“We Think We Know:” Individual and Regional Management of Migraines

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ABSTRACT

Migraine is a common neurological disease that affects approximately 14% of the world. Multiple methods of managing migraines exist worldwide, including tech-based interventions, which include migraine management apps and wearables to predict migraine attacks. However, migraine is a disease whose triggers and symptoms vary according to the environment. With limited research done on migraine management in Pakistan, our study investigates what methods and practices Pakistani migraine patients adopt to manage their migraines. We conducted 13 interviews with migraine patients and two interviews with doctors. We find that the current needs of migraine patients in Pakistan are 1) recognition of migraine as a serious mental disease, 2) establishing initial communication with doctors, 3) continued follow-ups with doctors, 4) recognition of individual triggers and symptoms, and 5) prevention of migraines in the long run. We also find that tech-based interventions like wearables would not be accepted by migraine patients in Pakistan in current times. We, therefore, discuss a modified tech-intervention method personalized to Pakistani migraine patients.

KEYWORDS

Migraines; migraine management; photophobia; phonophobia; wearables; self-medication; aura; postdrome; prodrome

1. INTRODUCTION

In recent years, technological innovation has led to the creation of devices that allow people to easily manage their chronic diseases. These technologies allow people to observe, reflect, and learn about how their external and internal conditions correlate with their illnesses. One such very common illness is migraine. Currently, there are a reported 14% of migraineurs throughout the world. Women are almost twice as likely as men to have migraines (21.0% and 10.7%, respectively) [26]. Migraine sufferers’ measured peak is set from 25 to 44 years of age, but migraines in childhood and adolescence are quite common as well. The condition starts in over 40% of the cases before 18 years of age [5]. Other than being unpredictable, migraines can be seriously debilitating, causing dysfunction in many areas of life. The World Health Organization (WHO) has classified chronic migraine attacks as among the most disabling illnesses, comparable to dementia, quadriplegia and active psychosis [5].

Migraines can be classified into many types. One way is to use a MIDAS (Migraine Disability Assessment) score that predicts the severity of the migraine [25]. Another way is to use monthly migraine days (MMD) to classify migraines, where MMD score is proportional to the migraine severity. One more approach is to use the frequency of headaches and other symptoms. For example, experiencing less than 15 headaches per month represents a mild migraine and experiencing more than 15 headaches per month along with other migraine features represents chronic migraine [31].

Migraines are quite subjective in nature. The way migraines begin in patients differ considerably. Migraines without aura are where the headaches and other symptoms start suddenly. In contrast, migraines with aura are preceded by a set of symptoms that can help migraineurs in detecting an in-coming attack. Migraine triggers also vary throughout migraineurs. These triggers include stress, weather, sleep quality, diet, environment, change in routine etc. This subjective nature of migraine not only makes it difficult for the patients to recognize their own symptoms, but also to seek professional help [27].

In a developing country like Pakistan, many patients are not aware of migraines, and usually assume it to be a simple headache due to lack of awareness. A study showed that most Pakistani migraine patients do not visit the hospital and prefer to opt for self-medication (40.2%). This self-medication can lead to future medical complications as well [13]. The lack of proper management by Pakistani patients shows that there is a need for better practices such as self-tracking apps and wearable tech. These interventions can be helpful, as corroborated by a study on behavioral management effectiveness in Pakistani migraineurs [1]. The different environmental and cultural factors from the currently studied populations indicate that these management practices be studied and modified in the context of Pakistan. This brings us to the three research questions of our study:

RQ1: **How do Pakistani migraine patients perceive the nature of their migraines**?

We focus on what do Pakistanis think they have when in fact they are suffering from migraine. And how do these thinking patterns affect the treatment of their illness? We explore whether all people are generally careless when it comes to treating migraines or are there people who are overly concerned as well about their diagnosis.

RQ2: **What are the current practices that Pakistani migraine patients adopt to treat their migraines?**

Migraineurs find it generally hard to finalize optimal techniques to manage their disease. Over here we focus on what are the different types of treatment approaches that Pakistani people adopt when it comes to migraine management. We dig deep into

the common triggers and symptoms for each patient and what is it that they do to prevent an attack as much as possible.

RQ3: **To what extent can tech interventions help in managing migraines for Pakistani patients?**

Not everyone is open to technology-based interventions in their daily life. While countries such as America have many people who use wearable technology and migraine management apps to manage their migraine [22], we explore the scope of such technology in the context of Pakistan. We focus on the willingness of Pakistani people to use such technology and what are their expectations from it.

To answer these questions, we conducted a total of 15 semi-structured interviews. Of these 15, 13 interviews were with migraine patients and 2 were with professional doctors. Each interview was transcribed to highlight the major themes and findings. We then categorically divided the insights to gain valuable insights regarding each of our research questions.

2. RELATED WORK

2.1 Migraine Management through Self Tracking

Migraines can be burdensome. Therefore, it is suggested that migraine patients understand the personal triggers that cause their symptoms [21]. A recommended way of identifying triggers is through migraine diaries. In a study conducted with 97 patients in Spain in 2005, 72% reported that keeping a migraine diary helped them better understand their symptoms and triggers [29]. However, in a study conducted on quantified-selfers, or people who use self-tracking, certain limitations were identified. Self-tracking can be a tiring process with problems including tracking too many factors, not tracking the right triggers, and insufficient understanding of data [2]. Therefore, for effective self-tracking, it is important to understand the needs of migraine patients.

