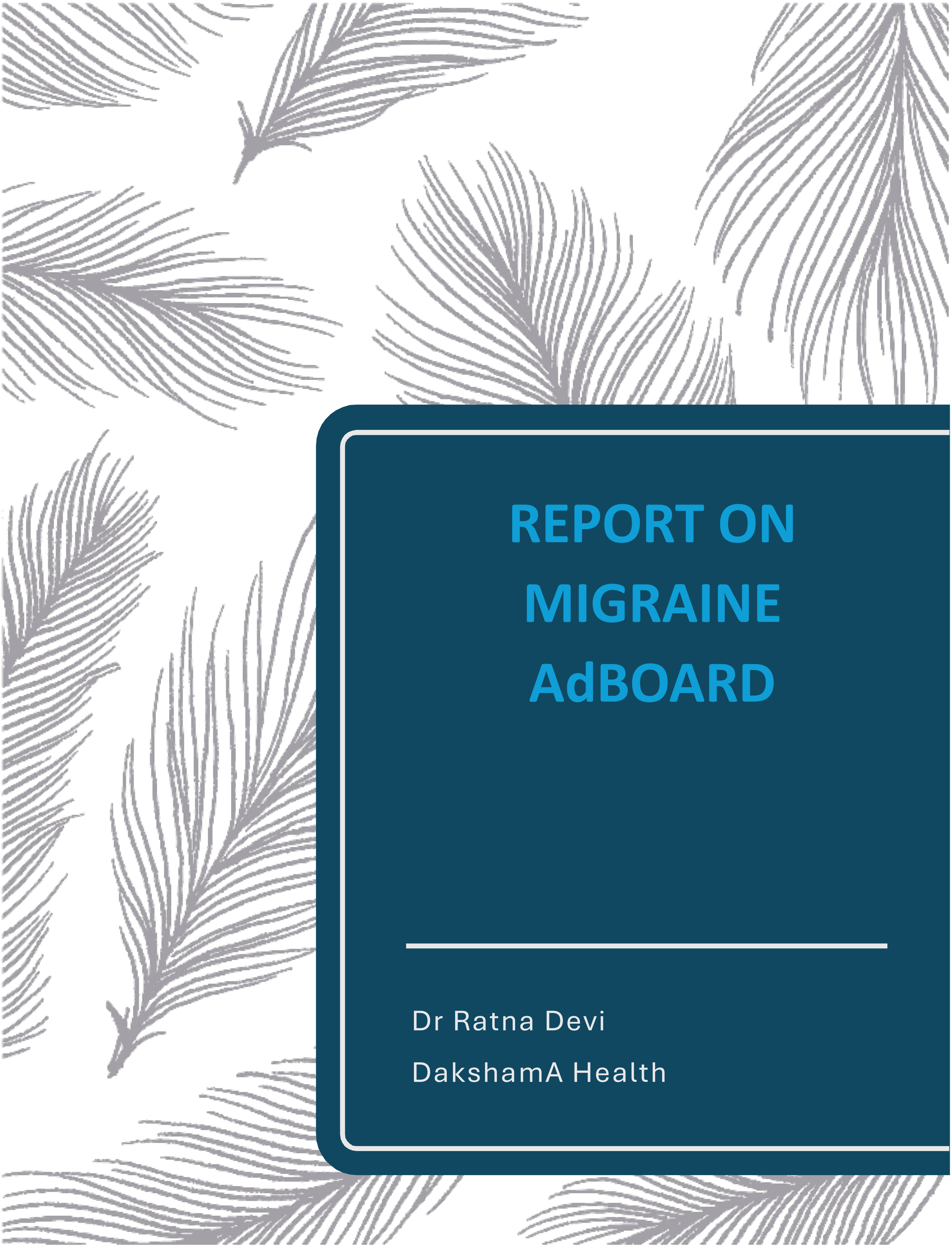

REPORT ON MIGRAINE AdBOARD

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Background

Migraine and related headache disorders are very common in India. In a study in south India by NIMHANS, the age-standardised 1 year prevalence of migraine was 25.2 % amongst rural population and prevalence was higher among females than males[1]. Population based studies are missing in India and studies involving neurological conditions include migraine as one of the symptoms. Independent studies on migraine are very few. Hemicranial location of pain as a cardinal feature of acute migraine attack has been recognized since ancient times. This notion has perpetuated through centuries, and a unilateral location of pain has been included in the diagnostic criteria of migraine (both with and without a typical aura) by the International Headache Society (IHS) according to the International Classifications of Headache Disorders (ICHD-1 and ICHD-2) conducted in 1988 and 2004, respectively[2,3] Studies in India have shown that women are more prone to Migraine than men[4].

