade I for “little or no disability” (0–5); grade II for “mild disability” (6–10); grade III for “moderate disability” (11–20); and grade IV for “severe disability” (≥ 21).

Note: one question was missed in the survey:

How many days in the last 3 months was your productivity at work or school reduced by half or more because of your headaches? (Do not include days you counted in question 1 where you missed work or school.)

Self-rated health

14. In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

Acute treatments

This section asks about what treatments you use when you get a migraine attack.

15. Do you or have you used paracetamol to treat your migraine attacks?

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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16. On how many days in the last month have you used paracetamol for a migraine attack?

0 30

17. Do you or have you used non-steroidal anti-inflammatories (NSAIDs) to treat your migraine attacks?

e.g., Aspirin, Ibuprofen (Nurofen, Brufen, Advil), diclofenac (Voltaren), naproxen (Naprosyn, Naprogesic, Noflam), celecoxib (Celebrex), meloxicam (Mobic)—including tablets that combine NSAIDs with paracetamol.

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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18. On how many days in the last month have you used NSAIDs for a migraine attack?

0 30

19. Do you or have you used sumatriptan (Imigran, Imitrex) to treat your migraine attacks?

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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20. On how many days in the last month have you used sumatriptan for a migraine attack?

0 30

21. Do you or have you used rizatriptan (Maxalt, Rizamelt) to treat your migraine attacks?

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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22. On how many days in the last month have you used rizatriptan for a migraine attack?

0 30

23. Do you or have you used opioids to treat your migraine attacks? e.g., tramadol (Tramal), codeine (including combined with paracetamol in Panadeine or ibuprofen in Nurofen Plus), Oxycodone.

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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24. On how many days in the last month have you used opioids for a migraine attack?

0 30

25. Do you or have you used anti-emetics (anti-nausea medications) to treat your migraine attacks? e.g., metoclopramide (Maxolon), ondansetron, prochlorperazine (Stemetil, Buccastem)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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26. Which of the following non-medication treatments have or do you use to treat your migraine attacks?

- Caffeine
- Occipital nerve block

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Neurostimulation device e.g., TENS machine
- Ginger e.g., tablets, tea
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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Preventive treatment

There are many medicines that can be taken to prevent migraine attacks. This section asks whether you have or would like to try preventive medicines and why you might have stopped taking them.

27. Which of the following anti-depressants have you used to prevent migraine attacks?

- Amitriptyline (Amirol)
- Nortriptyline (Norpress)
- Venlafaxine (Effexor)
- Fluoxetine (Prozac)
- Other (please specify)

Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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28. Which of the following anti-epileptic medications have you used to prevent migraine attacks?

- Topiramate (Topamax)
- Sodium valproate (Epilim)
- Gabapentin (Neurontin)
- Lamotrigine (Lamictal)
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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29. Which of the following anti-hypertensive or cardiac medications have you used to prevent migraine attacks?

- Nadolol (Corgard)
- Metoprolol (Lopressor)
- Propranolol (Inderal)
- Verapamil (Isoptin)
- Candesartan (Candesar)
- Lisinopril (Zestril)

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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30. Which of the following migraine-specific medications have you used to prevent migraine attacks?

- Pizotifen (Sandomigran)
- Erenumab (Aimovig)
- Galcanezumab (Emgality)
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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31. Which of the following hormone treatments have you used to prevent migraine attacks?

- Melatonin
- Estrogen, with or without progesterone e.g., hormone replacement therapy, combined oral contraceptive pill
- Progesterone on its own e.g., progesterone-only oral contraceptive, depot provera, progestin implant or intrauterine device/IUD
- Testosterone
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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32. Which of the following supplements have you used to prevent migraine attacks?

- Magnesium
- Riboflavin (vitamin B2)
- Coenzyme Q10
- Feverfew
- Ginger
- Butterbur
- Other (please specify)

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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33. Which of the following injections have you used to prevent migraine attacks?

- Botulinum toxin A (Botox) injections
- Occipital nerve block
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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34. Which of the following non-medication approaches have you used to prevent migraine attacks?

- Neurostimulation device e.g., TENS machine
- Meditation or mindfulness practice
- Yoga or tai chi
- Biofeedback
- Acupuncture
- Massage
- Cold therapy e.g., ice packs, cold baths
- Other (please specify)

Currently use	Previously used—stopped because of side effects	Previously used—stopped because it didn't work	Previously used—stopped for another reason	Never used—would like to try	Never used—don't want to try
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35. Aimovig, Emgality, Ajovy and Vyepti are a new class of migraine prevention medication developed specifically to target migraine (calcitonin gene-related peptide or CGRP monoclonal antibodies). They have fewer side effects than most other preventive medications. Only Aimovig and Emgality are currently available in New Zealand.

If you have ever tried one of these, please tell us about your experience.

If you haven't, please tell us why you would or wouldn't try one in the future.

Healthcare use

This section asks about health professionals you have seen to help your management of migraine disease.

