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Data Article

The Functional Assessment of Migraine Scale development datasets



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ABSTRACT

The Functional Assessment of Migraine Scale (FAMS) is a newly developed questionnaire that allows patients to indicate their response to migraine treatment [1]. The datasets provided in this article were collected on patients with migraine using survey methodology in two rounds of data collection. In the first dataset (n = 100), patients were shown 210 proposed questions for the FAMS and rated their usefulness and/or relevance for assessing their treatment response [2]. Using factor analyses, the best items were selected for the second data collection (n = 200). Patients completed the final proposed 72 items along with two other popular measures of migraine assessment [3]. Both datasets include demographic and migraine related information (gender, race, medication, number of headache and migraine days). These data provide a wealth of information about the number and types of medications a patient with migraine may take, coupled with information about their perceived response to treatment with those medications. Because the FAMS was developed to assess a wide range of concerns voiced by patients, this data offers new insights into a large health population beyond the normal scope of research studies.

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Specifications Table

Subject	Health	
Specific subject area	Patients with migraine, response to treatment	
Type of data	Datasets	
How the data were acquired	Survey using Qualtrics	
	Phase 2: https://osf.io/mpyhw	
	Phase 3: https://osf.io/9crn8	
	Please note that the OSF viewer sometimes displays these word documents	
	oddly, please download for better viewing.	
	Patients were emailed a link to complete the survey on any internet capable	
	device.	
Data format	Filtered	
	Anonymized	
Description of data collection	Patients who indicated interest in the study were screened to ensure they were the target population. They were at least 18 years of age, had a diagnosis	
	of chronic or episodic migraine for at least two years, no substance abuse	
	problems, and no uncontrolled psychiatric conditions. Participants were	
	recruited using mailing lists from the National Headache Foundation, other	
	medical professionals, and online forums.	
Data source location	Institution: Clinvest Research, LLC	
Data Source location	City: Springfield, MO	
	Country: USA	
	Participants completed data collection online, and locations were not collected.	
Data accessibility	Repository name: Open Science Framework	
Data accessionity	Data identification number:	
	Phase 2: 10.17605/OSF.IO/RMXWD	
	Phase 3: 10.17605/OSF.IO/64WSM	
	Direct URL to data:	
	Phase 2: https://osf.io/z6q4t	
	Phase 3: https://osf.io/w2xks	
Related research article	E.M. Buchanan, H.R. Manley, J.S. Sly, R.J. Cady, A. Wikowsky, A.L. Cunningham,	
	Development of the functional assessment of migraine scale using a patient	
	guided approach, Qual. Life Res. Int. J. Qual. Life Asp. Treat. Care Rehabil.	
	(2022). https://doi.org/10.1007/s11136-022-03279-9.	

Value of the data

- Migraine affects nearly 10% of the population [4] but represents an understudied area of neurological and behavioral health given its prevalence. These data represent information in both areas, assessing response to treatment across a wide domain of potential concerns, along with usefulness, relevance, and medication data.
- Medical professionals and researcher interested in all facets of migraine would be interested in this data for research purposes. Previous research suggests that patients are concerned with not only pain and frequency management for migraine [5], but also social commitments [6], quality of life, mental health [7]. This dataset is one of the few that covers a wide range of patient concerns.
- Educators can reuse this data for teaching statistics and survey design. Exploratory factor analysis is a popular statistical tool for development of psychometric measures [8]. This dataset would allow for multiple assessments of exploratory factor analysis on real, rather than synthetic data. Further, the results from these models could be used to

demonstrate multiple regression on headache or migraine data or t-tests using patient diagnoses.

• Further research with data could explore differences in migraine populations on the number and types of medications, thematic areas, number of headache/migraine days and their interactions. Other assessment scales [9] provide classification and severity values, which could be developed for FAMS scores.

1. Data Description

Table 1 denotes participant demographics. Both data descriptors include three files: phaseX_Qualtrics.docx, phaseX_deidentify.csv, and phaseX_codebook.csv. The Qualtrics document includes the survey items, flow, and answer choices for each portion of the study. The deidentify comma separated files include the processed data in which identifying information and columns have been removed. All participants who did not qualify for the study were also removed from these final datasets. The codebook comma separated files denote the match between the variable name and the exact item shown in Qualtrics. While this information is present in the Qualtrics word document, the codebook file is provided for clarity and ease in matching items and variable names. All files are denoted as Phase 2 and 3 from the original study, as the first phase of data collection cannot be shared due to privacy concerns.

Table 1

Participant demographics for both questionnaire datasets.

	Phase 2	Phase 3
Sample Size	100	200
Female	84 %	84 %
Non-Hispanic	99 %	97 %
White	96 %	94 %
Age	38.9 (13.3)	49.9 (13.2)
Monthly Headache Days	14.9 (8.2)	15.7 (8.8)
Monthly Migraine Days	9.7 (7.1)	11.9 (7.8)
Reported Chronic Diagnosis	70 %	80 %
Reported Episodic Diagnosis	24 %	30 %
Number Medications	14.5 (1.7)	14.9 (1.3)

Note. Diagnosis was a self-report multi-select item in which participants indicated any diagnosis they had received for migraine.

Missing data is denoted in the datasets as *NA*, unless items were an "other" text item. *NA* values indicate they did not enter an answer for that question or did not select that answer choice. For example, on multiple select items, such as medication or ethnicity/race, the answers are separated into wide format, wherein each possible selection is placed in one column within the dataset. Therefore, *NA* values for multiselect items are represented as not selecting that answer choice. If all options for a multiple select are *NA*, then the participant did not answer that question. On "other" text times, no text included in the column indicates they did not fill in an answer for the other text, which is often interpreted/coded as "" – a blank cell, rather than a cell specifically coded as *NA*.

