

Nonpharmacological Self-Management of Migraine Across Social Locations: An Equity-Oriented, Qualitative Analysis

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Deanna R Befus, PhD, RN¹ , Sharon Hull, MD, MPH²,
Justine Strand de Oliveira, DrPH, PA-C²,
Gillian Sanders Schmidler, PhD³, Morris Weinberger, PhD⁴, and
Remy R Coeytaux, MD, PhD⁵ 

Abstract

Background: Migraine is a disabling neurological disorder and the sixth biggest cause of disability worldwide. The World Health Organization has declared migraine a major public health problem due to a paucity of knowledge about cause and effective treatment options. Both in incidence and severity, migraine disproportionately affects people occupying marginalized social locations (SL). Managed pharmacologically, migraine is treated with daily preventive and as-needed abortive medications. Both come with high literal and figurative costs: intolerable side effects, medication interactions, and prohibitive prices. Cost prohibitive, ineffective, and unsustainable pharmacological treatment options have contributed to high levels of interest in complementary approaches by people with migraine, but little is known about their motivations, patterns of use or access, or how these may vary by SL.

Method: We conducted focus groups with 30 people with migraine to explore their desires and recommendations for migraine clinicians and researchers. We used qualitative content analysis to identify themes.

Outcomes: We identified 4 themes: a more holistic, collaborative, long-term treatment approach; medication as a short-term solution; high personal and economic costs of medication; and desire for more information and access to natural approaches. Across SL, participants expressed keen interest in integrative approaches and wanted better access to complementary modalities. Participants in marginalized SL described reliance on traditional/folk remedies, including engagement with family and community healers, who they described as more affordable and culturally accessible.

Conclusions: Holistic and integrative approaches were preferred over medication as long-term migraine management strategies. However, people in marginalized SL, while disproportionately disabled by migraine, did not feel as comfortable accessing integrative approaches through currently available channels. Engaging with these communities and using a critical lens to explore barriers to access can develop options to make complementary modalities more approachable, while also attending to systemic blind spots that may unintentionally alienate socially marginalized groups.

Keywords

complementary and alternative medicine, health equity, integrative medicine, migraine, self-management, social location

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¹Arthur Labatt Family School of Nursing, Western University Faculty of Health Sciences, London, Ontario, Canada

²Department of Community and Family Medicine, Duke University School of Medicine, Durham, North Carolina

³Department of Population Health Sciences, Duke University School of Medicine, Durham, North Carolina

⁴Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina

⁵Department of Family and Community Medicine, Wake Forest University School of Medicine, Winston-Salem, North Carolina

Corresponding Author:

Deanna R Befus, Arthur Labatt Family School of Nursing, Western University Faculty of Health Sciences, FIMS & Nursing Building, Rm 2331, London, Ontario, Canada N6A 5B9.
Email: dbefus@uwo.ca



Introduction

The fields of complementary, alternative, and integrative medicine (CAIM) have seen recent calls for intentional research and practice emphases on health justice and access issues to better: culturally and historically situate CAIM modalities, counter CAIM's reputation in many circles as medicine of the elite, and communicate what proponents defend as the potential public and population health contributions of CAIM.¹ However, the majority of CAIM research and discourse lacks critical, thoughtful engagement of health disparities, health equity, and social justice issues.^{2,3}

Although as words they are often used synonymously, the distinctions between the concepts of equity, equality, and disparity are important. To enable transparency and accountability, research and practice communities must clarify our language.⁴ Equality is a general descriptive term meaning sameness.⁵ Health disparities, strictly speaking, are health inequalities, or health differences between groups. Equity means social justice or fairness.⁶ Most health disparities/inequalities in North America are actually health inequities; they are avoidable and thus, unfair.

