

Abstract

Adherence to mobile health for Migraine: Individual and App-Based Predictors

Objective: This study aims to examine barriers to adherence to a mobile health diary tracking migraine occurrence. **Methods:** This convergent parallel research incorporates both secondary analysis of data and primary analysis of novel qualitative interviews. First, this study represents a secondary analysis of quantitative diary data from sixty-three adult participants previously diagnosed with migraine. All were asked to record demographic data as well as 30 days of data around headache and impact on daily activities; these were treated as predictor variables with headache diary completion as the outcome variable. This study incorporates primary analysis of qualitative interviews conducted with 7 adults with migraine who participated in research studies of digital diary tracking for migraine attacks. Participants answered questions regarding migraine symptoms impacting vision (UPSIS-12), usability of the migraine diary application (MAUQ), and broader strategies regarding migraine disruption in technology use and mitigation thereof. After 5 interviews, data was coded and analyzed for barriers to technology use and pursuant potential accessibility improvements for the application. Third, this study incorporates data from a qualitative research study of 20 headache care providers who identified considerations around prescription of digital headache diaries. A secondary analysis of primary data focused on spontaneous responses disclosing visual symptom impacts on provider willingness to recommend digital diary tracking for patients. **Results:** Individual and headache-level self-report variables were not significantly associated with headache diary completion. Participants reported several accessibility issues with using technology during headache attack. Headache providers disclosed that visual symptom impacts are anecdotally known to make digital diaries inaccessible and inappropriate for certain patients. **Conclusion:** Though personal variables do not appear to predict technology use during headache attack, participant self-report suggests significant impact of headache symptoms on technology use. Headache providers echo these concerns by patients and reveal anecdotal patterns in digital diary fit for certain patients. Across patient and provider self-report, patterns of digital diary avoidance during migraine attack risk biased clinical and research data for our most-impacted patients. Several design possibilities may be successful partial mitigation for barriers to mobile health use for migraine.

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Chapter 1. Introduction.

I. Migraine Characteristics and Diagnosis

Migraine is a recurrent, typically lifelong disease characterized by disabling symptoms including pain, aura, and photophobia in attacks of varying duration (Organization, 2011). Migraine is the second largest overall contributor to disability, and one of the top five leading causes of years lived with disability worldwide (Vos et al., 2017). Worldwide, approximately 1.04 billion people experience migraine every year (Stovner et al., 2018). Annually, an estimated 15.3% of all adults in the United States experience migraine (Burch, Rizzoli, & Loder, 2018). While migraine is not a diagnosable cause of death, it is a significant contributor to years lived with disability (Stovner et al., 2018). In 2016 alone, migraine contributed to 45.1 years lived with disability in individuals living with migraine (Stovner et al., 2018).

Migraine attacks, which include headaches that co-occur with sensory changes, may be divided into four overlapping phases: premonitory symptoms, aura, headache, and postdrome (Goadsby et al., 2017). While the exact origin of migraine attacks is not understood, there appears to be a relationship between migraine onset generally and a failure to habituate to sensory input (Fumal et al., 2006); sensory sensitivity is common across phases of an attack. Migraine typically begins with a premonitory phase that may include fatigue, phonophobia, irritability, and other symptoms (Goadsby et al., 2017). Approximately 20% of people with migraine then experience aura, which lasts as long as 60 minutes and includes neurological visual disruptions in roughly 90% of cases and may include other sensory changes (Goadsby et al., 2017). The headache itself, which may last up to 72 hours, also often incorporates photophobia, phonophobia, and/or nausea in addition to pain; the headache sequence then

concludes with postdrome, at which point the pain has reduced but other symptoms, including fatigue and distractibility, may linger (Goadsby et al., 2017). Studies of cortical excitation in migraine patients have yielded suggestions that changes in excitability in the brain can create vulnerabilities that allow aversive visual inputs, fatigue, or stress to trigger migraine attack: essentially, that a brain already prone to migraines can be triggered into an attack by cognitive or sensory stressors (Stankewitz & May, 2009). The sensory symptoms of migraine, including the visual symptoms during the aura and pain phases, have led to interpretations of migraine as a sensory processing disorder (Goadsby et al., 2017).

Two of the most common symptoms of migraine, photophobia and aura, represent interruptions of visual functioning. Photophobia is a diagnostic criterion for migraine, and sensitivity to light is a characteristic of migraine prodrome (IHS, 2013). Most migraine patients have photophobia, likely between 82.5% (Choi et al., 2009) and 92.4% (Russell, Rasmussen, Fenger, & Olesen, 1996). During episodes of photophobia, patients are especially sensitive to artificial light, with computer monitors being one identified source of uncommonly high discomfort; natural light, as in sunlight, is typically less problematic (Katz & Digre, 2016). In some migraine patients, light may not only be painful during a headache—it may be a headache trigger in itself (Katz & Digre, 2016). Aura prior to head pain, like photophobia, is listed in the diagnostic criteria (IHS, 2013). Migraine with aura occurs in roughly 7.9% of the population (Russell et al., 1996) and is visual 99% of the time (Russell & Olesen, 1996). In one study of 216 people who reported aura as one of their migraine symptoms, 98% reported visual aura symptoms, 36% reported sensory aura, and 10% reported dysphasia; most patients with aura indicated the appearance of their aura changes across attacks, as does the duration between occurrence of aura and onset of head pain (Viana et al., 2017). Symptoms of visual migraine aura

may include blurred or foggy vision, the appearance of heat waves, visual snow, zigzag lines, flashes of light, hemianopsia, and black spots, among other major visual disruptors (Viana et al., 2017). A metaanalysis of studies of visual aura presentations concluded light flashes, appearance of visual zig-zags, scotoma (partial blindness, or holes in vision), and foggy vision were the most commonly reported visual disturbances during aura (Viana, Tronvik, Do, Zecca, & Hougaard, 2019).

Migraine patients have significantly lower discomfort thresholds to light across wavelengths, and experience photophobia both during migraine attacks and between attacks (Main, Vlachonikolis, & Dowson, 2000). While treatments for photophobia specifically are not available, an exploratory study found light habituation does not reduce symptoms of photophobia; instead, photophobia improved after study participants spent at least an hour in a dark room, deprived of light (Matt et al., 2022). This suggests that photophobia is not best managed by ongoing exposure to light. This is also consistent with general observed clinical practice that people diagnosed with migraine with aura who are currently enduring migraine attack experience some symptom relief by retreating from light and other stimuli into a dark room (Kikkeri, 2022).

II. Mobile Health

Smartphone use is ubiquitous in the United States. Median smartphone ownership across economically-advanced countries is 76%, with the United States showing even higher rates of ownership at 81% (Silver, 2019). Nine in ten Americans under the age of 34 own a smartphone, and ownership among older adults is increasing with time (Silver, 2019).

Prior to the Covid-19 pandemic, mobile health already held a significant presence in the current smartphone marketplace. In the United States, an estimated 58% of smartphone users had downloaded one or more mobile health applications in 2015 (Krebs & Duncan, 2015).

Demographic predictors in the general US population of using a mobile health app included younger age, higher income, higher education, and self-identification as Latino (Krebs & Duncan, 2015)

However, despite the general prevalence of smartphone use, telehealth, and mobile health, patient termination of use of digital interventions remains an area of concern. An estimated 45% of smartphone users have stopped using at least one mobile health app, citing among other factors loss of interest, burdensomeness, and poor usability (Krebs & Duncan, 2015).

During the Covid-19 pandemic, Americans reported increased use of technology (Drouin 2020), and the pandemic appears to have prompted increased use of technology worldwide (GlobalWebIndex, 2020, as cited by (Zoppolat et al., 2022)). Telehealth use also increased during the Covid-19 pandemic at a significant pace and scope (Doraiswamy, Abraham, Mamtani, & Cheema, 2020). One study of headache telemedicine utilization between March and September of 2020 found that 57.5% of participants had used telemedicine as part of their headache treatment, with high rates of satisfaction (82.8% providing "good" or "very good" experiential ratings) and even higher rates of desire to continue using telemedicine for headache (89.8% stating preference to use telemedicine for at least some headache visits in the future) (Chiang et al., 2021). Recent federal legislation meant to improve care access in migraine and other diseases included increased funding for telemedicine (Monteith, 2022) suggesting care access via technology is likely to continue to increase in coming years generally and for migraine in particular. Furthermore, migraine patients not only engage with their doctors via telemedicine but may also engage in other behavioral interventions that are smartphone-based. People with migraine may also use digital means to access behavioral therapy, including biofeedback and

relaxation interventions (Stubberud & Linde, 2018). This data suggests that current practices in headache care have increasingly relied on digital means of delivery in recent years, and that this trend is likely to continue.