36. Which of the following health professionals have you seen about migraine?

- Primary care/GP
- Neurologist
- Emergency department or urgent care physician
- Osteopath

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Chiropractor
- Pain specialist
- Physiotherapist
- Nutritionist/dietitian
- Occupational therapist
- Dentist
- Pharmacist
- Acupuncturist
- Naturopath
- Massage therapist
- Optician or eye specialist
- Other (please specify)

Seen in the last 12 months	Seen in the past (>12 months ago)	Never seen—would like to	Never seen—don't want to
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37. How would you rate the knowledge of migraine and treatment options in the health professionals you have seen? (If you have seen more than one, rate the one you have seen most recently)

- Primary care/GP
- Neurologist
- Emergency department or urgent care physician
- Osteopath
- Chiropractor
- Pain specialist
- Physiotherapist
- Nutritionist/dietitian
- Occupational therapist
- Dentist
- Pharmacist
- Acupuncturist
- Naturopath
- Massage therapist
- Optician or eye specialist
- Other (please specify)

Excellent	Very good	Good	Fair	Poor	Not applicable/ haven't seen
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38. Have you ever wanted to see a health professional for migraine but were unable to?

- Yes
- No

39. Which health professional(s) were you unable to see for migraine?

40. Why were you unable to see a health professional for migraine? (multiple responses allowed)

- It was too expensive
- Waiting time to be seen was too long
- Unable to get or was declined an appointment
- Service not available where I live
- Had no transport to get there

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Difficult to take time off work
- Could not arrange childcare or care for a dependent
- Other (please specify)

41. What could be done to improve your life with migraine?

Co-morbidities

The next question is about long-term health conditions. A long-term health condition is a physical or mental illness or condition that has lasted, or is expected to last, for more than six months. The symptoms may come and go or be present all the time.

42. Which, if any, of the following long-term conditions have you been diagnosed with and currently have (in addition to migraine)? Please select all that apply

- Anxiety
- Arthritis
- Asthma
- Depression
- Epilepsy
- Fibromyalgia
- Heart disease
- Hypertension/high blood pressure
- Insomnia
- Irritable bowel syndrome
- Low back pain
- Stroke
- I do not currently have any other long-term health conditions
- Other (please specify)

Stigma

43. How often do you hide or minimise migraine symptoms for fear of being judged or misunderstood?

- Always
- Often
- Sometimes
- Rarely
- Never

44. How often do you feel judged or misunderstood because of your migraine disease by your:

- Spouse or partner
- Family
- Friends
- Workplace
- School/place of education or training
- Health professional
- Other (please specify)

Always	Often	Sometimes	Rarely	Never	Not applicable/ don't know
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Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

45. Is there anything else you want to tell us about living with migraine in New Zealand?

Demographics

The final questions are about you.

46. How old are you?

47. What is your gender?

- Male
- Female
- Another gender
Please specify

48. Which ethnic group or groups do you belong to?

- New Zealand European
- Māori
- Samoan
- Cook Island Māori
- Tongan
- Niuean
- Chinese
- Indian
- Don't know
- Refused
- Other (please specify)

49. Where do you live?

- Northland
- Auckland
- Waikato
- Bay of Plenty
- Gisborne
- Hawke's Bay
- Taranaki
- Manawatū-Whanganui
- Wellington
- Tasman
- Nelson
- Marlborough
- West Coast
- Canterbury
- Otago
- Southland
- Other (please specify)

50. What is your current employment status?

- Employed full-time
- Employed part-time
- Retired
- Student
- Stay at home carer (e.g., of children, parents)

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

- Not employed, looking for work
 - Not employed, not looking for work
51. What is the impact of migraine on your ability to work? (if you are not currently working, imagine trying to work with your current migraine condition)
- Cannot work
 - Can only work part time
 - Have had to choose a type of work with more flexibility
 - Full-time work but less than best performance
 - No work-related difficulties
52. In the last 12 months, what are all the ways that you yourself got income? Please do not count loans, including student loans
- Wages, salaries, commissions, bonuses etc, paid by an employer
 - Self-employment, or business you own and work in
 - Interest, dividends, rent, other investments
 - Regular payments from ACC or a private work accident insurer
 - NZ Superannuation or Veteran's Pension
 - Other superannuation, pensions, annuities (other than NZ Superannuation, Veteran's Pension or War Pension)
 - Jobseeker Support
 - Sole Parent Support
 - Supported Living Payment
 - Student allowance
 - Other government benefits, government income support payments, war pensions, or paid parental leave
 - Other sources of income
 - No source of income during that time
 - Don't know
53. What is the total income that your household got from all sources, before tax or anything was taken out of it, in the last 12 months?
- Zero income or loss
 - \$1–\$20,000
 - \$20,001–\$30,000
 - \$30,001–\$50,000
 - \$50,001–\$70,000
 - \$70,001–\$100,000
 - \$100,001 or more
 - Don't know
54. Do you have health or medical insurance?
- Yes
 - No
 - Don't know/unsure

Have more to say?

Migraine is under-recognised in every way—in funding, research, diagnosis, treatment and understanding. Telling your story about living with migraine sheds light on this disease, reduces stigma, raises awareness and helps with advocacy.

Appendix 1 (continued): Migraine in Aotearoa New Zealand survey.

Question title

55. If you would like to find out more about telling your story, please leave your contact details and we will get in touch with you. These details will be kept separate from your survey responses and will not be shared beyond Migraine Foundation Aotearoa New Zealand.

Name

Email

Thanks for taking part in our survey!

We will use your responses to advocate for better treatment and support for people with migraine in New Zealand.

Please forward the survey on to other people you know with migraine who would like to contribute (this is the link: <https://www.surveymonkey.com/r/XNSTFM5>)

For more information about migraine in New Zealand, visit our website <https://www.migrainefoundation.org.nz/>

For questions or feedback about the survey, please email info@migrainefoundation.org.nz