Methodology

Potential patients were identified using direct outreach through our networks and calling for expressions of interest to be part of a workshop on migraine management. 42 applications were received and one on one screening interviews were conducted using a semi structured questionnaire to understand the journey, medication history and establish if there was a diagnosis of migraine. Through the screening process 16 potential participants were invited and sent an invite for an in person workshop. 9 participants attended the patient advisory board. The advisory board was conducted in a semi formal setting with pre prepared questions that patients were encouraged to answer. Discussion amongst the participants was encouraged to elicit personal experiences. The questionnaire is annexed as Annex 1

Patient Selection criteria

Demographic Criteria
Age
Gender
Patient from higher socio eco status
Vocal , Converses well in Hindi / English
Busy Lifestyle vs Less occupied
MEDICAL CRITERIA
Low frequency vs High frequency History of chronic migraine (50-50)
Newly Diagnosed vs Long term (After Diagnosis)
Triptan treatment failure / insufficient response vs Well managed

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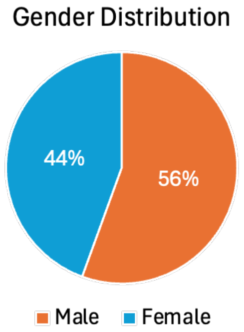
[1] Kulkarni GB, Rao GN, Gururaj G, Stovner LJ, Steiner TJ. Headache disorders and public ill-health in India: prevalence estimates in Karnataka State. J Headache Pain. 2015;16:67. doi: 10.1186/s10194-015-0549-x. Epub 2015 Jul 22. PMID: 26197976; PMCID: PMC4510104.

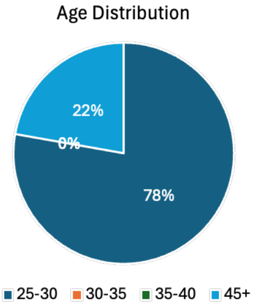
[2] Headache classification committee of the International Headache Society Classification and Diagnostic criteria for headache disorders, cranial neuralgias and facial pain. *Cephalalgia*. 1988;8:1–96. [PubMed] [Google Scholar]

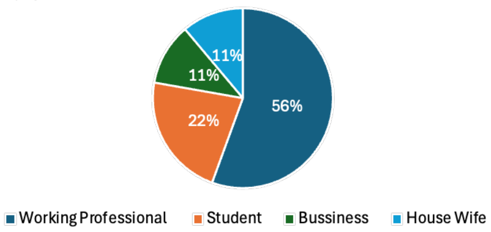
[3] Headache classification subcommittee of the International Headache Society. The International Classification of Headache Disorders. *Cephalalgia*. (2nd ed) 2004;24:8–160. [Google Scholar]

[4] https://doi.org/10.18203/2320-6012.ijrms20191083

The demographic distribution of the patients is as per below







Key Summary Points
Migraine is not understood well amongst patients and families as well as Health care providers
There are very few studies on Migraine and headache disorders and evidence as well as data is missing in the context of India. More research is needed to understand the actual burden of disease
Patient stories suggest migraine is not considered to be a disease, diagnosis is often delayed and/or incorrect, and that achieving of symptom control is variable. The first point of contact is not a neurologist.
Increased awareness and understanding of migraine is needed for it to be taken more seriously by society and reduce stigma, improve quality of life and enhance productivity of Individuals
Reduction in pain was the most important factor highlighted by patients and a cure/medicine that will provide faster reduction in pain
Physician education and initiatives to address gaps in the care pathway to increase recognition of migraine as a disabling disease and facilitate its timely and appropriate diagnosis and treatment. Robust referral mechanisms for appropriate control
Having dedicated migraine/headache clinics and awareness around availability of these clinics
Patients strongly felt there is a need for reliable sources of information and a support group/mechanism for patients and families to discuss issues.
Patients also suggested a strong need for workplace policies and awareness amongst offices and other places of work for provision of a "quiet space" for those having an attack to rest and recuperate

Key discussion points

Delayed Diagnosis

Patients had varying experiences depending on their first point of contact with a health care provider. In India patients do not follow a care provider referral pathway and are free to choose their provider. 6 patients reported to a general physician while one went to an ophthalmologist and two to a neurologist. Most patients had to go to at least 2 physicians before they were diagnosed. Most patients were diagnosed between six months to two years.