To understand the challenges of managing migraines, Park and Chen conducted contextual interviews with twelve migraine patients and two providers. They determined that patients require 1) a social need of recognition of the problem, 2) recognition of their personal triggers, and 3) coping strategies for their migraines. They also came to the conclusion that the unpredictable nature of migraines made it difficult for patients to self-track their triggers. Moreover, they noted a huge difference in tracking methods between patients of severe migraine and mild migraine, where the current systems are unable to cater to the needs of mild migraine patients [27]. Schroeder et al. built upon this research and surveyed 279 migraine patients, followed by 13 interviews with survey respondents and 6 with health workers. The paper highlights that self-tracking migraine patients have four goals: 1) to understand questions about migraines, 2) to predict and prevent their migraines, 3) to monitor and manage their migraines over time, and 4) to get social recognition about the problems associated with migraines. Based on these results, they suggest the following goals and needs in migraine management systems: 1) avoid common pitfalls, 2) support customization and flexibility, 3) account for burden, negativity, and lapsing, and 4) support management with uncertainty [10]. With these concerns in mind, many people use mobile health apps for documentation of migraine-related information, finding them to be more accessible, convenient, reliable, discreet, and overall less burdensome than paper diaries [14].

2.2 Migraine Self-tracking through Mobile Apps

To understand the impact that migraine has on the daily life of individuals, a study was conducted in 17 European countries with 3900 users of the app, Migraine Buddy, one of the most commonly used migraine diary apps. The study showed that the most common locations of migraine onset were home and work. Additionally, users sensed the onset of migraine by feeling weakness, fatigue, or numbness in the head, eyes, or ears. Common triggers were identified as sleep alterations, psychological factors, nutrition, menstruation, and environmental conditions. Common migraine symptoms were identified as body pains, nausea, anxiety, blurred vision, sensitivity to light, noise, or smell, and moodiness [22]. Likewise, another study with over 60,000 migraine buddy users, conducted in Australia, Brazil, Japan, France, and Germany, identified neck pain, dehydration, and bright-sun as migraine triggers in addition to the triggers above. The study also highlighted that the impact of migraine includes missed work, missed social activity, missed family time, lack of productivity, and difficulty in concentration [24]. Both these studies showed how Migraine Buddy can help users identify their triggers and symptoms, while also highlighting that demographics may lead to different triggers and symptoms. Another study was conducted with 358 migraine patients to understand the impact of digitally tracking patient reported migraine data using an app called Migraine Recorder. The results showed that app features like notifications and alerts were useful in providing reminders to take their medicine or enter data, making self-tracking easier [14]. Similarly, another study conducted with the relax-a-head app, showed that in addition to having tracking capabilities, users also wanted features that would improve user engagement in migraine detection apps [17]. Likewise, the importance of using mobile health apps was also determined in another experiment. The experiment highlighted that machine learning and data analysis techniques, when used with mobile apps, are useful in gathering predictive migraine data [28]. Therefore, extensive research on mhealth migraine apps has shown the role that they play in helping migraine patients identify their triggers and symptoms and consequently, predict their attacks. However, mhealth tracking apps have their own problems.

Privacy is a major concern when it comes to any health-based system that tracks data. In a study conducted with US adults, the Health Information National Trends Survey was used to analyze the concerns that people had about the security of their protected health information. Almost 70% of respondents were generally

concerned about their healthcare privacy, with almost 15% admitting to withholding information from healthcare providers due to these concerns [8]. In another study conducted with 236 survey participants and 41 interviewees, majority of whom were from Asia and Europe, a large number were concerned with their privacy in internet technologies. However, the majority of them were still willing to use a product with privacy concerns, as long as it fulfilled their needs [7]. Therefore, the research shows that there are varying responses to how people perceive privacy and the impact it has on their use of products, depending on demographics. However, trust still plays a major role in healthcare applications and privacy concerns must be addressed. In a study conducted by analyzing the policies of twenty-nine migraine/headache apps, it was concluded that the majority of Headache apps shared information with third parties, leading to privacy risks. This was because there are limited laws against the sale of data from medical apps to third parties [16]. Likewise, another app analysis, conducted on 15 apps, showed that while privacy policies may be available, they evade the knowledge of normal users. Therefore, while the apps are definitely useful in tracking data and predicting attacks, patients need to be careful about the risks and benefits of their data being tracked [15]. In addition to privacy concerns, there are features that users want from apps. In a study to determine what users want from migraine apps, 15 apps were selected from google play and apple store. 945 "most helpful" consumer reviews were then extracted into an excel file and coded into keywords, phrases, and themes and then used for qualitative analysis. The 4 main themes that emerged were as follows: 1) App allows users to track headache characteristics, potential triggers, and treatments, 2) App usability 3) Personalization and features to assess trends in data are key motivators for app use, and 4) Ease with exportation and viewing data is critical. Based on these themes, the authors suggested the following recommendations that headache apps should have a user-centered design with the ability to 1) customize key features including headache characteristics, potential triggers and treatments, 2) evaluate trends in data, and 3) view and export the data [17].

While the above suggested changes can always be implemented in migraine applications, the core problem associated with self-tracking still remains. It is a tiring process with multiple variables that make understanding or entering data difficult. Therefore, recent times have seen an increase in the use of wearables for health-based tracking.