Migraine: Incidence, Burden, and CAIM Use

Migraine is a disabling neurobiological condition affecting over 15% of the population in the United States.⁷ Characterized by a constellation of symptoms including throbbing, unilateral head pain, dizziness, nausea, vomiting, visual disturbances, cognitive disruptions, and fatigue, the World Health Organization (WHO) named migraine the sixth biggest cause of disability, or years of healthy life lost, worldwide.^{8–10} In its Atlas of Headache Disorders, the WHO declared migraine a major public health problem due to its high prevalence, underdiagnosis, unclear etiology, and lack of effective, accessible treatment options.^{9,11} Migraine affects over twice as many women as men.⁷ In both incidence and severity, people occupying marginalized social locations (SL) bear the greatest migraine burden.^{12–14} SL is a dynamic position on the social hierarchy determined by the ways intersecting socially ascribed identities are valued within shifting social, political, and economic contexts: racialized populations, people with less education, living in poverty, un- or underemployed, and those with high levels of chronic stress due to the unequal distribution of health-damaging experiences, for example, lack of clean and reliable food sources, unstable housing, prejudice and discrimination, and exposure to violence.^{15,16}

Managed pharmacologically, migraine is treated with daily preventive and as-needed “rescue,” or abortive, medications. Both types of medications come with high

literal and figurative costs: intolerable side effects, medication interactions, and prohibitive prices.^{17,18} Currently, none of the preventive migraine medications available in the United States were designed specifically for migraine.¹⁷ The most frequently prescribed abortive medications—triptans, nonsteroidal anti-inflammatory drugs, and opioids—have been associated with chronification of episodic migraine.¹⁹ Cost prohibitive, ineffective, and unsustainable pharmacological treatment options have necessitated self-management strategies as a primary management option for many people with migraine.²⁰ For many, self-management includes CAIM.

People with migraine use CAIM more frequently than those without migraine, citing pharmacological expense and ineffectiveness as rationales.²¹ Mind–body therapies and herbal supplements are the most common CAIM therapies used by people with migraine. Fewer than half of these CAIM users discuss it with their healthcare providers.³ The people with migraine who are least likely to use CAIM are those in marginalized SL: black or Hispanic, receiving Medicaid, immigrants, and those with lower levels of education.^{3,22} However, when definitions of CAIM are expanded to include words like prayer, relaxation, teas, and roots, documented use in marginalized populations is often higher than in the majority white, high income, and education groups that are more often polled.²³

Despite widespread patient use, education and support of nonpharmacological self-management, including CAIM, have not been a priority in clinical migraine management, and even less attention is given to the unique needs of the population most affected: people occupying marginalized SL.^{24,25} In this analysis, we explore the intersections between migraine and CAIM: both paradigmatic cases for health inequity and opportunities to provide more equitable, relevant care. The purpose of this study was to explore patterns of CAIM use, methods of accessing CAIM approaches, and interest in and motivations for using CAIM among a group of primary care patients with migraine from diverse SL.

Methods

The focus group data analyzed here were part of an exploratory feasibility study aimed at assessing the outcomes associated with a personalized health care plan for frequent headaches, primarily migraine, and identifying outcomes that are meaningful to patients.

Thirty established patients from a primary care practice in the southeast United States were recruited. For this convenience sampling, inclusion criteria were: (1) aged between 18 to 75 years; (2) fluent in written and spoken English; (3) an established patient at aforementioned medical practice, and; (4) seen within the previous 12 months for a headache-related complaint.

Eligibility was confirmed and participants were consented by the study coordinator. The intervention consisted of 3 study visits with a physician trained in integrative medicine, 2 clinical consultations with participants' established providers, and participation in a focus group. This study received Institutional Review Board Approval.

Each of the 3 focus groups met for 2 hours, divided into two 45-minute sessions with a 30-minute break, and facilitated by 1 of 2 members of the study team (DRB and JSO). Participants were asked 2 questions: "What do you want providers to know about your experiences with migraine?" and "What do you want migraine researchers to focus on?" Groups were audio recorded and professionally transcribed. Three study team members validated and cleaned the transcripts. All data were stored on a secure server accessible only by key study personnel.

