

# MyMigraine: A Patient Data Delivery Technique for Physicians and Patients Migraine Management

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## ABSTRACT

Migraine Headaches are sometimes-debilitating neurological condition faced by nearly 1 in 4 households in the US. There is insufficient research on the day to day triggers and symptom management of the condition and insufficient tools for patients to manage their own self-care and optimize prevention and treatment. And for the physicians, clinical decisions are made with difficulties based on patients vague memory. MyMigraine is using a smart phone and smart watch for novel data capture and using an image-based questionnaire to assess the severity level of patient's migraine status, which effectively minimize the patient's effort for migraine data input. It also visualizes the data for patients to explore personal triggers, and also for the physicians to make supported clinical decisions.

## Categories and Subject Descriptors

H.4 [Information Systems Application]: Miscellaneous; H.5.2 [Information Interfaces and Presentation]: User Interfaces

## Keywords

Migraine; Patient; Physician; Visualization; Management; Clinical Decisions

## 1. INTRODUCTION

Migraine is a complex neurological condition that affects millions of households in the US. The prevalence of definite migraine in adults is 11.5%, and probable migraine is 7%, yielding a total of 18.5%, and even greater prevalence in children and teenagers [1]. Even though there are many sufferers in the US, migraine still remains poorly understood. Poor self-rated health, increased use of health care and medication as well as unmet needs of health care all contributes to the magnitude of migraine [2]. Patients lack awareness and knowledge of proper migraine treatment.

Currently, migraine can be treated with medications or with lifestyle counseling; there are many environmental agents that have been linked to the onset of symptoms and identifying and avoiding triggers becomes part of migraineur's treatment plan. Discovering triggers is typically done by keeping a headache diary and sharing it with a physician. However, according to Dr. Joseph Safdieh, a headache specialist at Weill Cornell, patients mostly had difficulty recalling past migraines information, which made it even harder for the physicians to determine the migraine types and make clinical decisions.

There are several interactive smartphone apps that have been developed for this purpose, but these apps are limited in their utility because they require a large amount of user data input. This often negatively impacts patient adherence to these apps, and the

resulting lack of data limits the ways physicians can help, which eventually harm the patient outcomes.

Migraine is not only a personal health issue but also a public issue with social and economic consequences. According to Migraine Research Foundation [3], healthcare costs associated migraine is \$36 billion annually in the U.S., and employers lost more than \$13 billion each year because of 113 million work days off due to migraine.

In short, migraine is a complex medical condition and also a public health issue that needs better migraine management solution to help patients better understand migraine, minimize their effort in data collection, help physicians with clinical decisions, and as a result improve the patient outcome and reduce the healthcare economic loss.

## 2. RESEARCH STUDY

### 2.1 Clinic Decisions and Researches

(Clinic Decision – anatomy, headache types, medication)

There are two types of headaches: Primary headaches and Secondary headaches. Secondary headaches are usually caused by the increase of pressure on blood vessels, which will cause throbbing pain. Primary headaches are the most common migraine. About  $\frac{1}{3}$  migraine doesn't have throbbing pain, which is why ergotamine (a medication that relieve the blood vessels pressure) is not usually useful for migraine. Activation of the trigeminal vascular system may also cause aura, which is a popular migraine symptom. Another explanation is that migraine starts with underlying central nervous system disorder, which can only be determined by the patient description of migraine symptoms. [4]

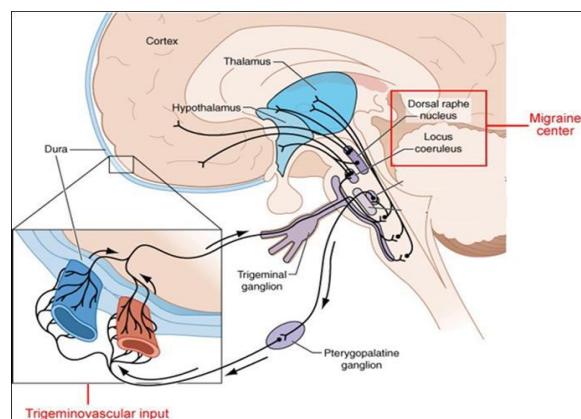


Figure 1. Migraine Pathophysiology

CT and MRI are usually helpful with primary headaches, but hardly with migraines. According to Dr. Kurth from The French National Institute of Health and Medical Research (Inserm), neuroimaging can only help when there is clear indication that the migraine is caused by another illness or other atypical features, which is a very rare case.