There were diverse opinions about public vs private sector doctors. While most patients felt that private sector doctors were more attentive and spent some time with the patients, one migraine patient felt that government doctors were better. in most private hospitals, patients decide which specialty they need to visit and because of poor awareness of migraine features many patients access other specialties (including ear nose and throat, ophthalmology, gastroenterology, and alternative medicine) before finally seeing a neurologist or headache specialist.

All patients said that doctors were busy and did not listen to the full history leading to generic prescriptions form headache and repeated visits to the doctor. According to one patient on the advisory board, patients affected by migraine are unlikely to seek treatment from a neurologist as headache was not seen or understood as a neurological disorder. Four patients on the advisory board associated chronic headache to an eye problem and three felt It was due to stress or long working hours. None of them felt that it was a condition that might need long term or even lifelong treatment and therefore delayed going to a doctor. None of them knew that migraine should be treated by a neurologist and the two patients who saw a neurologist were referred by other doctors. Eight of the 10 patients had no referral and were provided various medicines to manage the condition. Only one patient had attended a migraine clinic and was seen by a doctor specialized in migraine treatment. Three patients had an extensive history taken with screening questions for migraine, three underwent various procedures including a CT scan. One patient refused the scan due to the cost involved and having to pay it out of pocket. Vomiting was seen as a GERD symptom and combined with stress and other lifestyle factors, patients self-prescribed antacids. Patients also felt that the headache was due to excessive gas formation and bloating and took medication to relieve flatulence.

Misdiagnosis

Migraine in primary care is often incorrectly diagnosed as sinus headache or sinusitis and managed as such, with the similarity of sinusitis and migraine symptoms complicating the diagnostic process. One patient was advised surgery for nasal septum defect and did not undergo the procedure. Two patients who had seen an ophthalmologist were prescribed corrective glasses, but when the pain did not diminish were told it might be migraine.

According to one patient: ‘‘I have been taking medicines off and on and thought the headache was due to my late working hours. I was told my lifestyle and dietary habits were causing the headache and advised to improve sleep and diet. My ophthalmologist finally confirmed that it was migraine and prescribed medicine for three months. I stopped the medicines after three months and have not visited a doctor since.

Migraine is not understood well amongst patients due to low awareness. General physicians also lack clarity and there is a lack of knowledge and understanding amongst specialty physicians as well

All patients talked about the importance of seeing a doctor that specializes in migraine for their condition to be correctly diagnosed as migraine. One patient, after finally finding a migraine specialist who has successfully treated their condition, described it as a completely unique experience with respect to the questions the specialist asked, the tests done, and the treatments offered compared with their previous experience with healthcare professionals.

Quality of Life

The patients confirmed that migraine leads to lost days of study and work, having to miss social events, strained partner relationships, and not being able to provide childcare. One patient had to leave his studies and suffered from depression. His medications for depression did not reduce his migraine and eventually he dropped out of formal education completely. According to another patient on the advisory board who runs a cloud kitchen: ‘‘migraine has affected my business, my life, and my social life—I cannot serve my clients and this is further adding to my stress and leads to repeated attacks of migraine.

Two of the nine patients on the advisory panel reported being affected by migraine on at least 10 days per month, one person said almost every alternate day and three said once a week. Three patients said the pain lasted for 3-4 hours and they had to take leave from work to manage the pain. Though many of them had sympathetic supervisors and colleagues, they found it embarrassing to take time off frequently. Most offices did not have a quiet dark place to take time off and recover from the attack and most had to manage with lying down and taking medicines wherever possible. Some said that friends did not understand the intensity and discomfort and made fun citing this as an excuse to not join activities. Friends, family and colleagues felt that a migraine is like any other headache and can be managed with over-the-counter painkillers. One person said he had to miss school often due to headache and had problems managing his assignments.