Descriptive statistics and qualitative data analysis were completed using Microsoft Office. We used a qualitative description approach with manifest, or conventional, content analysis.^{26,27} This approach emphasizes staying close to the text without an a priori commitment to a specific theoretical perspective, which was appropriate for this exploratory, hypothesis-generating, feasibility study.²⁸

Three study team members completed initial open coding and met regularly to identify analytic leads for further exploration.²⁹ During this process, it became clear that nonpharmacological management, writ large, was a major overarching category across all 3 focus groups in response to both prompts. Upon discussion with the team, it was determined that such a prominent category warranted a subcoding strategy to explore and expand on the rich and varied data expressed by participants.²⁹ In the following rounds of coding, 3 coders assigned subcodes within the broader "nonpharmacological" category and after repeated meetings to reach consensus, grouped codes into 4 main themes. The expected outcome of qualitative descriptive analysis is a summary of information "organized in a way that best fits the data."²⁸ As nonpharmacological management was a dominant category across and within focus groups, data were analyzed as such and it is the focus of the findings. Three coders agreed that themes were consistent across groups and therefore, they will be presented at the aggregate, across group, level.³⁰

Findings

Participant demographic information can be found in Table 1. Four themes emerged during analysis: Desire for a more holistic, collaborative, approach to treatment; medication as a short-term solution; high personal and economic costs of medication; more information

Table 1. Participant Demographics (N = 30).

	n (%)
Gender	
Male	5 (16.67)
Female	25 (83.33)
Race	
Asian	1 (3.33)
black or African American	20 (66.67)
white	8 (26.67)
Other	1 (3.33)
Ethnicity	
Hispanic or Latino	1 (3.33)
Other	29 (96.67)
Age	
Mean (SD, min, max)	46.0 (15.2, min 19, max 74)
Social location^a	
More privileged	11
More marginalized	19

All participants had a diagnosis of migraine.

^aParticipants' social locations were categorized during analysis upon recognizing it as an important emergent finding. In this analysis, SL was based on a combination of 4 influential factors from the literature, as well as participant contributions to the focus groups: Black or African American race;^{31,32,33} highest education level of a high school diploma/general equivalency diploma or less;^{32,34} involuntarily un- or underemployment;³⁵ and receipt of public assistance, for example, Temporary Assistance for Needy Families, as an adult.³⁶

Table 2. Main Themes.

Theme 1	Desire for a more holistic, collaborative approach to treatment
Theme 2	Medication as a short-term solution
Theme 3	High personal and economic costs of medication
Theme 4	More information and access to "natural" and "alternative" approaches

and access to "natural" and "alternative" approaches (Table 2).

Theme 1: Desire for a More Holistic, Collaborate Approach to Treatment

Unanimously, participants wanted genuine partnerships with their providers characterized by depth and trust. They expressed wanting to be heard and treated like "whole people."

I think the most important thing is to treat the whole patient, not just the headache or prescribe medication every time there is a headache episode or the dizziness or nausea or vomiting, or whatever. There are other factors to consider. (J, FG3)

Participants expressed a sense of ownership over migraine and wanted to be resourced and able to make

good decisions for themselves. They saw the relationships with their providers as key to this. “I have learned what works and what hasn’t and [I] need new ideas but want to be part of figuring out what will work for me” (C, FG2). And, “being in that sort of participatory conversation really helped, for me. I feel like I have options now” (P, FG3).

Participants described the importance of treatment tailored to their unique needs and preferences.