As a result, clinical decisions rely significantly on patients' description and memory. When the information patients provide to the physician is unclear, it's especially difficult for the physicians to decide which medication could actually relieve the condition or what suggestion could possibly help avoiding the triggers.

## 2.2 Migraine Apps analysis

There are plenty of migraine apps in the market. A research was done to analyze these migraine apps performances according to clinical variables, usability, reports, etc. None of the applications have scientific published article support, and most of them require much patient effort to record migraine. Overall analysis result in table 1 shows that iHeadache gives the most accurate information for the migraine physician. [5]

**Table 1. Migraine Apps Analysis**

Name	Platform/ Version tested	Price, Can\$	App criteria Created with headache expertise	Published in scientific literature	Headache variables measured / Clinically relevant variables measured (out of 7)	Usability score (%)	Custom answer options / Custom reports	Reports/ Reports linking multiple variables	Export data from app criteria met (out of 7)	Number of patients
iHeadache	iOS/1.45	4.99	Yes	No	8/7	90	Few/Yes Many/Yes	Yes/No Yes/Yes	Yes	5
Headache Diary (ecofHeadache)	iOS/2.3	1.99	No	No	13/7	94	Many/Yes	Yes/Yes	Yes	5
Headache Diary Pro: Android/3.7	2.99	No	No	No	10/7	82	Few/Yes	Yes/Yes	Yes	5
Headache Diary Pro! iOS/1.5	3.99	No	No	No	12/7	94	Many/No	Yes/Yes	Yes	4
Migraine Diary	iOS/2.4.1	1.99	No	No	10/7	90	Many/No	Yes/Yes	Yes	4
PainCal	iOS/2.0	1.99	No	No	9/6	80	Many/Yes	Yes/Yes	Yes	4
A Migraine Diary for Headache and You	iOS/1.3 & 1.1	4.99/	No	No	13/7	62	Many/Yes	Yes/Yes	Yes	4
Migraine	iOS/1.1	Free	Yes	No	7/6	72	Few/No	Yes/Yes	Yes	3
Migraplex	iOS/1.1	Free	Yes	No	10/5	84	Few/No	Yes/Yes	Yes	3
Oh, My head	iOS/1.0	1.99	No	No	5/2	76	Few/Yes	Yes/Yes	No	3
Migraine Free	iOS/1.1	Free	Yes	No	5/5	74	None/No	Yes/Yes	Yes	3
Cluster Headaches	Android (2.0/04)	Free	No	No	4/3	80	Few/No	Yes/Yes	Yes	3
Headache Relief Log	Android/1.07	1.00	No	No	7/4	80	Few/No Many/No	Yes/Yes Yes/Yes	Yes	3
Headache App	iOS&Android 1.4.5 & 1.5	Free	No	No	9/6	76	Many/No	Yes/Yes	Yes	3
Headache Notes	iOS&Android 1.2.1 & 1.0.3	Free	No	No	6/5	84	Few/No	Yes/Yes	Yes	3
Migraine Meter	iOS/2.6	Free	Yes	No	9/7	82	Few/No	Yes/No	Yes	3
PainTrek	iOS/1.1	Free	Yes	No	8/5	66	None/Yes	Yes/Yes	No	2
American Migraine Foundation	iOS/1.0.1	Free	Yes	No	7/5	74	No/No	No/No	Yes	2

A study from American Migraine Foundation used another App, iMigraine, as a mobile phone headache diary application for a teenager migraine pain tracking [6]. According to the investigator of the study, this application would help teens monitor and report headache severity, characteristics, and duration. And Migraine Buddy is another application that was found massively popular among migraine patients.