2.3 Migraine Management and Wearables

The wearable market has grown over the past couple of years. Wearables allow for tracking through various sensors and bios-signals that can help predict chronic diseases [3]. As is the case with mobile apps, privacy and sharing of data are also concerns of people who use wearables. In a study conducted with seven focus groups about their health information privacy concerns (HIPC) with health wearables (HW), it was found that users were aware of the privacy issues with wearables, but felt that they had to forcefully accept the wearables in the current state, as wearables are useful in tracking and managing health data [20]. Another study elaborated that privacy concerns extend into concerns about 1) unawareness of privacy protocols, 2) location disclosure, 3) user's forgetting what data is being stored, 4) display of confidential data on wearables' screens, 5) lack of control on data, and 6) surveillance of data [32]. On the other hand, a study was conducted in Finland, where 565 people were surveyed to determine the willingness of people to use wearable technology. The survey showed that over 90 percent of respondents were willing to wear wearable tech to measure pre-symptoms of migraine, with the majority of the respondents preferring wearables that could be worn on their wrists. Additionally, the study highlighted the role that physicians could play in promoting wearables, with almost 50% of respondents mentioning physician recommendations or scientific support as a motivator to buy the device [4]. Therefore, privacy concerns can vary according to demographics, although there is a general acceptance for wearables.

With wearables increasing in demand, it is important to understand the role they can play in managing migraines. To understand what bio-signals migraine patients would want to be tracked through wearables, 12 interviews were conducted with migraine patients. The study deduced that migraine patients wanted sleep, pulse, blood pressure, stress levels, sleep apnea, and energy consumption to be tracked. Moreover, patients also wanted predictions that could help them take medicine on time, before a migraine attack [3]. The role that these factors can play in migraine prediction can be seen through multiple studies. One study tested the use of a wearable Empatica E4 sensor that measured blood volume pulse, heart rate optically, temperature, acceleration, and electrodermal activity, to manage migraines. The test was successful in measuring these factors and predicting early symptoms of migraine, but the device itself was not comfortable for all testers [5]. In another study conducted with the Empatica E4 sensor, sleep data only was used to detect migraine attacks. The study was limited with only 7 participants but still showed that 84% of migraine attacks could be determined a night prior to an attack using sleep data [23]. The bio-signals tracked through wearables are directly linked to the triggers that a person has before a migraine attack. In the above study, for example, sleep data can be used to track irregularities in sleep, which might be a trigger for migraines. Likewise, heart-rate can provide data on stress, which can be used to predict migraine attacks. However, research has shown that bio-signal tracking is beneficial in the long-run with constant data-tracking throughout this period [18].

Therefore, migraine management through wearables is changing the way data is tracked and predicted. However, limited research is done on the use of wearables in Pakistan. As discussed above, demographics play a major role when it comes to triggers, symptoms, and privacy concerns of migraine patients. Thus, while the above research provides an important framework on migraine management, Pakistani migraine patients must be analyzed in their own context.

2.4 Migraine Management in Pakistan

Even though Pakistan is the 5th largest population in the world having an endemic migraine problem, there exists a gap in the knowledge of prevalence of headache disorders in the region. In a survey conducted by Herekar et al., migraines were found to be the cause of 22.3% of all headache-related problems in the region, peaking in the age group of 40-49 years. Urban dwelling saw a positive correlation with migraine occurrence [6]. A study by Jinnah Sindh Medical University showed that most of the migraine patients have grade 4, i.e. severe disability [25]. The prevalence of headaches in the country is 8.1%, almost three times the global average of 3%, showing that there is an urgent need to address the problem [11]. A more significant effect is seen in females, increasing from adolescence (18–29 years) to middle age (30–49), declining slightly in the perimenopausal years (50–59), and sharply decreasing in the postmenopausal age group of 60–65. These trends can be attributed to the well documented influence on migraine of estrogen levels [9]. However, higher education level and financial affluence saw a negative correlation, factors which play a role in understanding and self-tracking medical conditions, and access to healthcare facilities respectively [30]. Migraine is more prevalent in married individuals. Within the country, there are further regional variations: migraines are more common in Punjab and Sindh than KPK and Balochistan [6]. Moreover, a novel trigger for the Pakistani population is fasting. A study by Aga Khan University revealed that migraineurs suffered from double the number of MDDs (Monthly Migraine Days) during Ramadan as compared to normal diet months [12].

Therefore, comprehensive literature is available related to demographics-related migraine problems in Pakistan. However, the research is limited in understanding migraine-management practices in Pakistan. Additionally, most of the studies were quantitative in nature and cannot provide an in-depth analysis of what migraine patients actually feel. Hence, we conducted a qualitative study with migraine patients in order to understand migraine management practices and potential improvements in the context of Pakistan.

3. METHODOLOGY

To understand migraine management methods in Pakistani migraine patients, we conducted interviews with thirteen migraine patients and two doctors.

The purpose of the interviews with migraine patients was to comprehend their understanding of migraines, recognize their symptoms and triggers, migraine management practices, and gauge their willingness to use migraine management apps and wearables. Participants were recruited by posting an online participation survey where participants could enter their contact details to participate in the study. Additionally, participants were also recruited by reference to the researchers such that patients or relatives of patients in the researchers' social circles were also recruited. Interviews were conducted online via Zoom or in-person as per the participants' convenience. The interviews, on average, were 20 minutes long and were audio-recorded with the consent of participants. Additionally, participants were encouraged to talk about sensitive matters and were reminded that their identities would remain anonymous in our research. Our participants ranged from 17 to 62 years old, although all of them had experienced migraines for at least three years as per their self-recognition. Moreover, out of the 13 participants, 6 were males and 7 were females. The demographics of all migraine participants are summarized in table 1.