III. Headache Diaries in Clinical Care: Formats and Adherence

Collecting data from patients on the nature of their migraines is essential for accurate diagnosis and treatment and is one area where clinicians are increasingly relying on digital means of care delivery and management. Differential diagnosis of headache disorders requires patients to recall varying characteristics of their headaches, which may be unreliable; if several attacks have occurred, or if the patient has multiple kinds of headache, their recall in medical appointments may be biased towards whichever attacks are easy to recall (Paola & Rigmor, 2010). To garner more accurate data, physicians treating migraine typically recommend patients track their headache occurrence, symptoms, and triggers using a headache diary (Armstrong & Gossard, 2016). Patients are typically asked to record these details daily on a written form or calendar for a period of at least one month (Paola & Rigmor, 2010), after which time the details of their recorded attacks may be used as clinical data for diagnosis and treatment planning. Though headache tracking broadly is standard clinical practice, exact tracking methods are variable, and include both analog and digital means, described below.

Written headache diaries and calendars have been in use in clinical offices since at least 1981 (Paola & Rigmor, 2010). The first research study into the diagnostic validity of headache diaries was conducted in 1992 included 61 headache patients who completed both a diagnostic clinical interview and subsequently a headache diary for 1 month, then allowed blinded reviewers to diagnose the headache patients based only on their diary results; after comparing diary diagnoses to clinical interview diagnoses, the study authors concluded diaries were valid and interpretable means of tracking headache for diagnosis per IHS criteria, and a significant

improvement over data collection solely via clinical interview (Russell et al., 1992). The value of diary tracking for accurate patient data collection has been validated in clinical research: in one cross-sectional study, 181 children tracked their headache in a diary for 4 weeks before reporting what they had tracked on an independent retrospective questionnaire (van den Brink, Bandell-Hoekstra, & Abu-Saad, 2001). Of these children, 40% mis-recalled on their questionnaire that they'd had significantly more headaches than they had recorded in a diary; another 31% reported having fewer headaches than they'd noted in their diary (van den Brink et al., 2001). Without the existence of a written record of the actual headache occurrence in these patients, patient recall may not have yielded sufficiently accurate data for diagnosis and treatment decisions.

Though headache diaries are widely considered more accurate sources of data than patient recollection, data missingness from headache diaries remains an ongoing clinical challenge. Clinical trials for migraine prevention therapies require the metrics recorded in such diaries to evaluate the effectiveness of the treatment (i.e. reduction of headache days or other such outcomes); additionally, missing data in a headache log may lead to erroneous beliefs in both patients and clinicians about a patient's headache disorder diagnosis, symptoms, and/or treatment (Seng, Prieto, Boucher, & Vives-Mestres, 2018). While headache diaries reduce disparities between patient self-report and headache occurrence, missing headache diary data still risks the accuracy of patient diagnosis and care. Therefore, any headache diary record must target high rates of diary completion in order to produce sufficient, accurate data to support clinicians in the diagnostic and treatment process.

Digital headache diaries have increasingly emerged as the gold standard for tracking migraine symptoms because they are time-stamped, permitting a higher level of control over the retrospective recall period (Minen et al., 2016). Mobile health (mHealth) migraine diaries

represent a key opportunity to track migraine, as in-the-moment data collection improves accuracy of symptom self-report (Krogh, Larsson, Salvesen, & Linde, 2016). Headache diaries help patients and clinicians identify headache triggers for clinical management, including management of triggers and medication to reduce headache occurrence (Hodge, 2013). Electronic headache diaries for migraine are accurate, efficient, and acceptable to users (Minen et al., 2016). There are many commercial applications for migraine, yet mobile health for migraine is significantly under-researched, with the fewest publications on mobile health applications of all the World Health Organization's most prevalent conditions (Martínez-Pérez, de la Torre-Díez, & López-Coronado, 2013). The available research supports key need for development of an evidenced-based mobile health migraine diary (Hundert, Huguet, McGrath, Stinson, & Wheaton, 2014).

Research into mobile health diary adherence is limited, but one study of patients with a chronic health condition found that demographic and individual differences were significantly related to health behaviors, such as diary keeping in mobile health users (Mahmood, Kedia, Wyant, Ahn, & Bhuyan, 2019). Attrition from mobile health studies for headache is better documented: the highest attrition rates in a meta-analysis of internet-based interventions for chronic pain were in headache, ranging from 31.9% to 56% (Buhrman, Gordh, & Andersson, 2016). This suggests that digital headache diaries may be more successful from a clinical perspective than traditional paper diaries, if data missingness from the diary can be mitigated.

IV. Reducing Barriers to Digital Headache Diary Use

Visual symptoms of migraine are among migraine's diagnostic criteria ((IHS). 2013) but no research has been published on such symptoms and mobile or mobile health use. Despite their prevalence, visual symptoms' impact on the behavior and experience of people with migraine is poorly understood (Hanson et al., 2018), and their specific impact on engagement with mobile

phones--which inherently require functioning vision and looking directly at a light-emitting device--is not known. Whether visual symptoms negatively impact patients' ability to engage with mobile diaries is therefore a necessary area of inquiry to promote adherence to headache data collection tools.

In assigning headache data collection tools, consideration of personal factors known to impact mobile health adherence may inform the selection of the app assigned. These same personal factors may similarly inform the quantity of support needed to support adherence. Personal characteristics have been identified as a key area of study in mobile health for application customizing and targeting (Nunes, Limpo, & Castro, 2019). If adherence to mobile health is impacted by several personal factors that may not be modifiable, these factors may nevertheless be addressed with education and tool selection. For example, users' personal characteristics and beliefs about mobile health appear to significantly impact application use (Tuveson, Eriksén, & Fagerström, 2020). Individual differences are associated with mobile health use: younger age, higher income, higher education, and Latino identity all increase odds of using mobile health (Krebs & Duncan, 2015). Additional research into who within the migraine population is most likely, or least likely, to complete the number of digital headache diaries necessary for diagnosis and treatment is needed.

Mobile health diary applications are often constructed to be relatively static programs, with little flexibility to make changes in content and form. However, more easily modifiable diary applications yield opportunities to adapt the application to improve adherence. GeneDoe is a modifiable research-grade mobile health application and online platform designed for clinical research (Metts, 2021). The use of a flexible research-grade platform to systematically modify app accessibility elements and carefully test user experience provides an opportunity both to

improve the current platform for migraine accessibility, and to gain generalizable scientific knowledge to improve the (often one-off) apps created for migraine tracking in variety of clinical and research contexts. While this application is significantly more easily modifiable than an individuals' non-changeable personal characteristics, the amount of time required by developers to adjust the applications can be significant. Therefore, the developer responsible for this application benefits from research into verifiable, testable needs-based application modifications before making changes; this allows the developer to best prioritize application changes in the landscape of competing application modification and maintenance needs.

V. Usability in Mobile Health

Poor usability is known to contribute to user attrition in mobile health (Eysenbach, 2005). Accessibility, one element of usability, describes the extent to which a person with any range of ability or disability can use an application or product, inclusive of physical, sensory, and cognitive considerations (Yu, Parmanto, Dicianno, & Pramana, 2015). As migraine symptoms impact individuals' cognition and sensory perception (Goadsby et al., 2017), and cognitive and sensory stressors appear to trigger migraine attacks in some individuals (Stankewitz & May, 2009), incorporating accessibility concerns into mobile applications designed for use in people with migraine seems a reasonable step to make applications feel usable during migraine symptom occurrence. However, criteria for acceptability and usability of electronic diaries for headache tracking are not well defined (Bandarian-Balooch, Martin, McNally, Brunelli, & Mackenzie, 2017). Characteristics of apps for migraine that contribute to positive user perception of their accessibility and usability is therefore a key area of study.