These are the three best migraine applications from the perspective of physicians, researchers, and patients.

**Table 2. Apps Analysis Between Three Best Migraine Apps**

App Name	Migraine Record	Passive Data Collection	Data Visualization
iHeadache	Easy	None	Text Report
iMigraine	One time, but complicated	None	Chart, Text Report
Migraine Buddy	Twice per time, long	Sleep, weather, etc	Trigger analysis, Chart Report (future feature)

Table 2 shows a comparison between these three applications. Massive user input effort seems to be inevitable for a complete

data visualization or report, along with passive data collection. As a result, there isn't a mobile migraine application that can export satisfying data visualization or migraine report without much patient's self-reporting data input.

## 2.3 Chronic Migraine Management

Researchers have been designing systems to help chronic disease management. A study about migraine self-management, Patient-Centered Migraine Management by Ann Drapinski Rechtzigel, St. Catherine University [7], is using a "patient-centered and evidence-based" patient education intervention tool - the Headache management plan (HMP) - to "foster better communication, accuracy and outcomes" for diagnosed migraine patients self-management. The headache control performance is evaluated based on headache assessment tools and the abortive medications used.

The HMP system was evaluated by making both patients and neurology providers to take surveys before and after receiving patient education at home from the HMP. Study result showed a mostly positive feedback from both migraine patients and neurology provider groups.

The HMP was an innovative chronic disease management strategy that could possibly raise people awareness and knowledge of migraine. The actual implementation of HMP requires further discussion, but the presentation of patient education could be a notification of tips when the users have abnormal data analysis results.

## 2.4 Patient Community

More than 80% of the interviewed migraine patients suggested a great help from the patient community. Popular patient community for migraine includes but not limited to Patients and Me, Inspire, Migraine.com, The Migraine World Summit, Medline Plus, My Migraine Miracle, and the Daily Migraine.

From the conversations, it can be seen that most patients report positive feedback after the discussion in the community, even if the conditions may not applicable to different individuals. The condition may not be improved after the discussion, but more than half of the community user expressed a feeling of in control of their health.

As a result, patient community has a positive impact on migraine patient's self-management.

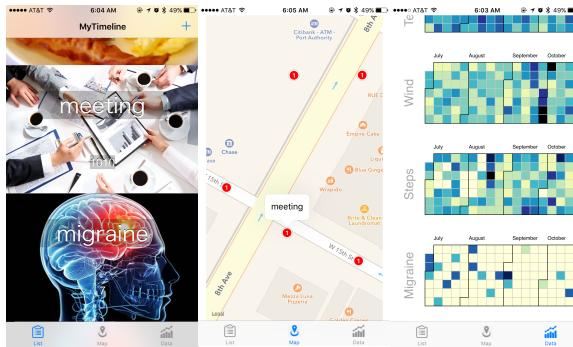
## 3. THE SYSTEM

MyMigraine is an iOS application that integrates an Apple Watch App for migraine record, a timeline iPhone App to show the user records in a timeline as well as in map view, an image-based questionnaire system (YADL), and data visualization calendar view built with D3JS.



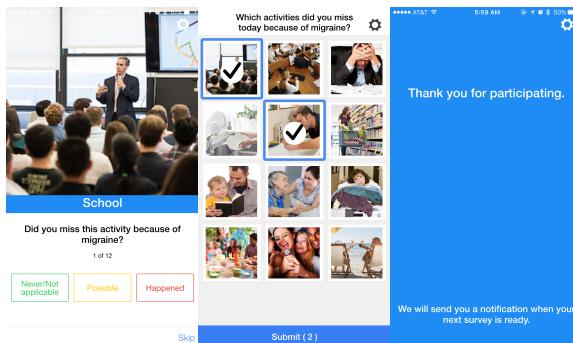
**Figure 2. MyMigraine on Apple Watch**

When a migraine attacks, the patient can simply open the watch app, select a severity level, and hit “Migraine Start” button. (Figure 2)