All interviews were semi-structured with some baseline questions formulated based on previous research. For patient interviews, these included questions related to their years of experience with migraines, their triggers and symptoms, their current migraine management methods, and their willingness to use migraine management apps or wearables. Additionally, while we did not conduct pre-interview MIDAS tests with participants, we integrated MIDAS questions into our interviews and used the MIDAS scale to gauge an approximate estimate of patient migraine severity. For the neurologist, our base questions were related to his migraine treatment practices, with the interview majorly guided according to the themes the neurologist talked about. Participants were also encouraged to follow up and elaborate on certain points to understand the contexts behind their answers.

Furthermore, we also conducted one interview with a neurologist to gain expert opinions on migraine management practices in Pakistan. Our neurologist had 25 years of experience in the field and was contacted by reaching out to him on his number directly. An interview was set up, and the interview was conducted in his clinic, where he treats his migraine patients. The interview lasted for an hour and was audio recorded with the consent of the neurologist. The interview was semi-structured with basic questions relating to how he diagnoses migraines, what treatment methods he uses, what concerns patients generally have, the degree of seriousness with which patients treat their migraines, and the potential benefits or drawbacks related to pursuing technological interventions to migraines. We also conducted one other expert interview with a doctor who had experience as a researcher with migraine interventions. The interview was valuable in gaining insights on current migraine practices around the world and how they are linked to our study.

Following each interview, the interviews were transcribed and coded to highlight major themes and findings. In the context of triggers and symptoms, each participant's triggers and symptoms were identified and are summarized in table 2. Additionally, themes related to migraine perceptions in Pakistani migraine patients, migraine management procedures, and usability of apps and wearables were also identified. These themes will now be discussed in detail in the next section.

Participant ID	Gender	Age	Number of years	City	Migraine with Aura/without	Previous use of any

			with migraine		Aura	health management app
P01	Male	17	7 years	Lahore	Without	No
P02	Male	20	12 years	Lahore	Without	No
P03	Male	21	10 years	Lahore	Without	No
P04	Male	21	3 years	Lahore	Without	No
P05	Female	21	6 years	Lahore	Without	Yes
P06	Female	22	4 years	Lahore	Without	No
P07	Female	22	3 years	Lahore	Without	No
P08	Male	31	3 years	Lahore	Without	No
P09	Female	35	15 years	Lahore	Without	Yes
P10	Female	45	15 years	Lahore	Without	No
P11	Female	46	34 years	Lahore	With	No
P12	Female	51	43 years	Lahore	With	No
P13	Male	62	49 years	Lahore	With	No

Table 1: Demographics of Interview Participants

4. FINDINGS

In this section, we will discuss the insights obtained through our methodology. Our study reveals the different challenges doctors and patients experience regarding migraines. We delve into individual themes starting from the perceptions migraineurs have about migraines and then covering the wide range of symptoms and triggers they experience. Lastly, we discuss the scope of wearable technology and migraine management apps in the context of Pakistan.

4.1 Perceptions

Ideas about migraines are not only limited to misconceptions about the disease. People who suffer from different types of headaches also have strong fears about what they are going through. These patients usually diagnose themselves with a chronic disease, which eventually increases their anxiety levels. For example, many migraineurs think that they have a brain tumor or some other severe brain disease. The neurologist we interviewed further explains this:

"*Many patients fear that there is some sinister pathology inside the brain. There is some serious illness like a tumor."*

Adding onto this, the neurologist explains how people have stigmatized illnesses like tumor and find it hard to accept that they may be diagnosed with it. On the other hand, people have glamorized the disease of migraine and easily accept its diagnosis.

"*People easily accept that migraine is an affluent person's disease. But to have tuberculosis is stigmatized."*

However, there are many people who do correctly diagnose their migraine. But amongst these people, there is a common misconception that migraine is an incurable disease. There are strong notions about no treatment existing for migraines that are passed down through generations. This increases the severity of the diseases in both men and women. However, different types of treatments do exist such as acute treatment and preventive treatment.

"There *is a common misconception based on previous knowledge that there exists no treatment for migraine. However, treatment is present. Both, preventive and acute".*

Since migraines primarily revolve around headaches, it is something that only the migraineur experiences and not the people around him/her. Due to this nature of migraines, many females in the rural areas of Pakistan are subject to neglect regarding the illness. In such areas, women have an inferior status and are compelled to follow a socially constructed model that disempowers and deprives them of basic necessities such as healthcare [33]. They do not get proper treatment due to which they have to suffer in the future. As explained by a neurologist that we interviewed:

"*Many times, females are not given attention and their illness is neglected. People think that they are just pretending to be sick. This turns the migraine into chronic migraine and they suffer heavily".*

4.2 Triggers

As discussed in the theme of perception, migraine has a tendency to be misdiagnosed, mostly pertaining to self-diagnosis and eager acceptance of the glorified illness. After comparing patients' experiences with classical patterns of migraines, and their consultations with doctors, we ascertained those patients were indeed suffering from migraines, and then moved to the next step. A list of triggers was gathered through a thorough literature review. This list was then discussed with patients. As each migraine patient's experience can be different, each patient's unique triggers (those not available in the list) were also considered. The neurologist outlined how these triggers are discussed, and how unique they can turn out to be.