The intersection of digital headache dairies, visual symptoms of migraine, personal characteristics informing adherence to diaries, and modifiable application features all suggest a need for research into mobile application accessibility specific to migraine visual disturbances.

Research into the landscape of applications tailored to individuals with disabilities found significant requests for applications that were compatible with users' existing limitations, i.e. need to use screen readers or inability to use specific gestural technology, as well as for applications tailored specifically to participants' disabilities (Jones, Morris, & Deruyter, 2018). The authors concluded that mobile healthcare has not been sufficiently researched in people living with disabilities to generate broad accessibility guidelines, including for those living with loss of vision, despite understanding that mobile health applications need to be designed with accessibility features for those living with visual, cognitive, and motor disturbances in mind to prevent worsening healthcare disparity (Jones et al., 2018). While people with migraine may only live with these criteria during prodrome, aura, and/or attack, mobile health diaries that require completion during one of these phases should therefore take accessibility during interim periods of disability into account.

The accessibility needs of patients with migraine and non-migraine-related disabilities further merit consideration and inclusion. Best practices for mobile health accessibility research include centering the actual needs of the population in question to develop app-based accessibility solutions addressing the highest-priority needs of people living with disabilities (Jones et al., 2018). Successful application design centering the needs of people with disabilities has previously taken the format of qualitative interviews with individuals attempting to use an initial version of the app, modifying the app to improve use based directly on the participants' feedback on use and barriers, and re-presenting the application to these users to assess the impact of the attempted design improvements (Zhou, Saptono, Setiawan, & Parmanto, 2020). An equivalent study focused on mobile application accessibility for people living with intermittent

visual disturbances has not yet appeared in the literature, for migraine or other vision-impacting conditions.

Patient recording of headache diaries is beneficial for quality of patient diagnosis and care, particularly recording headache diaries on applications mobile health applications such that providers have accurate, in-the-moment clinical data rather than subjective data from patient interview that is likely to be incomplete and/or subject to recall bias. It is particularly helpful when patients record diaries on mobile health applications that facilitate complete and accurate in-the-moment details of attack occurrence, symptoms, and management, to mitigate this bias and missingness of data. The value of this data collection is widely known and understood in clinical settings. Furthermore, mobile health diaries are broadly considered acceptable to both patients and clinicians as means of collecting the necessary data to facilitate clinical treatment decisions. Despite the known benefits and the known wide acceptability of mobile health app use to record headache data, information on the patients completing these diaries—specifically, which patients are likely to adhere to digital headache diary collection-- is not yet understood. In addition to person-level factors that may impact diary completion, evidence on app-based features that may represent barriers to data collection has not yet been collected. In fact, identification of easily modifiable app-based factors that may be managed to improve usability and reduce barriers to data collection has never yet been conducted in a migraine-specific population. Identification of such usability factors is especially significant given the intermittent visual impairment that occurs in most people with migraine, via light sensitivity or via headache aura.

During migraine attack, at which time data collection is ostensibly most important, people with migraine attempting to complete headache diaries do so via apps without migraine-

specific usability in mind. This means the migraine clinical and research data is collected in patients with known ictal visual impairment, including aura-related visual disruption or deletion, pain when looking at light, and requirement to closely engage with backlit surfaces for periods of several minutes at a time, without standard accessibility for any of these visual impairments incorporated into the experience. It is probable that persons who have been diagnosed with migraine due to their photophobia or visual aura are nevertheless being asked to participate in clinical data collection that causes them physical distress while symptomatic. It is further possible that due to this physical distress, these patients either fail to complete data collection sessions or complete data collection sessions quickly and with insufficient accuracy in order to mitigate this distress.

To date, the broader field of headache clinical care and research has not paid sufficient attention to accessibility issues within headache data collection apps. The accessibility issues described above have likely led to key inaccuracies in data collection; these inaccuracies are in turn likely a direct result of the migraine attack phenomena evaluated in this study. These issues appear to be exacerbated in the specific groups evaluated in this project: persons who experience photophobia and/or visual aura related to their headache attacks. The potential impacts of research into this oversight are significant, as changes to data collection methods (i.e. making visual accommodations in applications) may be completed quickly, minimizing risks to data collection and maximizing experiential benefits to patients. The results of this study stand to mitigate unnecessary suffering in migraine patients due to clinical data collection via otherwise acceptable and accessible methods. Essentially, the lack of accessibility considerations for this population are likely to cause discomfort for our study participants and our clinical patients as a direct result of the symptoms we are trying to track and manage—which is fundamentally

counterproductive to the goals of this data collection. This study represents the first review of the current landscape of headache diary completion during visual symptoms of migraine, and the first generative qualitative research into mobile health accessibility for people living with migraine.

Chapter 2. Methods.

Study 1 – Quantitative Analysis of Headache Diary Data

The present study is a secondary analysis of previously collected digital headache diary data. The parent study was a clinical trial regarding the efficacy of mindfulness for migraine (NCT02443519), though only baseline data not including an intervention were analyzed for this analysis. The study was conducted between July 2015 and September 2018.

This analysis was meant to assess possible predictors of headache diary non-completion. Participant person-level factors, i.e. demographic characteristics, were analyzed as predictors. Other certain headache-level factors, such as indicators of visual sensitivity to light, were also treated as predictors. The outcome in all cases was the completion status of the diary as a binary completed/non-completed.

Participants and Recruitment

Participants in the quantitative analysis were adults recruited from the greater New York City area via local advertisement, online advertisement, and neurology practices. Enrollment in the primary study initiated in July 2015, and data collection completed in September 2018. Recruited participants were instructed to complete 30 days of headache dairies as a means of baseline data collection, prior to being randomized to the intervention; these 30 days of baseline data were analyzed for this secondary analysis.

Eligibility and Exclusion Criteria

Inclusion criteria in the quantitative study were as follows: a) met criteria for diagnosis with migraine per the ICHD-3 beta headache criteria; b) self-reported at least 6 headache days

per month (participants enrolled in the study past baseline must have had distinct headache episodes and confirmed via diary; however, for this data review, all participants who recorded data were included); c) be an adult between the ages of 18 and 65; d) able to read English; e) able to consent to participate. Exclusion criteria for this study were failure to meet inclusion criteria a) through e), as well as f) plan to engage in new migraine medication treatment during the study; g) psychiatric illness sufficiently severe to prevent participation in the study.

Procedures

While the parent study included interventional data, only the participants' baseline data (i.e. their first 30 days of data) was included in this analysis.

Informed Consent

Informed consent was provided orally and in writing during their baseline screening for participation. Informed consent was stored separately from all participant responses. Participants were provided with a copy of the informed consent document for their own records.

Screening and Enrollment

Screening was conducted online, via the study webpage, and/or over the phone, depending on participant preference. Screening questions confirmed eligibility per study criteria. After this initial screening and prior to beginning data recording for the study, participants completed baseline questionnaires to again confirm their eligibility. These questionnaires included solicitation of demographic information and reconfirmation that participants met diagnostic criteria.

Study Visits

On a monthly basis during the parent study, participants completed psychosocial surveys including the MIDAS. Participants were prompted daily to complete a headache diary on a mobile device running iOS (i.e. iPhone, iPod). Participants who did not possess their own iPhone or iPod were loaned an iPod Touch by staff. Study visits were a daily headache diary to be completed in the app (rather than an in-person visit). Prompts to complete the diary occurred daily, in the evening (i.e. 5-9 pm), at the same time each day. Questions in the headache diary solicited the presence of headache attack and/or other associated symptoms. The application transmitted data from these diaries to RedCap, a HIPAA-compliant data storage system.

Participant Drop-out and Removal

Participants were permitted to terminate this initial participation in the study at any time. Participants were eligible for removal from the baseline 4-week recording period only if they reported changing their pain management treatment (e.g. starting a new preventative medication). Eligible participants continued in the diary study with randomization into study arms; however, only the first 4-week baseline data record is incorporated into this study, in order to incorporate a maximum number of participants with poorer diary adherence.