**Figure 3. MyMigraine on iPhone**

After the pain is relieved, the patient can open the app on iPhone, check the timeline and map to see when and where the migraine attacks, so that the patient may figure out the correlation. By clicking the record, the user can easily edit a record, or manually add a migraine record or any other activity such as meeting and breakfast. In the calendar view, the patient can see an overall migraine data along with other passively collected data such as weather, heart rate, steps, so that the patient can have an insight on personal migraine trigger. (Figure 3)



**Figure 4. Image-based Questionnaire**

By the end of the night, the patient would be asked to answer the image-based questionnaire for diet, missing work or school, reduce productivity, and the system will send the data to the Omage-omh server, and generate an assessment of the patient's migraine severity level. (Figure 4)

## 4. DESIGN METHODS

### 4.1 Patients Data Input Method

In order to collect useful patient data for the physicians, three neurologists from Weill Cornell Medicine were interviewed. They responded with similar answer – migraine frequency, severity, medicine and its effectiveness for the past three months are the four vital data for migraine diagnosis, and any other data such as emotion, sleep, diet would be helpful.

For migraine patients, they showed great concern about the long questionnaire in the existing migraine apps because the aura and the pain make them impossible to look at the screen. Also, many

patients expressed little curiosity about the trigger analysis, either because they know exactly their triggers or the prediction was hardly accurate.

Therefore, in order to satisfy both the data collection requirement by the physicians and the easy data input requirement by the patients, MyMigraine uses Apple Watch to record migraine frequency and severity.

### 4.2 Patient Activity

In order to improve patients' awareness of their migraine condition, patients should be notified when their migraine affect their daily life severely. The MIDAS or Migraine Disability Assessment Test is a test used by doctors to determine how severely migraines affect a patient's life [8].

#### The Migraine Disability Assessment Test

The MIDAS (Migraine Disability Assessment) questionnaire was put together to help you measure the impact your headaches have on your life. The information on this questionnaire is also helpful for your primary care provider to determine the level of pain and disability caused by your headaches and to find the best treatment for you.

#### INSTRUCTIONS

Please answer the following questions about ALL of the headaches you have had over the last 3 months. Select your answer in the box next to each question. Select zero if you did not have the activity in the last 3 months. Please take the completed form to your healthcare professional.

- 1. On how many days in the last 3 months did you miss work or school because of your headaches?
  - 2. How many days in the last 3 months was your productivity at work or school reduced by half or more because of your headaches? (Do not include days you counted in question 1 where you missed work or school.)
  - 3. On how many days in the last 3 months did you not do household work (such as housework, home repairs and maintenance, shopping, caring for children and relatives) because of your headaches?
  - 4. How many days in the last 3 months was your productivity in household work reduced by half or more because of your headaches? (Do not include days you counted in question 3 where you did not do household work.)
  - 5. On how many days in the last 3 months did you miss family, social or leisure activities because of your headaches?
- Total (Questions 1-5)

**Figure 5. MIDAS Questionnaire**

Patient activity data can hardly be collected passively, so MyMigraine used an image-based questionnaire system, YADL [9], to present activities as images to the patients, and convert the result into MIDAS score. The patients would be asked, “*Did you miss this activity because of migraine*”, and would be given three answers to choose from: “*Never/Not applicable*”, “*Possible*”, and “*Happened*.”

Twelve activities were designed based on the five questions in the MIDAS:

(In the format of <Activity><question number in MIDAS>)

{School 1, Work 1, Reduced productivity 2, Housework 3, Home repairs and maintenance 3, Shopping 3, Caring for children 3, Caring for relatives 3, Reduced household productivity 4, Family activities 5, Socializing 5, Leisure activities 5}.

After the patients have finished this full assessment, the system would store all the activities that the user chose “Possible” or “Happened” to generate the daily spot assessment. So in the daily questionnaire, the patients would only see the activities that applicable to them.

### 4.3 Data Analysis

The result of YADL is a number in each category, which shows the number of days for the last three months that this kind of activity was missed because of migraine. So the actual number of images in each category doesn't matter, but the number of days in each category does. According to MIDAS, if the number in total is 6 or more, the patient is in mild disability from migraine and requires medical care.