"An important question is what triggers their migraine... it can be anything from chocolate, cheese, to hunger and sleeplessness. The patients themselves mark these triggers out."

There were some common trends apparent in triggers. Most patients related stress and fatigue to the onset of migraines. As suggested by related works, there were also a series of triggers

and factors unique to the Pakistani region. These triggers included heat, travel, pollution, fasting, a sedentary lifestyle, and lack of routine in most patients.

The characteristically high temperatures in the region are a trigger for many patients. 3 patients marked it one of the main triggers for their migraines.

"If I am exposed to direct sunlight and the light is too bright, not just sunlight, but it's too bright. And especially in summers, when it's super-hot, it's one of the major triggers." - P05

Traveling long distances also triggers migraines in some patients. More than traveling, it is the exhaustion, pollution, and disturbance that lead to the migraine.

"While I'm travelling, there's loud noise and that can be a trigger. Especially at night because of the lights, the flashing lights come and go so that is a trigger". - P07

Female patients, particularly P06 and P07, notably identified menstruation as a key trigger in their migraines.

"Menstruation, fatigue and stress are the main triggers for me."

As Pakistan is a predominantly Muslim country, fasting, either during Ramzan or on holy days, is an important part of life. However, this can cause difficulties for migraine patients as it relates to the primary and most common trigger: hunger. Hunger and dehydration were reported as key triggers by 4 out of 13 participants, directly relating migraine frequency to fasting.

Other than physical triggers, emotional triggers also show up as a trend. Stress was the most common trigger reported, with 7 out of 13 patients linking it to their migraines. Moreover, patients linked academic stress to migraines the most (P02, P06, and P13), a factor that goes away as the patient matures and grows out of the stressful academic phase of life (P13).

"My migraines are as frequent as academic stress. I study on my computer, so when I have to study a lot, my screen time goes up too, that just adds on to the migraine's pain" - P02

"I feel emotionally drained after migraines because I think it has a lot to do with my mental health" - P06

"I had a lot of migraine attacks right before the day of an exam. I think it was the anxiety of the exam."-P13

Emotional triggers also include mental health and wellbeing of the patient. P10 reported that overthinking, negative thoughts that hurt her self-esteem and self-respect tended to exacerbate the condition. P06 also quoted mental health to be an important factor.

"When you think about things that hurt you, it leads to depression and that leads to migraines"-P06

Moreover, migraines can also be set off by a particular stacking of triggers. This stacking is difficult to identify and measure, but tech-based interventions can be key solutions to this.

4.3 Symptoms

There is a classical pattern of a migraine attack. However, most patients' experience tends to be individualistic in nature. As the triggers discussed above are unique to each individual, the symptoms, with some overlap, tend to follow the same pattern. Patients with more severe migraines put in the effort to mitigate triggers and keep track of ways to manage migraines. Moreover, there seems to be a general confusion with some patients about whether the feeling is a trigger or a symptom, e.g., photophobia, some patients highlight it as a trigger, and some as a symptom.

Our interview with the neurologist lent deep insights into the classical pattern of migraines. It has the following phases: 1) prodome, 2) aura, 3) headache, and 4) postdrome. Prodome is the initial phase of the cycle, where migraine symptoms such as mood changes, fatigue etc., start showing up. This may be hours or days before the actual headache phase. The next phase is called aura. It is not very common and comes about in a few migraine patients. Symptoms of this phase start showing up around an hour or less before the headache phase. This phase is marked by flashing or wavering lights and disturbed senses. The next phase is the headache phase. It is commonly marked by a pulsating headache in all or some region of the head, photophobia, phonophobia, vomiting and travelling pains. It usually incapacitates the patient and most put everything off to sleep in and recuperate. The last phase is the postdrome phase. This phase is marked by emotional and physical drainage while the effects of the migraine are subsiding. Any of these phases can be missing in a cycle, even headache.

Even though the underlying pattern is similar, each patient has an individual experience. The most commonly reported symptoms include phonophobia, photophobia, along with a pulsating headache.

"Half of my head hurts a lot. Light and sounds make it worse, I'm very sensitive to them during the migraine" - P03

"One side of the head hurts a lot. Sometimes it goes up to your neck too, for me. I feel it in my collarbone. And then, you know, you, you just really, you can't really open your eyes. And you can't really open your eyes, when there's a lot of light" - P06

Vomiting was also mentioned as a common symptom.

"I feel like vomiting every time. If I eat something before the attack, I almost always vomit. Otherwise, I feel nauseous" - P04

Symptoms experienced by patients are commonly used to classify their migraine, i.e. with aura and without aura migraines. 3 out of 15 migraine patients shared that they get aura migraines. An advanced stage of an aura migraine includes not just flashes and flashing lights but vision loss as well.

"When I have migraine, I have partial vision loss. About 75% vision loss. Like I get vision loss for about 20 minutes. The last time I had it was for an hour and a half. So, I lose like 75% of my sight, and then it comes back, and then I know that I'm going to have a retinal migraine. So yes, there are symptoms plus I get a lot of nausea as well and very strange burping as well."

Along with variations in physical symptoms, the pain felt by the patients is different as well. When asked how they rated their pain on a scale from 1-10, we got varied responses. These responses are summarized in Figure 1 and Table 2.