Participant compensation

Participants were compensated \$30 for completion of the baseline 4-week questionnaire, as well as the two baseline individual questionnaires. As this study was a secondary analysis, they were not additionally compensated for the analyses described as part of this study.

Measures

Demographics

Demographics were solicited via self-report in the initial baseline questionnaires survey. Gender, Ethnicity, Race, Employment Status, Education, and Marital Status were included as person-level demographic variables. Key clinical characteristics were also collected and treated as predictors, including headache-related disability as measured by the Migraine Disability Assessment questionnaire (MIDAS) Severity at intake, Aura, How Often Visual Changes Occur, and How Long Visual Changes Last. All person-level variables were evaluated for their association with adherence to the headache diary. Sensitivity to Light was measured by the American Migraine Prevalence and Prevention diagnostic scale (AMPP) and migraine-related disruption of activities as measured by the Migraine Disability Index (MIDI) responses were used as headache-level predictors. Alphas were set to .05.

General Headache Disability: Migraine Disability Assessment (MIDAS)

Headache-related disability was assessed using the MIDAS. The Migraine Disability Assessment (MIDAS) (Stewart et al., 1999) is a 5-item, self-report instrument measuring disruption experienced due to migraine. Items target role functioning and ask about lost days of housework, job-work, and non-work activities. Each item is an open question, allowing entry of number of days lost over a given period (the validated MIDAS uses a period of 90 days). Total scores are categorized into four graded levels of disability severity defined by numeric ranges. The instrument was developed to aid doctors and patients in communication about interference in functioning due to migraine. Several studies have shown the test to have good internal consistency, reliability and construct validity and suggest that it may be useful in clinical practice settings and improve the quality of healthcare (Stewart, Lipton, Dowson, & Sawyer, 2001). In the parent study, the MIDAS showed good internal consistency ($\alpha=0.76$) (Seng et al, 2019).

Headache Impacts on Specific Life Activities: Migraine Disability Index (MIDI)
Headache-related prevention from doing work-related tasks was measured by the

Migraine Disability Index (MIDI). The MIDI consists of 4 questions, measuring 4 different domains: Family and Home, Recreation, Social Activity, and Job/Occupation. Responses to the MIDI are on a Likert scale from 0 to 10, with 0 indicating no prevention from engaging with this domain and 10 indicating the migraine completely prevented engagement with that domain. Scores on each question range from 0 to 10; scores on the questionnaire are averaged across questions to present an average level of migraine impact. The MIDI has both good internal consistency ($\alpha=0.89$) and test-retest reliability ($r_s = .88$) (Nicholson et al., 2012). 3 of the 4 domains reference use of some backlit technology, i.e. “Recreation: How much did your headache keep you from doing things in your spare time? For example: exercise, gardening, hobbies, sports, arts / crafts, being on the internet, or reading.” As such, responses to these three relevant questions--Recreation, Social Activity and Job/Occupation—were included as independent predictor variables associated with headache diary adherence. Cronbach’s alpha for the three items included in this study showed good consistency ($\alpha=.835$).

Headache Diary Use

Headache diary use was calculated as a binary variable depending on participants’ answering of at least the first question of the diary. If participants responded to the first question of the diary, they were marked as having completed the diary for that day (1) whereas if response to the first question was missing the diary was recorded as incomplete for that day (0).

Quantitative Data Analysis Plan

Data for this quantitative analysis were examined, cleaned, and analyzed by the author of this dissertation at Yeshiva University, under the supervision of the primary investigator for the parent study, Elizabeth Seng, PhD. Statistical analyses were conducted in SPSS version 27 (add SPSS citation in EndNote). Analyses were conducted with alpha set to two-tailed, .05 level.

Prior to completing analyses, all data were visually inspected for abnormal values, i.e. values outside the range of the scale. Abnormal values were corrected individually.

Participant demographics were reported using descriptive statistics. Mean scale scores for the predictor variables, including on the MIDI, MIDAS subscales, self-reported vision changes, were also reported.

Power Analysis

Power analysis for the parent study leveraged effect size estimates from previous studies of behavioral treatment in migraine; per these estimates, a sample of $n=70$ subjects with an alpha of .05 yielded a power of .90 for detection of a large effect size (Seng et al., 2019). Ultimately, this study enrolled 63 participants.

Primary Analyses

All participant data recorded in month 1 of the parent study was included in this analysis. Data was visualized using P-P and Q-Q plots to check for extreme values. Gender, Ethnicity, Race, Employment Status, Education, Marital Status, headache-related disability (as measured by the MIDAS Severe or not at intake), Aura, How Often Visual Changes Occur, and How Long Visual Changes Last were person-level predictors evaluated for their association with adherence to the headache diary in independent logistic regression analyses. Headache Today, Sensitivity to

Light, and migraine-related disruption of activities (as measured by the MIDI) responses were used as headache-level predictors.

Data Analysis Plan for Specific Aims

Aim 1A: Evaluate individual characteristics for association with adherence to a diary application. Individual characteristics were evaluated for their correlation to adherence to a mobile health diary application for migraine. The following person-level relationships were evaluated: Gender, Ethnicity, Race, Employment Status, Education, Marital Status, Headache-related Disability (as measured by the MIDAS's Severity at Intake), Aura, How Often Visual Changes Occur, and How Long Visual Changes Last.

Aim 1B: Characterize the extent to which photophobia and aura impact use of backlit technology, including mobile phones. Day-level characteristics of headache i.e. occurrence of photophobia were analyzed for their relationship to headache diary use.

Gender and adherence

The relationship between gender and diary adherence was evaluated. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and participants' self-reported gender. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

Ethnicity and adherence

The relationship between ethnicity and diary adherence was evaluated. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and participants' self-reported ethnicity. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

Race and adherence

The relationship between race and diary adherence was evaluated. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and participants' self-identified race. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

Employment Status and adherence

The relationship between employment status and diary adherence was evaluated. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and participants' present level of employment. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

Education level and adherence

The relationship between education and diary adherence were evaluated. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time (i.e. day of the study)

and participants' education. Random effects were time and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

Marital Status and adherence

The relationship between marital status and diary adherence were evaluated. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and marital status. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

MIDAS Severe and adherence

The relationship between headache-related disability as measured by whether a MIDAS score is in the severe range were evaluated for association with diary adherence. Correlation analyses were conducted in a bivariate normal model. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and whether each individual's MIDAS score met the cutoff for severe disability. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

Lifetime Occurrence of Aura and adherence

Whether aura has any relationship to diary adherence was evaluated. Participants' response to whether they have ever had a migraine with aura were treated as the independent predictor variable with diary adherence as the outcome. Correlation analyses were conducted in a bivariate normal model. A mixed effects model was used to look at whether responses to a question regarding prior aura are related to diary adherence; diary completion, yes/no served as

the outcome. Fixed effects were time and responses to this question on the MIDI. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

How Often Visual Changes Occur and adherence

The relationship between a patient's reporting of how often they have vision-related symptoms and headache diary adherence was evaluated. Correlation analysis was conducted in a bivariate normal model. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and whether each self-reported how often vision change occur. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

How Long Visual Changes Last and adherence

The relationship between a patient's reporting of how long they have vision-related symptoms and headache diary adherence was evaluated. Correlation analysis was conducted in a bivariate normal model. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and whether each self-reported over how much time vision changes occur. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

Sensitivity to Light and Adherence

In the diary, all participants responded daily to a question evaluating whether light was bothering them at the time of headache completion. Whether this response has any association to

same-day diary completion was evaluated. Presence of photophobia as indicated by a “yes” to this question were treated as the independent variable, with same-day diary completion the dependent variable. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and participants’ self-reported photophobia, yes/no. Random effects were time (i.e. day of the study) and each respondent’s intercept. The covariance structure utilized in this analysis was AR1.

MIDI - Recreation and adherence

Responses to the MIDI question “Recreation: How much did your headache keep you from doing things in your spare time? For example: exercise, gardening, hobbies, sports, arts / crafts, being on the internet, or reading” (Nicholson, Chibnall, Tait, Banks, & Smith, 2011) and diary adherence were evaluated. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and responses to this question on the MIDI. Random effects were time (i.e. day of the study) and each respondent’s intercept. The covariance structure utilized in this analysis was AR1.