Triggers for an attack were mainly bright light, loud noise, strong smells, long screen time, lack of sleep and irregular meal times. All patients agreed that the attack would often be relieved only after a bout of vomiting often repetitive in nature. This necessitated the availability of washrooms which was often a problem in public places. One person said traveling in public transport and severe crowds triggered her migraine.

Women and migraine

The questionnaire was shared with a group of women suffering from endometriosis. Several responded in the affirmative saying they had migraine like symptoms that were associated with hormonal treatments. Many said that endometrial pain reduced after starting hormonal pills but led to severe headache, mood swings and general lack of energy. Patients undergoing treatment for infertility had more severe headache and were told by their physicians that hormonal additives sometimes cause disturbance and retention of water that could lead to headache. None of the women have been clinically diagnosed as migraine, however they associate the headache with throbbing pain, vomiting and nausea- signs similar to migraine. Some women felt that gluten or lactogen intolerance was causing the headache and explained that they felt better after going gluten and lactogen free

Cost of treatment

8 of the ten patients paid out of pocket for a doctor’s consultation and medicines as well as tests for diagnostics. One patient was prescribed a medication for continuous use but was taking it episodically as and when he had an attack, to minimize the costs of medicines. Three patients discontinued medications after initially starting them, partly due to lack of knowledge on migraine management and partly due to the costs of treatment. One person has left her job due to migraine and is trying alternate treatments. Almost all persons on the advisory board said it is difficult to concentrate at work when having an attack, deadlines are missed, and sometimes extra hours have to be put in at personal cost to cover up for the loss of time at workplace. The stress of having an attack prompted several to take OTC pain medication when they felt an episode was imminent.

The treatment was always out of pocket and insurance did not cover diagnostics or treatment as headache is not considered a debilitating long term disease. Two patients who sought advise from a public hospital were also prescribed medicines that had to be purchased. This could be due to non-availability of these medicines in the government hospital and will have to be probed further. All patients on the advisory board expressed concern about their future in career and the inability to think long term due to the uncertainty of the attacks and the impact on their work life, as well as the lack of knowledge on what the future holds for them in terms of progress of disease.

Unmet Needs for Migraine management

Control of Migraines

All patients had tried over-the-counter (OTC) analgesics, and one patient had tried prescription analgesics to manage the headache. Patients had no knowledge on prevention or prophylactic medication and used OTC analgesics when they preempted an attack. All patients said that managing pain was the most important factor for controlling migraine. OTC medicine does not have an immediate relief in reduction of pain and more than one dose is required. Patients felt that medication that could give faster and more sustained relief would help them manage the migraine better. They also expressed that if intensity of pain could be brought down faster, other associated symptoms like nausea, brain fog and vomiting could be minimized. One patient said that even though pain was relieved after analgesics, he felt tired and drowsy making it difficult to concentrate at work. Three patients said that migraine medicine made them drowsy and they fell asleep after taking the medicine. Almost all patients said that the time of attack or the frequency could not be predicted and that the pain could happen anytime. Almost all related lack of sleep or stress as a factor that might trigger an attack.

Adherence to Treatment

None of the patients advised migraine specific therapy continued their treatments. Most stopped after two to three months and were managing with OTC pain medicine. Reasons for stopping varied from – there was no perceptible difference between the pain medicine and migraine medicine effect to inability to pay and the fear that long term medicine might make them dependent. Almost all felt that long term medication might have harmful side effects and preferred to manage with dietary changes and lifestyle modifications. Two patients had very severe headache, yet did not continue therapy

Patient Education and Support

Patients had not heard of support groups and felt that a support group would have been useful to understand and share their experience. All of them had browsed the web to search for migraine information and one patient had listened to Youtube videos by an expert. About half of them had not heard about migraine, the other half had seen family and friends with similar symptoms and some had a diagnosis of migraine. All of them expressed an interest to join a support group.

All patients said that the lack of a credible resource for information had led them to search several websites and felt that information was sometimes contradicting or confusing. Patients also said that most of them gave up treatment as they had no one to discuss their symptoms with (a counselor for example) and suggested that headache clinics should have a helpline or a counselor whom they can reach out to.