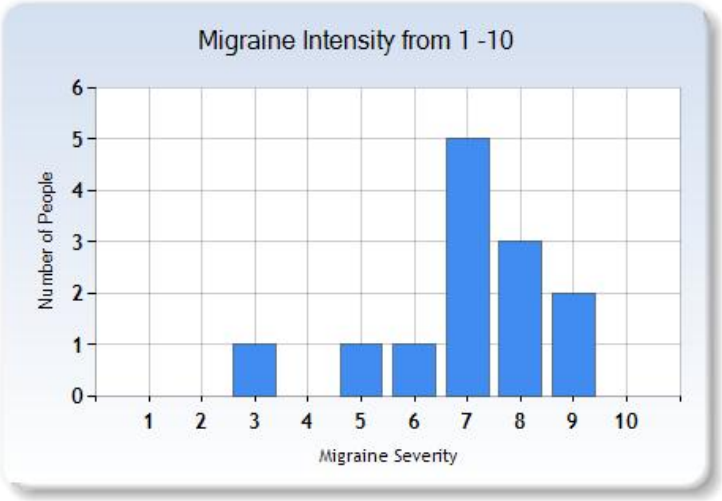

Figure 1: Severity of migraine experienced by our participants from 1 to 10

Participants	Triggers	Symptoms
P01	Lack of sleep, Lack of rest, Certain types of chips	Photophobia, Retinal migraine
P02	Excessive use of computer, Fatigue	Vomiting, Heavy head, Pain in right eye,
P03	Lack of sleep, Missing a meal, Hot weather, Dehydration	Pain on one side of head, Phonophobia, Photophobia
P04	Lack of sleep, Missing a meal	Photophobia, Phonophobia
P05	Exposure to bright light / hot weather, Fatigue, Skipping a meal, Stress, Dehydration	Nausea, Dizziness, Phonophobia
P06	Overthinking, Lack of sleep, Menstruation, Fatigue, Stress	Pain on one side of head that goes to collarbone, Difficulty in opening eyes, Photophobia
P07	Dehydration, Fatigue, Stress, missing a meal, Traveling	Severe headache, Photophobia
P08	Fatigue, Hot weather, Lack of sleep, Stress	Headache
P09	Lack of sleep	Photophobia, Nausea, Dizziness
P10	Overthinking, Negative thoughts that hurt self-respect and ego, Lack of sleep, Stress, Upset stomach	Phonophobia, Photophobia, Vomiting, Pain on one side of head that goes to the body
P11	Certain food like spices, Stress, Upset stomach, Bad air quality	Nausea, Retinal migraine, In the aura phase, the patient suffers from vision loss.
P12	Lack of sleep, Stress, Excitement, Fatigue, Certain foods like cheese and chocolate	Pain from one side of head to neck and shoulders, Vomiting, In the aura phase, the patient has blurry vision and sees zigzag lines, blind spots, and flashing lights.
P13	Fatigue, too little / too much sleep, Anxiety, Certain foods like certain lentils	Headache, Photophobia, In the aura phase, the patient experiences wavering vision

Table 2: Triggers and Symptoms of Interview Participants

4.4 Management practices

We describe the migraine management techniques that are most used by migraineurs after carrying out interviews with both migraine patients and doctors. Our findings are divided into two parts: Doctors' Insights and Patients' Insights.

4.4.1 Doctors' Insights

After the analysis of the interviews we conducted, we found out that there are two main ways patients manage their migraines (preventive treatment and acute treatment). Acute treatment includes getting rid of the headache by taking different painkillers while preventive treatment aims to reduce the frequency of the headaches through several types of medicines. Even though the symptoms and triggers of migraines can be unique for every other individual, people always come down to these two forms of treatment. However, there is a general trend as to when patients use which form of treatment. Patients usually adopt an acute or abortive approach before consulting a doctor about their condition. This includes taking painkillers like Panadol, Brufen, and Ponstan. As the neurologist says:

"*Before reaching out to the neurologist, majority of the patients are taking acute treatment. They take medicines like Panadol or any other painkiller that suits them. It takes time for the patient to reach a preventive treatment".*

When talking about preventive treatment, we found out that there are diverse groups of medicines that help in reducing the occurrence of headaches.

"*Some antihypertensives that are designed primarily for hypertension or blood pressure are effective in treating migraine. Likewise, antiepileptics or antidepressants also help prevent migraines without addressing the primary illness such as depression"*

"After patients give consent for a preventive treatment, doctors usually device a 6 months course for them in which they take the medicines and come back for follow-ups."

4.4.2 Patients' Insights

Talking to different patients also enabled us to explore the different migraine management techniques they use. From the 13 migraine patients we interviewed, 10 patients adopted an abortive approach. This means that the patients took medicines only when they were undergoing the headache.

"*I always take Panadol during an attack and it helps, in my case". - P05*

"I just take my medicines and lay down quietly. The medicines that work best for me are Panadol and Alp". - P10

On the other hand, three patients used a preventive approach. This included taking medicines on a daily basis to prevent any incoming headaches.

"*Sibilium is a medicine that I have to take daily every night. This has reduced my migraine to twice a month from three to four times a week". - P07*

"My migraine medicine has helped me a lot. It has stopped my nausea and the spinning inside my head. But interestingly, I left this medicine about 10 days to two weeks ago, and today, I got up with a migraine, so I've taken the migraine medication again". - P11

All the patients we interviewed also adopt non-medicinal ways to decrease the severity of their attacks. We found out that photophobic people completely shut off the lights and go to a dark place. Likewise, people with phonophobia prefer to lie down in a completely quiet place.