2. Experimental Design, Materials and Methods

The experimental design for both datasets was a survey. Participants were recruited using online forums and mailing lists from migraine specialists and foundations. They were screened to ensure they met the inclusion criteria: 18 years of age or older, a diagnosis of migraine for at

least two years, no substance abuse problems, and no uncontrolled psychiatric conditions. Participants were paid to complete the survey. Sample sizes for each dataset were determined by two factors: 1) power analyses and 2) grant funding. For the Phase 2, we collected the minimum number of participants (n = 100) suggested by power analyses for exploratory factor analysis [10], and for Phase 3, using guidelines from MacCallum et al. [10], we recruited n = 200participants to provide coverage for high item inter-correlations for exploratory factor analysis.

Survey items were developed from the first phase of the original study which included interviews with patients over their migraine treatment and assessment. The research team developed 210 items covering twelve thematic areas identified in previous research and the first phase of the study: associated migraine symptoms, concentration problems, frequency of headache/migraine, medication, normal functioning, pain, productivity, self-worth, social life, provider/doctor, education, and financial/insurance. These items were developed to provide change scores across assessments, and therefore, many include phrases to denote improvement (e.g., "I am improving"). An example of a social life item *I skip social activities with friends because of migraine* or a pain item *Overall, my head pain has decreased* shows how scores may change if treatment improves these thematic areas. Items were also included that did not include this language to explore what items would be perceived as the most beneficial to patients. Each item used a 5-point Likert-style scale with the following anchors: 1 = *Strongly Disagree*, 2 = *Somewhat Disagree*, 3 = *Neither Agree nor Disagree*, 4 = *Somewhat Agree*, and 5 = *Strongly Agree*.

In each phase of data collection, Qualtrics was used to deliver the survey online to any qualified participant with an internet capable device. Item randomization was used to scramble items to prevent order effects. Demographic data was first collected (see attached codebooks), followed by migraine specific factors and medications. A definition of migraine was provided in this section to direct patients. Survey items were shown in blocks of five which were randomized across blocks and items. Each item was given the instruction to mark their agreement with the statement based on the <u>last month</u> of their treatment for migraine and/or symptoms. In the first dataset, participants were asked to mark if they found the item useful for treatment assessment (yes/no), and specifically, to mark no if they did not understand the item. Item instructions were slightly modified for the provider, education, and financial/insurance items, as they were designed to be part of an add-on scale. In these items, participants simply marked their agreement with the statement (no time period or migraine assessment). They also indicated if the item was relevant for assessing barriers to access to treatment and were told to indicate no if the item did not make sense to them.

In Phase 3, 54 items from the response to treatment items and 27 items from the barriers to treatment (doctor, financial/insurance, medication) selected from Phase 2 were shown to participants with the same instructions as above. Participants were not asked to assess the usefulness or relevance of each item in this stage. Two other migraine scales were included for validity assessment: the Headache Impact Test (HIT-6)TM [11] and Patient Perception of Migraine Questionnaire-Revised (PPMQ-R) [12]. This section was not randomized as directed from the original scale developers. Patients completed the survey in their own time. At the end of the survey, they indicated their preference for gift card payment and exited the survey.

The HIT-6TM includes six items that measure headache impact as a brief screening questionnaire. Scores can range from 36 to 78. The data is coded from never (1) to always (5), and total scores are calculated by multiplying each anchor point by a score and then summing all six items. Higher scores indicate higher headache impact. Guidelines for interpretation include little to no impact (<= 48), some impact (50-54), high impact (56-58), and severe impact (60+). Items include questions about severe pain, daily activities, concentration, and irritation. The PPMQ-R is the revised version of the PPMQ [13] with 32 items across several subscales (efficacy of treatment, functionality, ease of use of treatment, cost of treatment, and bothersomeness of treatment). Twenty-two of the PPMQ-R items use a scale from 1 (*very satisfied*) to 7 (*very dissatisfied*), and ten items ask participants to respond using a scale from 1 (*not at all*) to 5 (*extremely*). Scores are summed and converted to a 100-point scale, and higher scores indicate better outcomes. Questions cover the impact of medication and treatment on a wide range of

Ethics Statements

All participants completed an informed consent, and the research was performed in accordance with the Declaration of Helsinki (Missouri State University: IRB-FY2018-733).

CRediT Author Statement

Erin M. Buchanan: Conceptualization, Methodology, Software, Formal analysis, Investigation, Resources, Data curation, Writing – original draft, Writing – review & editing, Project administration, Funding acquisition; **Ryan J. Cady:** Conceptualization, Methodology, Investigation, Resources, Writing – review & editing, Funding acquisition; **Heather R. Manley:** Conceptualization, Methodology, Investigation, Resources, Resources, Writing – review & editing, Project administration, Funding acquisition; **James S. Sly:** Conceptualization, Methodology, Software, Formal analysis, Investigation, Resources, Data curation, Writing – review & editing, Funding acquisition; **Addie Wikowsky:** Conceptualization, Methodology, Software, Formal analysis, Investigation, Resources, Data curation, Writing – review & editing, Funding acquisition; Resources, Data curation, Writing – review & editing, Funding acquisition, Resources, Data curation, Writing – review & editing, Funding acquisition, Resources, Data curation, Writing – review & editing, Funding acquisition, Resources, Data curation, Writing – review & editing, Funding acquisition, Resources, Data curation, Writing – review & editing, Funding acquisition, Resources, Data curation, Writing – review & editing, Funding acquisition, Resources, Data curation, Writing – review & editing, Funding acquisition, Resources, Data curation, Writing – review & editing, Funding acquisition, Resources, Data curation, Writing – review & editing, Funding acquisition.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data Availability

The Functional Assessment of Migraine Scale Development Datasets (Original data) (Open Science Framework).

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