Way forward

Lack of Epidemiological data and patient registries make it difficult to estimate the burden of disease, however the adboard suggested that the scale of migraine as a health concern in India is greater than the what is present in published literature. The impact on quality of life and the DALYs lost is still not understood well and there is a great need to raise awareness of the condition and examine the patient experience. Patient Education and awareness for family members and friends of patients with migraine is needed to enhance their awareness and understanding of the incapacitating effects of migraine symptoms.

Suggested initiatives to help address gaps in migraine awareness and knowledge among healthcare professionals are dedicated headache medicine rotations for neurology residents and for residents specialising in family and internal medicine to spend time in neurology and headache clinics during their neurology rotation. We also support medical students and interns attending neurology and headache outpatient clinics during their neurology block to gain experience in assessing headache cases that they would not normally see during their neurology rotations.

Quotes from Patients

My headache is so bad, I cant think straight or concentrate on my work. I run a cloud kitchen and taking time off affects my business. I am unable to expand my business because of my migraine- Sujata

I had to see three doctors before my migraine was diagnosed. Inspite of trying several treatments, the pain doesn't go away completely. I finally left my job to concentrate on my health and am a home maker now- Deepa

Annex 1

Migraine patient ad board

Objective: To understand migraine patient’s journey for diagnosis, treatment and identify challenges & Potential solution in the context of Indian patient

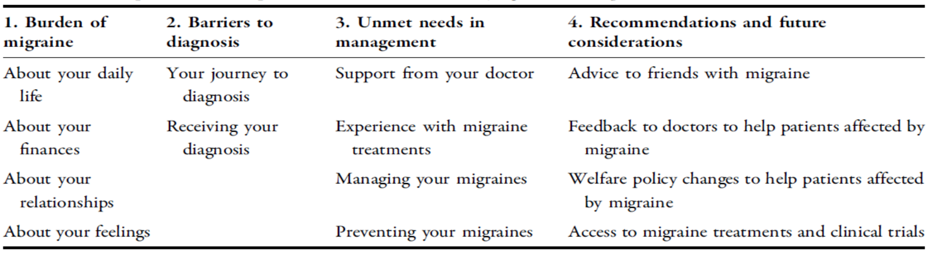
Partners

DakshamA Health & Education
Your Voices Your Choices

Ad Board design

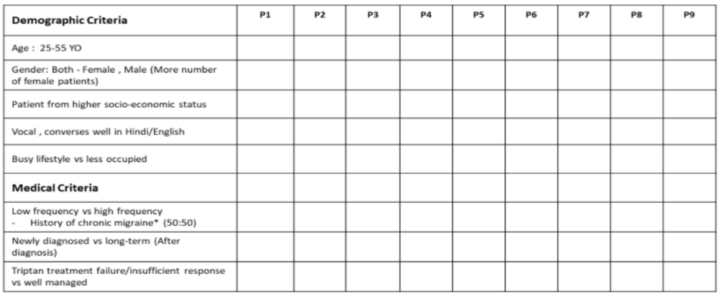
- **Total Participants: 10-13**
- Patients- 8-10
- Moderated by agency
- Location: At one of the participating institutions

Discussion points



1. Burden of migraine	2. Barriers to diagnosis	3. Unmet needs in management	4. Recommendations and future considerations
About your daily life	Your journey to diagnosis	Support from your doctor	Advice to friends with migraine
About your finances	Receiving your diagnosis	Experience with migraine treatments	Feedback to doctors to help patients affected by migraine
About your relationships		Managing your migraines	Welfare policy changes to help patients affected by migraine
About your feelings		Preventing your migraines	Access to migraine treatments and clinical trials

Suggested patient profile



Demographic Criteria	P1	P2	P3	P4	P5	P6	P7	P8	P9
Age : 25-55 YO									
Gender: Both - Female , Male (More number of female patients)									
Patient from higher socio-economic status									
Vocal , converses well in Hindi/English									
Busy lifestyle vs less occupied									
Medical Criteria									
Low frequency vs high frequency - History of chronic migraine* (50:50)									
Newly diagnosed vs long-term (After diagnosis)									
Triptan treatment failure/insufficient response vs well managed									

*High frequency : headaches on at least 15 days per month for at least 3 months, with the features of migraine on at least 8 days per month
The patient, or a family member, is not in a current Pfizer-supported clinical study , patients with co-morbidities to be included (psychiatric /)

Tentative date of meeting– 30gh August

Expected outcome:

- Map patient journey
- Identify &
- Validation of care gaps