"*During the attack, I just close my eyes and go to a quiet place where there is no one. I also turn off all the lights". - P03*

Those who feel their sleep is not complete sleep while those who missed a meal go eat something to decrease the intensity of the attacks. One of our participants also found massages to be soothing.

"*If someone gives me a massage, then the pain decreases. I find neck and shoulder massages to be comforting during my attack" - P12.*

All in all, we see how the different ways our participants manage their migraine can fall under the two categories of acute and preventive treatment. People take different medicines that best suit their needs. However, there are non-pharmacological ways as well that our participants found comforting during their migraine attack.

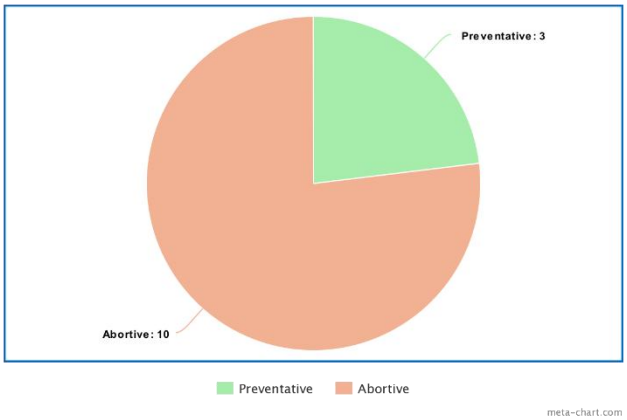

Figure 2: Preventative and Abortive Measures Proportion

4.5 Apps and wearables

One of the major focuses of our patient interviews was to understand the willingness of our participants to use migraine management apps and wearables. None of our 13 participants had ever used a migraine management app, although two participants had experience with other health-based apps. The majority of these participants did not know what migraine-management apps are, and the researchers had to explain the concept behind these

apps. After understanding how migraine management apps function, four participants were not willing to use a migraine management app. In the case of wearables, researchers had to explain what wearables can do in the context of migraines to all participants. Based on that information, five people were unwilling to use wearables, out of which four were the same who were unwilling to use a migraine management app.

When asked what features or expectations participants would have from migraine management apps, the majority talked about an app that is not exhausting. They wanted to be able to access their information, follow trends in their attacks, and generally be able to predict or prevent their migraines on a timely basis. Moreover, the two participants who already had experience with health-based apps talked about how they would want similar outlooks and features as other health-based apps. One participant elaborated upon features that she would want in the app.

"I should be able to promptly see all the information of my records, and that I can see what I've been doing on last month. It should also allow you to add items like what we have been eating, our sleep cycle, all that, because it would give a complete picture then." – P09

Therefore, participants had a major focus on their triggers and symptoms whereby the app could predict their migraine attacks by using their data. Similarly, for wearables, the participants' acceptance was based on the idea that wearables might be efficient methods of predicting their attacks and expected that it would require minimum user input. However, multiple participants also raised concerns related to the price of wearables, while others said that their current limited understanding of wearables means that their acceptance might change with more information. Additionally, out of the five people that were unwilling to use wearables, all five talked about privacy concerns related to their data. At the same time, they also felt that using wearables was not a necessity for them as they already knew how to manage their migraine attacks. One participant also talked about how wearables would be uncomfortable for him.

"I mean, it sounds like a good idea, but I don't even wear a wristwatch, so I don't think I'll wear one (wearable). I just don't like to wear stuff." – P01

When talking specifically about why participants were not receptive to the idea of migraine management apps, like with wearables, all four felt that there was no need for them to use an app. They felt that they were aware enough of their own conditions that they could assess an attack and then take deal with it according to the situation. As one participant put it,

"I wouldn't want to use an app because I feel my sixth sense is good enough. A hundred percent of the time it gives me an idea that I'm going to have an attack." – P03

Our neurologist elaborated upon this idea, talking about how migraine patients are typically aware of an attack based on their physical or mental condition. He felt that technological interventions are of limited use and that very few of his migraine patients might be willing to try using a migraine management wearable. As such, he specifically talked about such systems in the context of their needs.

"I feel that very few people would use wearables. This is mainly because there is a thing known as unmet needs that need to be addressed immediately. However, in this case, there are no unmet needs as the patient can recognize the attack himself."

Therefore, our results show that wearables are not an adequate solution to help Pakistani migraine patients. Even in the case of patients who were willing to use wearables, price concerns and a lack of knowledge meant that the overall number of wearable users would be negligible. As such, our results highlight two major findings: 1) migraine management solutions cannot be generalized around the world, especially in third-world countries, and 2) the major problem that Pakistani migraine patients face is a lack of communication, not a lack of migraine management methods.

These findings however, contrast with previous research conducted in the US and the fact that the number of migraine apps, and their users is very high in regions other than Pakistan. Consultation with a researcher who worked on this revealed the main reason behind this.

"In the best case, some patients can predict their migraines about half of the time. By that time, it is already too late, as the patient has entered prodrome, the first phase of the cycle. By using a combination of a mobile phone app and a wearable device, migraines can be predicted even before they begin."