MIDI - Social Activity and adherence

Responses to the MIDI question “Social Activity: How much did your headache keep you from doing things with family or friends? For example: going out (party, dinner), seeing a movie or show, watching sports, going to your kids' activities, attending church or club meeting” (Nicholson et al., 2011) and diary adherence were evaluated. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and responses to this question on the

MIDI. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

MIDI – Job/Occupation and adherence

Responses to the MIDI question “Job/Occupation: How much did your headache keep you from doing your job? For example: both paying and non - paying jobs, volunteer activities” (Nicholson et al., 2011) and diary adherence were evaluated. Correlation analysis was conducted in a bivariate normal model. A mixed effects model was used to look at whether responses to this question are related to diary adherence; diary completion, yes/no served as the outcome. Fixed effects were time and responses to this question on the MIDI. Random effects were time (i.e. day of the study) and each respondent's intercept. The covariance structure utilized in this analysis was AR1.

Study 2 – Qualitative Analysis of Migraine Symptom Impact on Diary Completion

Participants in the qualitative study, Migraine Mobile Application Usability (MMAU), were recruited across two studies utilizing the same migraine diary mobile application for research. All participants were adults who had previously been diagnosed with migraine and had consented to complete mobile health headache diaries tracking headache attack occurrence and migraine symptoms for at least 7 days.

Participants and Recruitment

The study population consisted of participants diagnosed with a headache disorder who participated in a study using the Gene Doe app. We recruited 7 participants to review the version of the app currently in use across studies. Over of 50% of participants (4 participants) reported experiencing visual aura at least once.

Eligibility and Inclusion Criteria

Participants consisted of participants in one of two parent studies who used the Gene Doe app at least once daily for at least a week (i.e. at least 7 diaries recorded total, or the equivalent across a longer duration). These parent studies were Clinical Decision Support Tool for Patient Migraine Management study and the Migraine Interictal Neuropsychological Evaluation study. All participants were adults previously diagnosed with migraine and with diagnosis confirmed via the Structured Diagnostic Interview for Headache (SDIH) during the parent study. All participants did not have other critical mental health or substance use diagnoses that would preclude them from participating in research for migraine.

Procedures

The present study was a primary analysis of qualitative data. The Mobile Migraine Application Usability study received approval from the Einstein IRB (#2022-13919) and was approved as exempt by the Western IRB (Study Numbers 1308633, 1308646). Participants were recruited between July 2022 and January 2023.

Recruitment

The lead researcher recontacted via email participants who met the inclusion criteria and had completed participation in a parent study. Interested participants were given the option to schedule a 30-to-45-minute phone interview for a later date. On this call, a brief phone screen solicited participants' interest in participating in research and assessed changes to participants' migraine, health, and lifestyle status from their participation in the parent study. Interested participants from the historical (i.e. not ongoing) parent study completed an oral informed consent on the phone with the lead researcher, before beginning their interview. All participants

received Qualtrics links shortly prior to the interview that delivered copies of the following instruments for them to complete: the Utah Photophobia Symptom Scale (UPSIS-12) (Cortez et al., 2019) and the adapted mobile health App Usability Questionnaire (MAUQ) (Zhou, Bao, Setiawan, Saptono, & Parmanto, 2019). Participants from the historical parent study (CDST) were compensated for their participation in the form of an Amazon gift card worth \$10. Participants from the ongoing parent study (MIME) were not additionally compensated as their participation in this project was incorporated into their consent and onboarding procedures for their ongoing study.

Informed Consent

Participants in the parent studies previously provided their informed consent to participate in qualitative interviews regarding the study materials.

Screening and enrollment (15 min)

As this study consisted entirely of participants who have completed parent studies, initial screening served occur from the parent studies' data samples (i.e., confirming participants completed the minimum number of diary entries). Enrollment in this study occurred via recruitment, in which interest and informed consent for participation are solicited. Participants who were eligible and expressed willingness to engage in this study confirmed availability for the study interview and scheduled a phone call with the researcher over email and received two surveys links that they completed before the researcher called.

Study Visits

Upon enrolling in the study, participants were emailed two links to Qualtrics surveys. On accessing that link, they completed 2 baseline questionnaires that took an anticipated maximum

of 15 minutes to complete: the 12-item Utah Photophobia Symptom Scale (UPSIS-12) (Cortez et al., 2019) and the 21-item mobile health App Usability Questionnaire (MAUQ). For participation in the parent studies, participants previously completed the MIDAS and provided their number of headache days per month, which were used as baseline data for the present study. Completion of these materials included responses about level of visual symptom impact for migraine, as well as questions about attitudes towards technology use for health.

Participant Drop Out and Removal

Participants were permitted to terminate their participation in the interview at any time. Participants would have been eligible for removal from the study if they appeared unable or unwilling to complete the interview, but this did not occur in this study.

Measures and Instruments

The full qualitative interview delivered in this study was semi-structured and can be reviewed in full in Appendix A. Supplemental survey material included prior to completion of the qualitative interview is described below.

Utah Photophobia Scale (UPSIS-12)

On initialization, participants were asked about interictal photophobia via the Utah Photophobia Symptom Scale (UPSIS-12) (Cortez et al., 2019), as well as lifetime occurrence of visual aura. The UPSIS-12 is a 12-item scale that has demonstrated internal consistency and validity ($\alpha = 0.95$) for persons with migraine and with other headache disorders (Cortez et al., 2019). On the UPSIS-12, participants use a 6-point (0 to 5) Likert scale to rate their agreement with statements indicating photophobia (e.g. “How difficult is it for you to look at a computer

screen for any period of time?”). Scores are summed to indicate overall photophobia, and therefore range from 0 to 60. Higher scores indicate greater impact of photophobia.

The UPSIS-12 asks participants to evaluate their experience of light sensitivity and how that sensitivity impacts activities of daily living by responding to impact statements on a 5-point Likert scale; higher scores indicate greater photophobia impact. Presence of photophobia and aura were also solicited in each diary.

mobile health App Usability Questionnaire (MAUQ)

The mobile health App Usability Questionnaire (MAUQ) (Zhou et al., 2019) acted as a review of the overall usability of the Status/post application. The MAUQ is a 21-item scale ($\alpha=0.93$) with 3 subscales: ease of use ($\alpha=0.90$), interface and satisfaction ($\alpha=0.83$), and usefulness ($\alpha=0.90$); responses are a Likert scale (1 to 7) with items phrased such that lower scores (1, strongly agree) indicate better usability (Zhou et al., 2019). Questions on the MAUQ are focused on user perception of mobile health app use, such as “Whenever I made a mistake using the app, I could recover easily and quickly” (Zhou et al., 2019). Reviews using this survey may be presented by full scale or by mean subscale scores. In the qualitative interview, participants were asked to expand on their MAUQ responses, e.g., if they indicated the application was helpful in managing their health, or challenging to navigate, what contributed to their response. Participant responses to this questionnaire were reported in aggregate and were used individually to inform areas of follow-up in the post-study qualitative interview. Interview data characterized the relationship between experience of the application and adherence.

The MAUQ (Zhou et al., 2019) is a 21-item scale ($\alpha=0.93$) with 3 subscales: ease of use ($\alpha=0.90$), interface and satisfaction ($\alpha=0.83$), and usefulness ($\alpha=0.90$). Responses are a Likert scale (1 to 7) with items phrased such that lower scores (1, strongly agree) indicate better

usability. Participants were asked to expand on their MAUQ responses, e.g., if they indicated the application was helpful in managing their health, or challenging to navigate, what contributed to their response.