As much as we want relief—you know, immediate relief—I think that doctors need to give us a little time to figure out what the hell is wrong with us before they start writing prescriptions. I mean somebody already figured out what they are going to give you before you walk in the door. (F, FG1)

Similarly:

I don’t think it’s that common for doctors to look at it from a perspective other than pharmaceutical. I’ve asked every time I’ve gone to a new doctor, “help me understand what I can do that isn’t medication.” “Oh let me prescribe this.” Not what I was asking for. I’ve walked out of more than one office and said “sorry you’re not listening to me.” (M, FG2)

One comment from a participant occupying a more marginalized SL received vocal support in her group: “most of the doctors, you know, give good advice but you haven’t walked in our shoes, you really don’t know” (L, FG1).

Theme 2: Medication as a Short-term Solution

All study participants took some sort of medication for migraine, primarily abortive. They acknowledged the need for this, but repeatedly expressed a desire to use nonpharmacological approaches for prevention, long-term migraine reduction, and contributions to overall health. “I also think that they should be able to look at your chart or your medical background and come up with some short-term solutions while keeping the long-term goal out in front” (F, FG1).

Participants were not opposed to using medication but wanted additional options. “I take tons of ibuprofen, but that’s a band-aid. It can’t be a long-term band-aid” (P, FG3). Similarly,

I need migraine medication when I get the migraine, but I get migraines for 3, 4, 5 days at a time. Medicating to be functional, after day 4, I’m a little dangerous. I can’t do that 5 times every month. (M, FG2)

Participants commonly expressed a sense of hopefulness around potential relief in alternatives to medication. “I would like to find other options that would involve me not taking as many pills that don’t seem to really take the migraines away” (M2, FG1). As one participant explained, “we all have the drug that we know keeps us moderately functional, but I don’t want to just exist. I want to be better than that” (C, FG2).

Theme 3: High Personal and Economic Costs of Medication

All participants discussed multiple unpleasant side effects of migraine medication, including a host of troublesome symptoms, such as dizziness, nausea, fatigue, and “spaciness.”

Several participants wondered whether the side effects were worse than a migraine episode. For example, “[The medication] did, as a matter of fact, help my headache but I’m not sure I want to go through that again. It was totally disorienting. I went off to planet Saturn for a while” (F, FG1). Another participant explained, “That’s the price I pay for [taking the medication], and it seems not equivalent to the relief that it provides” (M, FG2).

And,

To me the problem was always that once I took them it was like I was done for the day. I mean I could call it, I was gonna go to sleep. Usually when I woke up I felt better but it pretty much shot the whole day. And when you’re getting them 4 or 5 times a month, that’s a lot of time that you’re giving up, it’s hard. (J, FG2)

Others were not convinced that their medications were effective:

I never knew quite if it was the migraine or the meds that left me hungover and fuzzy and just not able to function. You force yourself to function which makes you more tired because I could not afford to miss 4 or 5 days. I’ve never been able to figure it out. (C, FG2)

For some participants, the medication side effects were significant enough that they discontinued treatment, even if it was effective.

I’m not too keen on taking 3 pills a day but I tried it. The only problem I have is I’m walking around tired all day long and that’s not me. I need my energy. So I stopped taking them. I need to be moving. You know, I am a lively person, I’ve got a lot on my plate, and you know I’d rather avoid the things that I know that trigger than

have to walk around like a zombie all day. I can't do that. (J, FG1)

Participants occupying more marginalized SL frequently mentioned financial constraints.

They should give us alternatives for medications that are less expensive because some medications are more expensive than others. Some of us are on fixed incomes and can't afford the medication that they're giving. (B, FG1)

Many explained that the restrictions on medication allowed by Medicaid and some insurance policies meant that they often ran out.

[Abortive medication] is something that I'm using but insurance only allows 8 pills a month, and I have 14 or 15 headaches a month. And so I kinda decide "should I take a pill now or should I wait it out and see if I can make it through it?" which I don't think is healthy at all and it's not addressing the problem of the migraine. (O, FG1)

One participant described her exasperation with the trial-and-error process of finding an appropriate medication and at the perceived insensitivity of her clinician: "So you can't tell me what's wrong with me, but you're going to give me a new medication that costs \$100? I'm trusting in you that this is going to work!" (L, FG1).