5. DISCUSSION

Our findings highlight the migraine management methods in Pakistan. While some of our findings coincide with previous research, our findings additionally reveal that there is limited scope for tech-based migraine management interventions in Pakistan. For patients aware that they have migraines, in most cases, they are able to identify their migraine attack on time, taking appropriate measures accordingly. However, the largest problem with migraines in Pakistan is that it not given appropriate attention, especially in rural areas and, more specifically, for females in rural areas, although this problem does extend to urban areas as well. Therefore, the need for migraines in Pakistan is recognition and communication of migraine patients with doctors.

Informed by our findings, we discuss design interventions for migraine patients in the context of Pakistan. We look at the current needs of migraine patients, mainly, 1) recognition of migraine as a serious mental disease, 2) establishing initial communication with doctors, 3) continued follow-ups with doctors, 4) recognition of individual triggers and symptoms, and 5) prevention of migraines in the long run. Our findings and discussion also hold value for other poorly-understood diseases in Pakistan.

5.1 Role of Human Centered Design

Our interview findings reflect a low reception for the idea of migraine management apps and wearables. The most common perception among users is that they can already predict their migraines and do not need technological intervention. It is apparent from the high number of migraine app management users internationally, that it does meet the management needs of

migraine patients. Even though the triggers and symptoms in the Pakistani region are unique, the underlying pattern of the disease is similar. A common perception is that users do not need a predictive model, and that they can predict migraine onset on their own. However, when patients are predicting the incoming headache, they have already entered the migraine cycle, most specifically, the prodrome phase. By the time they enter the migraine, it is already too late to manage it properly or take precautionary measures.

This is another factor where the users from Pakistan deviate. Migraine management apps and wearables in the US, with high retention rates, allow the users to predict their migraines even before they have entered the prodrome phase, allowing users a much longer period where they can manage their affairs.

This contrast highlights an important phenomenon in HCI: the failure of human centered design. It is a widely acknowledged fact that the user knows their needs the most. Yet, the users can have many misconceptions or wrong notions about the problem at hand as well. In his paper on the possible harmful role of HCD, Don Norman, the pioneer of HCD, argues that making the process only HCD-centered can limit the benefits that can be derived. Instead, one should take a broader, activity-centered view. By focusing on the task, and not just on the person, we can broaden the benefit that the intervention can bring [34]. By focusing on the physiological trends, instead of the user's experience and their notion of the disease, we can create tech-based interventions that can truly improve migraine patients' lives.

5.2 Bridging the Gaps

Our findings and discussion have showed that human-centered design fails in the context of migraine management in Pakistan. Therefore, we must adopt an approach to eventually make migraine patients aware of the benefits of tech-based interventions. To achieve this, we first need to bridge the communication and knowledge gaps that migraine patients in Pakistan face. In the context of communication gaps, we first propose creating a connection between doctors and patients. Considering how almost everyone owns a smartphone nowadays, an app can be used to create communication between doctors and patients. Specifically, the app could remind users of their appointments, and allow users to enter and track their migraine triggers and symptoms. As such, this migraine management system would allow patients to be connected to doctors and can be extended to cater to other diseases as well. At the same time, having a functioning management system will allow users to gain knowledge on migraines. If successful, individual patients would become more aware of their migraines, which in turn would create awareness in general. As such, this method could bridge the current gaps in knowledge and communication that exist in migraine patients in Pakistan.

As discussed above, wearables have low receptibility in Pakistan. However, wearables are a proven and efficient method of predicting migraine attacks. Therefore, while wearables may not be a current need, they could be needed in the future. Our neurologists also elaborated on this point, talking about how scientific breakthroughs take time to be adopted in the medical industry. As such, a small 3-month study can be conducted with users willing to use wearables to gauge the effectiveness of wearables in predicting migraines. The results, if positive, could be invaluable in future integration of wearables as predictive instruments for medical diseases in Pakistan.

6. CONCLUSION

In this paper, we have designed and conducted an interview study with migraine patients from Pakistan, specifically Lahore. The triggers, management patterns, and perceptions about the role of tech intervention were markedly different from patients in the US. We find that the glorification of migraines as an affluent sickness has led to an increased rate of acceptance, even leading to self-diagnosis or over-diagnosis. Due to a change in the physical environment, Pakistani patients' triggers vary from their American counterparts. We see that heat (related to the region's tropical climate) and travel (commuting long distances through polluted air) are particular to patients of this region. The lack of proper healthcare for female patients means that their needs often go unaddressed, exacerbating their illness. Moreover, the trends in management techniques include abortive techniques more so than preventative ones. Whether their pattern is abortive, or preventative also has a role in patients understanding how the tech intervention can help them. The most common perception in these patients is that they can predict their migraines, so a tech-based solution is not viable for them. We discuss how this idea is linked to the failure of Human-Centered design, and the fact that it should be modified to activity-centered design in this context.

This study has set the base work for an extension to bridge the gap between current practices and best possible interventions for patients. There is a need to create awareness about the available solutions and to deal with the misconceptions patients currently have. As a tech-based intervention can predict migraines even before prodrome, it can bring much better value to the patients' lives.

The next phase of our project focuses on just that. Using wearables, we will collect data from migraine patients over a period of 3-6 months, use it to train the machine learning model, and connect it to an application on the user's phone. The design of these applications, and the ML framework is the next step. None of our patients had used migraine management applications previously but eight participants agreed to join the 3–6-month period of data tracking.

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