Qualitative interview and Study Completion

Experience of the application was evaluated via qualitative interview: 7 participants (4 of 7 or 57% with at least one migraine aura event in their lifetime, confirmed in interview) completed one semi-structured phone interview regarding their experiences after completing their parent study (incorporating the MAUQ and the UPSIS-12). The existing qualitative interview for the Clinical Decision Support Tool for Patient Migraine Management study was the basis of this interview, with irrelevant prompts removed and new prompts drafted to fully address Aim 2. Retained prompts included "Describe how you interacted with the application" and "What pieces of the application were difficult to figure out or were annoying." Prompts added asked about facilitators of and barriers to mobile health use (e.g. "How do your migraine symptoms affect when you're willing or able to use backlit technology—things like your phone, computer, or TV? " and "What's an example of an app that you think is very usable?"). Participants were asked to what extent migraine symptoms impacted their use of the application, as well as physical comfort using mobile health during headache. Those who indicated photophobia or aura in the diary were asked to about symptom impact on their experience, as well as what changes to the app might improve its usability during photophobia or aura.

Adherence to the mobile health Diary

Participants were asked about their engagement with the mobile health diary. Participants were also asked about blocks to and incentives for adherence. Participants were asked about other mobile health experiences and how they compare to using the present mobile health diary,

especially in relation to their visual symptoms of migraine. Participants were asked whether photophobia and/or aura ever impacted the use of their mobile device, or the mobile health diary in particular, during data collection.

Qualitative Interview (30 minutes)

Participants completed one approximately 30-minute qualitative interview regarding their experiences of using the digital diary application, of photophobia and aura in general, and of photophobia and aura as they impact use of technology (i.e. computers, mobile devices) specifically. Participants were asked about challenges they experienced while using the application and to explore possible solutions, as well as about strengths of the use experience from an accessibility and usability perspective.

Data Analysis Plan

Qualitative analysis used an interpretive phenomenological analysis (IPA) approach (Clarke & Braun, 2013), with a focus on comparing differences in symptom impact, beliefs about the app, and other facilitators and barriers to mobile health identified by the participants. A thematic analysis meeting to review the data and to develop codes included study staff, the medical professional who created the application being researched, a practicing health psychologist for headache, and a medical professional with expertise in treating headache; this permitted agreement on and triangulation of perspectives. Based on responses across interviews, we believe data saturation was attained with n=7 interviews. As this research was generative in nature, the primary research goal of this initial data collection and analysis was to yield a single viable, testable change in the application to significantly increase accessibility for users living with severe visual symptoms of migraine; due to the quantity of ideas garnered from these 7 interviews, n=7 was determined by the research team to have sufficiently met the research need.

Data Analysis Plan for Specific Aims

Aim 1B: Characterize the extent to which photophobia impacts adherence to a mobile health app for migraine. Adherence data (Study 1) were leveraged in conjunction with a qualitative interview (Study 2) to characterize whether individuals reduce technology use during occurrence of photophobia and/or aura. Participants were asked in qualitative interview whether their symptoms have ever caused them to be unwilling to, or unable to, use technology. They were also asked about compensatory mechanisms for technology use while symptomatic, including when required to use technology day to day and when they are required to engage with backlit technology during photophobia (i.e. how they handle discomfort looking at light in their day to day activities, and how they handle severe discomfort looking at light when they need to look at devices).

Aim 2. Qualitatively characterize app-based accommodations to improve accessibility for patients with migraine. An existing qualitative interview for Dr. Seng's mobile health studies was the basis of this interview, with irrelevant prompts removed and new prompts drafted to fully address Aim 2. Participants were asked to what extent migraine symptoms impacted their use of the application, as well as physical comfort using mobile health during headache. Those who indicated photophobia or aura in the diary were asked to about symptom impact on their experience, as well as what changes to the app might improve its usability during photophobia or aura. Interviews were recorded, subsequently transcribed in a two-pass method (Patton, 2014), and coded by hand (an acceptable alternative to software) (Patton, 1980) with codes generated from the data to ensure theoretical saturation. Codes were thematic and extracted directly from

participant responses (i.e. a bottom-up, phenomenological approach). A data dictionary generated after the first 5 codes was maintained and updated for the final two interviews (Appendix B).

The following scales were analyzed and incorporated into our findings:

UPSIS-12 Score and Reported Impact of Photophobia (Qualitative)

Participants' UPSIS-12 scores were analyzed using descriptive statistics and provided in aggregate. Participants were asked qualitatively about the impact of photophobia on their use of mobile health and other technology, and the relationship between photophobia as measured by the UPSIS-12 and reported photophobia impact on mobile health use were characterized. UPSIS-12 scores were evaluated in the context of participants' provision of qualitative data regarding whether they have ever had to modify or limit technology use due to photophobia and/or other visual symptoms of migraine. Reliability for this scale was strong, and sufficient for this study ($\alpha=.867$).

MAUQ Score and Reported Usability Challenges with the App

Participants were asked additional detail on their responses to the MAUQ to facilitate proposal of accessibility and usability improvements to the mobile health application. MAUQ scores for the application were characterized using descriptive statistics.

Power Analysis

Qualitative research sample size is based on quality and quantity of data obtained from participants (Morse, 2000). No strict guidelines for qualitative sample size exist. Some estimates place sufficient sample sizes for usability testing as low as $n=5$ (Nielsen, 2000), which the present study exceeded.

Study 3– Qualitative Analysis of Provider Concerns in Requesting mHealth Diaries

This qualitative virtual study was conducted from the NYU Grossman School of Medicine. Study proceedings were reviewed and approved by the NYU Grossman School of Medicine Institutional Review board. The study consisted of semi-structured qualitative interviews with 20 headache clinicians currently in practice. Study questions evaluated clinicians' current practices and attitudes around headache diary data, both via paper diary collection and digital diary. Participants were asked to provide details of their current concerns and considerations around digital diaries, and furthermore to describe how they pictured new prospective diaries filling their needs as clinicians and integrating into their practice.

Participants and Recruitment

Participants in this study were medical clinicians who treat headache (clinicians with an MD, DO, NP, or PA degree). Participants were recruited via clinical list serves and social media advertisements. Prospective participants responded to study staff and were scheduled for a semi-structured interview inclusive of informed consent proceedings, demographics collection, and the interview itself.

Eligibility and Inclusion Criteria

Clinicians who participated in this study were required to presently be in roles where they treat patients with migraine for at least one full day per week or equivalent.

Procedures

Participants completed informed consent and demographics collection with the study coordinator. Participants then completed a semi-structured qualitative interview during the same WebEx call with this qualitative researcher. Interviews lasted approximately 1 hour. Participants who completed the study received \$200.

Qualitative interview and Study Completion

The qualitative interview focused on participants' current clinical practice, use of diaries, and participants' attitudes towards digital diaries as compared to pen-and-paper diaries.

Participants were also asked to consider potential risks and benefits of integrating mHealth diaries into their clinical practice. Participants were considered to have completed the study at the termination of their one-hour interview.

Participant Characteristics

The mean number of years providers had been in clinical practice was 11.7. Of the 20 providers who participated in this study, 3 (15%) spontaneously contributed content directly relevant to concerns around mHealth use and accessibility. This content was subsequently re-analyzed for incorporation into the present project, with permission by the study lead (Dr. Mia Minen, NYU Grossman School of Medicine).

Data Analysis

Interviews were transcribed in full, then coded via IPA. Codes were aligned on between coders. Content related to the codes associated with provider concerns around mobile health accessibility in migraine was review in the context of the present study.

Data Analysis Plan for Specific Aims

Aim 1B: Characterize the extent to which photophobia impacts adherence to a mobile health app for migraine. Data were analyzed in the context of providers' concerns around patient adherence to a mobile health app for migraine. Existing transcripts were re-analyzed to evaluate provider attitudes towards digital diaries for migraine using IPA. Provider report of patients' physical discomfort was re-analyzed in the context of accessibility and usability considerations for such applications in patients diagnosed with migraine.

The thematic occurrence of provider concerns around patients' discomfort using these applications suggests not only that patients do experience notable discomfort when completing

digital diaries for migraine, but that provider concerns around this discomfort may affect their willingness to request such diaries in clinic.

Chapter 3. Results.