How to analyze migraine frequency and severity data from MyTimeline is depended on the physician, for it requires a clinical decision in the data analysis.

#### 4.4 Data Visualization

There are three data visualization views in the iPhone app (or MyTimeline): the timeline, the map view, and the calendar view. All three of them are designed to give the user an insight of their possible trigger. The timeline is more direct and straightforward so that it can be used as a daily review and edit records by the end of the day. The map view is to help with memory recalling. The patients may forget the exact time, but can be hard to forget the location and scenario. The calendar view is more of an exploration that storytelling. The user can easily see their migraine trend in a week, a month, or a year, and find the correlation between migraine and any other data. In figure 6, for example, the patient only has severe migraines on weekdays, so the trigger may relate to school or work. The patient's migraine data also shows correlation with wind level, so the wind may also be the trigger.

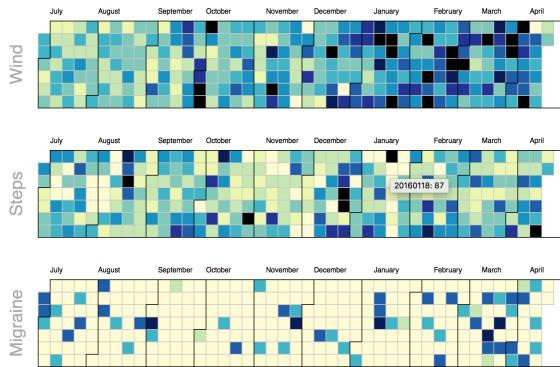


Figure 6. Migraine Data Visualization in Calendar View

## 5. RESULTS

MyMigraine is a simple, professional data collection tool that can be easily understood and quickly got used to. Adult patients who just start using MyMigraine took up to 2 minutes to record their first migraine and took up to 30 seconds to record a migraine afterward. Other apps such as iMigraine, for example, took up to 4 minutes for the same patients to start recording.

## 6. DISCUSSION

There are several problems that might require further discussion and development if MyMigraine can truly help the patients and the physicians in migraine management.

### 6.1 Apple Watch Dependency

For migraine patients who don't have a smart watch, it would be hard to see MyMigraine's advantage. Even though it allows iPhone manual input as well, the problem of reaching screen during migraine attacks still exists. It needs a better solution for those patients who don't have an Apple Watch.

## 6.2 Migraine Duration

Migraine attacks usually last for 4-7 hours, and the severity level kept changing during the attack. Should the user record several times during one migraine, or should the patient change the severity level to the maximum after a migraine stops? Also, how to assess migraine duration if the system doesn't require the user to log both the beginning and the ending?

## 6.3 Calendar View

If the calendar view lists all of the possible trigger data together, the correlation would be really difficult to see for the patients. Patients should be able to customize the data source in the calendar view, or show them one by one with the migraine data.

## 7. FUTURE WORK

For the last semester, I've learned much from the physician's prospective. For the next semester, I need to understand migraine patients more in detail. What is their prior concern? What would they do when migraine attacks? What encourage them to see a doctor? Why would or wouldn't they use mobile migraine diary apps?

In order to answer these questions, I would start with migraine patient discussions from online migraine communities like Migraine.com, and use NLP, data mining and data visualization techniques to dig out the answers.

I will also follow-up three to five chronic migraine patients closely for up to two weeks, learn their daily lives, record their migraine triggers, find the actual problem in their migraine self-management, and figure out a solution.

Then I will finish the app development, including the data visualization for the physician, integrate YADL with ResearchKit, necessary data collection, and possibly other ResearchKit tasks. After making sure the app is functional, I will conduct user studies for both the patients and the physicians to test the app, redesign, and test again.

Patient self-management and physician data visualization are the specific healthcare areas that I wish to devote in the future. By the end of the specialization project, I am expecting to have full stack development skill, healthcare project management knowledge, medical research experience, HCI method practice, and a working migraine app than I can be proud of.

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