The oft-expressed sacrifices, financial and/or personal, inherent in pharmacological migraine management were summed up by 1 participant, whose explanation was met with energetic agreement in her group: "It's the question of what are you willing to sacrifice to have some relief? To try and have a normal life? You know, what do you pay for that?" (M2, FG2).

Theme 4: More Information and Access to "Natural" and "Alternative" Approaches

To a person, participants expressed strong interest management approaches that were more "natural." "What I keep trying to find is things that are more healthy and more natural—ways of being healthy that don't require taking drugs" (N, FG3).

Nonpharmacological approaches mentioned in the focus groups included: specific food or drink, physical manipulation, supplements and vitamins, acupuncture, massage, meditation or relaxation, "therapy," hydrotherapy, reflexology, compresses, and folk remedies.

Many participants occupying more privileged SL were already using formalized CAIM approaches such as massage, yoga, and mindfulness meditation. These were widely considered to be effective by those who used them.

Participants occupying more marginalized SL also relied heavily on nonpharmacological modalities for migraine management, but not those more popularly considered CAIM, often because they were not able to access or afford them. "I mean, I felt a whole lot better after I left [the hydrotherapy session], but I don't have \$25.00 to do that 3 times a week when I get a headache" (K, FG1).

And, "my doctor also suggested acupuncture and I know there was an acupuncture clinic here, it's no longer here. It's in [nearby town] and they don't take my insurance now so I haven't been able to exercise that option." (J, FG3)

They also tended to trust recommendations of family or community members about what to try, or tailor provider recommendations that they could not afford or preferred not to access. For example, "another thing [providers] tell you: therapy. Well, I just get in a room by myself and act like I'm at the beach, you know? Just don't think about the headache" (B, FG1).

Participants with more constrained resources described using more folk- or traditional-medicine remedies than did more affluent participants. Often, these folk remedies were passed down through generations of women in participants' families. One particular method was cited by several participants as being effective: "cotton flannel soaked in sardine oil and wrapped around the head like a bandana, as tightly as possible. And go and lie down" (D, FG1).

Another approach that was discussed by several participants was seeing a known community healer, or "root doctor." Multiple people described driving to a neighboring state to see this healer every month, who would recommend plants, roots, and other materials to be made into teas, soaks, and poultices. These participants had often traveled with their parents to see this healer when they were children and were now continuing the practice with their own children.

Among many marginalized participants, there was a sense of formal CAIM not being for them, and that it was an intentional exclusion. "They don't do [acupuncture] anymore, and I'm a little bit resentful over the fact that I was having a treatment that was working and suddenly, "We don't do that anymore." Like you don't count" (F, FG1).

Discussion

Within a diverse group of 30 people with migraine, we identified 4 themes related to their interest in and use of nonpharmacological approaches for migraine management: desire for a more holistic, collaborative approach to treatment; medication as a short-term solution; high personal and economic costs of medication; and more information and access to "natural" and "alternative"

approaches. SL was a key determinant in how people engaged. Participants in privileged SL used more structured opportunities and options, like yoga and mindfulness-based stress reduction. More marginalized participants used many home- or traditional remedies that were located in their communities, and recommended by their families, people they respected, and providers they considered more relatable. This has important clinical, research, and public health implications. We suggest that, based on our findings and extant literature on CAIM use for self-management of chronic health conditions like migraine, exploring these implications using a critical complexity lens is an important first step to understand and meaningfully address health inequities in CAIM and migraine. A critical approach to complexity nuances our recognition of unique histories, structures, operations, and contexts that influence processes and outcomes in complex adaptive systems, such as decision-making processes and health-care navigation. It is imperative that we identify and assess these structures, processes, and practices that perpetuate health inequities and guard against recreating these patterns in practice and research.^{35,36}

Clinical Practice

Complex adaptive systems such as migraine self-management are context-dependent.^{15,35} What about many of our CAIM spaces and offerings is not attractive or approachable to people like the more marginalized participants in this study? An equity-oriented approach requires investigating all aspects of the care experience and CAIM modalities themselves to uncover implicit assumptions.³⁷ For example, are locations accessible by a variety of transportation forms? Is childcare offered? Are evening and/or weekend appointments available? Are multilingual options offered? What forms of payment are accepted, and are sliding scales or payment plans available? Do CAIM providers reflect the diversity of the surrounding community?