Results – Study 1 (Quantitative Analysis)

Participant Demographics

166 adults were assessed for eligibility to participate in this study. Of these, 100 did not meet criteria: 96 before intake evaluation, 3 because they did not meet headache diagnostic criteria upon intake, and 1 due to severe psychiatric symptoms at intake. 66 were then enrolled in the study, of whom 1 declined to participate and 2 reported no migraine attacks during the baseline data collection period. 63 adults carrying a previous diagnosis of migraine who had at least 1 migraine during this period were therefore evaluated for this secondary data evaluation. Participants had a mean age of 39.7 (SD=12.5) and were predominantly white (82.5%) not Hispanic or Latino (84.1%) women (92.1%). Most participants were full-time employed (63.5%) and highly educated, with either a graduate degree (55.6%) or a college education (33.3%).

Table 1. *Participant demographics – quantitative patients.*

Demographics	M (SD) or N (%)
Age	39.7 (12.5)
Gender	
Woman	58 (92.1%)
Man	5 (7.9%)
Race	
White	52 (82.5%)
Black	1 (1.6%)
Asian	3 (4.8%)
Other	7 (11.1%)
Ethnicity	
Hispanic/Latino	10 (15%)
Not Hispanic/Latino	53 (84.1%)
Marital status	
Single	31 (49.2%)
Married	21 (33.3%)
Separated/divorced	6 (9.5%)
Live with a domestic partner	5 (7.9%)
Education	
Graduate degree	35 (55.6%)

College degree	21 (33.3%)
Some college or technical school	6 (9.5%)
High school	1 (1.6%)

Note: M represents mean; SD represents standard deviation. N represents the number of participants and % the number accounted for of total participants.

Headache Characteristics

Most participants had had at least one experience of aura (57.1%), reported light bothered them more than half the time (79.4%), and noted visual changes with migraine during the prior year (50.8%). In the 1,890 diaries recorded by these participants during the 30-day baseline data collection period, participants reported that light bothered them nearly half the time (852/1890, 45.1%).

Table 2. *Migraine characteristics.*

Migraine Characteristics	M (SD) or N (%)
Aura (ever)	
Yes	36 (57.1%)
No	26 (41.3%)
Don't Know	1 (1.6%)
Light bothers you	
Never	1 (1.6%)
Rarely	2 (3.2%)
Less than half the time	10 (15.9%)
Half the time or more	50 (79.4%)
MIDAS	
Severe migraine disability	12 (19%)
Not severe	51 (81%)
Visual migraine changes within year	
Yes, within past year	32 (50.8%)
No	31 (49.2%)
Visual changes during migraine	
Never	21 (33.3%)
Rarely	20 (31.7%)
Less than half the time	11 (17.5%)
Half the time or more	10 (15.9%)
Visual changes - duration	
1-30 minutes	24 (38.1%)
Over 30 minutes	14 (22.2%)

AMPP – Light bothered you

No	332 (18.4%)
Yes	502 (27.9%)
N/A	966 (53.7%)
Mean Midi Scores	
2 – Impacts on leisure	3.45 (32.1)
3 – Impacts on social life	2.80 (2.2)
4 – Impacts on work	2.78 (2.0)

Note: M represents mean; SD represents standard deviation. N represents the number of participants and % the number accounted for of total participants.

Person-Level Predictors

Person-level predictors did not yield significant associations with the outcome variable of digital headache diaries completed. There were no significant findings associated either with personal characteristics (i.e. age, gender, attainment of a college education) or with individuals' reported general headache characteristics (i.e. how long visual changes typically last during attacks, or whether visual changes occurred for them within the past year).

Table 3. *Person-level predictors of diary completion.*

Person-Level Predictors			
n=63	Odds Ratio	95% CI	P value
Age	1.00	0.98 – 1.02	0.91
Aura (Ever)	0.68	0.07 – 6.7	0.74
Education (College)	1.05	0.54– 2.03	0.89
Employment (FT)	0.88	0.47 – 1.63	0.68
Ethnicity (Hispanic/Latino)	1.35	0.60 – 3.00	0.47
Gender (F)	0.72	0.25 – 2.12	0.56
Light Bothers (Rarely)	0.91	.17 – 4.96	0.92
Marital Status (Single)	1.72	0.51 – 5.78	0.38
MIDAS – Severe at Intake	0.91	0.43 – 1.96	0.82
Race	0.54	0.21– 1.37	0.20
Visual Changes- In Last Year	1.37	0.75 – 2.5	0.31

Visual Changes – Often (Never)	0.68	0.27 – 1.69	0.41
Visual Changes (<30, 30- 60, <60)			
Never	1.34	0.58-3.08	0.49
Less than 30 mins	1.18	0.51-2.74	0.70

Day-Level Predictors

Day-level predictors also did not yield significant associations with the outcome variable of digital headache diaries completed. There were no significant findings associated with whether patients were reporting sensitivity to light at the time of the headache completion, nor with the extent to which their present headache was affecting their activities for fun, socially, or at work.

Table 4. Headache-level predictors of diary completion.

Headache-Level Predictors

<i>N=63</i>	Odds Ratio	95% CI	P value
<i>Sensitive to Light Now (AMPP - Mean)</i>	0.71	0.28 – 1.77	0.46
<i>Midi – 2 (Mean) Recreation: How much did your headache keep you from doing things in your spare time?</i>	0.91	0.79 – 1.05	.20
<i>Midi – 3 (Mean) Social Activity: How much did your headache keep you from doing things with family or friends?</i>	0.94	0.82 – 1.08	0.40

<i>Midi – 4 (Mean)</i>	0.91	0.77 – 1.07	0.25
Job/Occupation: How much did your headache keep you from doing your job?			

Results at the level of average symptoms during reported migraine attack approached significance, despite the small sample size of the study. While patient reporting of current sensitivity to light did not reveal significant trends in this population, questions asking about the impact of patients' head pain that included examples of limited use of backlit technology all approached significance.

All three questions assessing impact of headache on day to day lives, specifically including accessing backlit technology during headache (*Midi – 2 (Mean) Recreation: How much did your headache keep you from doing things in your spare time (CI: 0.79-1.05)*, *Midi – 3 (Mean) Social Activity: How much did your headache keep you from doing things with family or friends (CI: 0.82-1.08)*, and *Midi – 4 (Mean) Job/Occupation: How much did your headache keep you from doing your job (CI: 0.77-1.07)*) all showed evidence in the expected direction for reduction of diary completed due to impairing headache symptoms. This underscores need for further research in migraine patients with impairing photophobia, as the lack of statistical significance in these findings may be due to restricted values range in the present study population.

Results – Study 2 (Qualitative Analysis of Migraine Symptom Impact on Diary Completion)

6 participants completed 2 surveys each (the MAUQ, about application usability; the UPSIS-12, about light sensitivity) prior to completing one approximately 30-minute qualitative interview. Survey completion time was expected to be under 15 minutes per participant, with most completers needing only a few minutes to complete each survey. Qualitative interviews

ranged between 17 minutes, 40 seconds and 32 minutes, 32 seconds in duration (mean=26 minutes, 34.5 seconds; std deviation=7 minutes 5.6 seconds).

Of these participants, two were recruited from a previous study in which they completed 30 days of diaries approximately 1 year ago. Recruitment from this study was conducted under the oversight of Einstein IRB (2015-5743). Seven potential participants were contacted over email based on how recently they had completed their diaries, with most recent participants in the parent study contacted. Two participants answered this initial outreach, both of whom completed participation in surveys and interviews. Five participants did not respond to outreach and were not enrolled. The remaining four participants were recruited from an ongoing study under the oversight of Western IRB (2021-2127) in which they had completed data collection within weeks of their interview for the present study. Participants were contacted over email as they completed their headache diaries. All participants contacted enrolled in this study as part of their participation in the parent study (i.e. their exit interview).

Table 5. *Participant demographics – qualitative patients.*

Demographics	M (SD) or N (%)
Age	37.4 (4.2)
Gender	
Woman	6
Man	1
Race	
White	5 (71.4%)
Black	1 (14.3%)
Multiracial	1 (14.3%)
Ethnicity	
Hispanic/Latino	2 (29.6%)
Not Hispanic/Latino	5 (71.4%)
Education	
Graduate degree	5 (71.4%)
College degree	1 (14.3%)
Associate's degree	1 (14.3%)

Note: M represents mean; SD represents standard deviation. N represents the number of participants and % the number accounted for of total participants.