Cultural incongruence is a major reason that people from marginalized communities do not engage with CAIM.^{38,39} By collecting data on social and structural determinants of health, such as in the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) guidelines, providers can better partner with patients to tailor recommendations.⁴⁰ Furthermore, we must acknowledge the SL homogeneity of many modern CAIM approaches. While limited, evidence demonstrates that culturally adapted CAIM modalities are well received and hold real promise for groups alienated by perceptions of white, heteronormative, costly CAIM.^{41–43} A growing body of resources offer CAIM that may be relevant and meaningful to people from diverse backgrounds, such as oppression-

sensitive mindfulness trainings,⁴⁴ trauma-informed and social justice-centric yoga practices,⁴⁵ and acupuncture offerings tailored for low-resource care settings and Medicaid reimbursement.^{46,47}

Research

To make research maximally relevant to people with migraine and to contribute to a robust CAIM evidence base, social and structural drivers of equity and health must be operationalized and addressed. Self-management of chronic illnesses is arguably more complex with limited resources and higher disease burden. Methodologically, systems thinking approaches may be helpful here, as they can capacitate complexity and explain relationships between structures and individual outcomes, as well as offer tools to explore, assess, and evaluate complex systems and their interactions on multiple levels.¹⁵ Partnering with patients using community-engaged approaches can enhance validity and accountability of research aims, processes, and goals.⁴⁸ Conceptually, compared to socioeconomic status (generally defined as education, income, and employment), SL—a complex, intersectional concept—enables a more critical, nuanced understanding of the structural determinants that dictate how value and opportunity are socially assigned. Finally, the majority of both migraine and CAIM research suffers from an overrepresentation of people from privileged SL.^{2,3} Future research should make efforts to include participants from groups who have been historically underrepresented.¹¹

Public Health

Health equity can only be realized when health disparities and the systems that perpetuate them are recognized and ameliorated.⁴⁹ A crucial corollary to recognizing how political, economic, legal, and medical systems disproportionately disadvantage some populations is acknowledging the implicit *advantages* these systems confer upon other groups. This involves looking critically at our personal practices, research agendas, and policies and asking who we are implicitly welcoming and excluding, and how our own SL influence our perspectives, biases, and expectations. To genuinely embody a holistic CAIM philosophy, current guiding concepts like “cultural competence” must be replaced with “structural competence” and “cultural humility,” which involve critical self-reflection, recognition of our participation in systems that disproportionately privilege some groups while disenfranchising others, and acknowledgment of power dynamics that influence what opportunities and behaviors are available to whom.⁵⁰ In doing this, CAIM practitioners and researchers can lead health equity

efforts by beginning to reveal the systems and structures that perpetuate poorer health outcomes for marginalized populations and prevent CAIM efforts from gaining traction in communities that could benefit from them.

Conclusion

Integrative approaches were *desired* by everyone in the focus groups, but in their current incarnations, were not necessarily *available* to everyone. Trauma-informed, culturally humble engagement in practice and research with awareness of policies and social structures that can confer disproportionate disadvantage can make CAIM more approachable. In this way, we can begin to attend to some of the systemic blind spots that may unintentionally alienate groups living in marginalizing conditions.



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ORCID iD

Deanna R Befus  <https://orcid.org/0000-0003-3714-7885>
Remy R Coeytaux  <https://orcid.org/0000-0002-1542-9016>

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