Table 6. MAUQ Responses.

Question	M (SD)	n=7
1. The app was easy to use.	1.57 (1.13)	
2. It was easy for me to learn to use the app.	1.29 (0.49)	
3. The navigation was consistent when moving between screens.	2.14 (1.46)	
4. The interface of the app allowed me to use all the functions (such as entering information, responding to reminders, viewing information) offered by the app.	1.71 (1.50)	
5. Whenever I made a mistake using the app, I could recover easily and quickly.	2.29 (2.14)	
6. I like the interface of the app.	2.43 (1.51)	
7. The information in the app was well organized, so I could easily find the information I needed.	2.14 (1.07)	
8. The app adequately acknowledged and provided information to let me know the progress of my action.	1.43 (0.53)	
9. I feel comfortable using this app in social settings.	1.29 (0.76)	
10. The amount of time involved in using this app has been fitting for me.	2.57 (1.40)	
11. I would use this app again.	3.43 (2.07)	
12. Overall, I am satisfied with this app.	2.71 (1.60)	
13. The app would be useful for my health and well-being.	4.14 (2.54)	
14. The app improved my access to health care services.	5.14 (2.61)	
15. The app helped me manage my health effectively.	4.71 (2.50)	
16. This app has all the functions and capabilities I expected it to have.	2.86 (2.34)	
17. I could use the app even when the Internet connection was poor or not available.	2.86 (2.85)	
18. This mHealth app provided an acceptable way to receive health care services, such as accessing educational materials, tracking my own activities, and performing self-assessment.	3.86 (2.34)	

Note: M represents mean; SD represents standard deviation. N represents the number of participants. Responses were on a 7-point Likert scale, with 1 indicating strongly agree and 7 indicating strongly disagree.

Table 7. UPSIS-12 Responses.

Question	M (SD)	n=7
1. Overall, how severe do you consider your light sensitivity? (Where 0 equals no light sensitivity, and 5 equals the worst light sensitivity possible.)	2.71 (1.25)	
2. How unpleasant is strong light during the headache free period? (Where 0 equals not unpleasant, and 5 equals very unpleasant.)	1.71 (1.80)	

3. How unpleasant is strong light during a headache?	4.0 (1.15)
4. How often does strong light provoke a headache?	2.14 (2.67)
5. How much stronger is your sensitivity to light during the attack than when headache free? (Where 0 equals the same, and 5 equals much stronger.)	2.57 (1.81)
6. Please answer questions 6 to 10 on a 0-5 scale concerning your light sensitivity during the headache free period, with 0 being no limitation, 3 being moderate limitation due to light sensitivity, and 5 being marked limitation because of light sensitivity.	1.29 (1.50)
How difficult is it for you to look at a computer screen for any period of time?	
7. How much does light sensitivity affect your ability to watch television?	1.29 (1.38)
8. How much does light sensitivity affect your ability to do housework or work outside the home?	1.14 (1.21)
9. How much does light sensitivity affect your ability to drive?	1.29 (1.11)
10. How much does light sensitivity affect your ability to ride in a car?	1.14 (1.86)
11. Do you wear sunglasses to decrease headaches?	0.57 (0.53)
11a. If yes, where?	0* (0)
12. Do you currently drive?	0.14 (0.38)
12a. If NO, is it because of light sensitivity? (n=2)	1 (0)
12b. If YES, does light sensitivity affect your ability to drive? (N=4)	0.67 (0.52)
12c. If YES, what effect does it have? (n=2)	0.67 (0.58)

Note: M represents mean; SD represents standard deviation. N represents the number of participants. Responses were on a 6-point Likert scale, with 0 indicating smaller effects and 5 indicating strong effects. 0 on question about sunglasses wearing indicated use of sunglasses outside. 0 on question about current driving indicated yes. 0 on question of if light sensitivity affects driving indicates yes; 0 on current effect on driving indicates participant cannot drive at night due to light sensitivity.

Participants completed the UPSIS-12 and the MAUQ surveys prior to participating in their individual interviews. Their responses on the UPSIS-12 and MAUQ were followed up on for clarity and elaboration in interview as needed. Several themes were generated from the participants' data.

Table 8. *Themes emerging from qualitative interviews.*

Theme	Subthemes	Quotes
Impacts of visual disturbance in migraine	I. Impact of light sensitivity in migraine is severe, and impacts patients' day to day	“So typically, even like light filtering in behind my eyelids is uncomfortable. And so I um, definitely do not want to use any kind of backlit technology whether it's a computer, a cellphone, I don't even want to like...open my eyes...because it hurts so much. I mean, that's like on a severe headache. But. Also like...that kind of light can exacerbate a migraine.”
	II. During light sensitivity, participants avoid backlit technology	“But when I'm, um, oh when I was doing some of the activities, if I had a migraine, sometimes I would start to get a little nauseous because you know because they require a lot of focus, and like a lot of direct focus on your phone.”
	III. During aura, patients withdraw from most visual activities, including technology use	
	IV. During visual disturbances, patients have reduced ability to focus on details	
	V. During visual disturbances, patients have reduced ability to read fine print	
Coping with light sensitivity	I. To cope with light sensitivity, patients reduce activities where they must sustain attention on bright devices	“Oh...um. I just have, like, most of my, most of my, most of my ones I have like everything's turned down really low, like the li—like the...the, um, the backlight is turned down pretty low to begin with. So I just have most of my settings turned down low really. But I can't think of any, like, particular app that is really, like...user-friendly in that
	II. To cope with light sensitivity in migraine, patients reduce phone brightness and use dark modes	
	III. To cope with light sensitivity in migraine, patients reduce focus on bright devices (i.e. use things quickly, minimally, in read-aloud mode)	

	IV. To cope with light sensitivity, patients withdraw entirely (dark room, lying down, eyes closed)	way. I just have my, my settings, are, are, are pretty low to begin with.”
	V. Use of screen color filter or tinted lenses or sunglasses	
Visual impacts associated with cognitive changes	I. Hard to work during migraine generally	
	II. Can't concentrate visually	
	III. Visual disturbance increases errors in written work	
	IV. Need to take breaks during diary due to cognitive fatigue (and forget to resume)	
Impacts of light sensitivity on diary	I. Patients miss data entry on migraine days or enter incorrect data	“On the days that I was filling out diary entries with a headache, it was not pleasant to have to look at a phone and log symptoms. And I think I even like there were times that I answered questions acci—like not correctly because it was just like so disoriented.”
	II. Patients force themselves to engage and/or experience secondary symptoms while using diary	
	III. Many reported they were able to complete the diary without significant discomfort	
	IV. Patients would not normally use app like diary during light sensitivity (i.e. always limit technology use, always use app in dark mode, etc)	
	V. Patients may need to take breaks while completing a diary due to light sensitivity and discomfort	
Patients struggle to “work around” aura	I. Few coping mechanisms work for aura	“Just because, like, if, if from what I recall, it was a white background, I think that with an aura that would be really hard to see...I also, like, when I have auras, don't want to—I don't want to try to focus enough to like read something. It's just...really...painful.”
	II. Difficulty focusing on white screens with aura	
	III. Difficulty reading fine print with aura	
	IV. Difficulty retaining information with aura	
	V. Aura as true visual impairment	
Improving accessibility for migraine	I. To improve app usability for visual disturbance in migraine, avoid white background	“Maybe like have like a headache mode, like, migraine mode, like, give your users an option of like setting it to....I would call it

II.	To improve app usability for visual disturbances in migraine, increase font size	like a migraine mode, and if you switch over like everything gets darker...?
III.	To improve app usability to patients' baseline, implement dark mode	There'd be black, or dark blue, something. And like, or maybe it's customizable settings so people could choose like I need larger font or I need darker colors, or...maybe...I don't answer as many questions, I don't, I don't know. Um. But I think definitely, like, the light would help, and maybe making the font bigger?
IV.	Migraine mode / customizable settings	
V.	Streamlining: fewer questions, less stimulation, less time in app	
VI.	Escape hatch: if patients indicate migraine, end the diary	
	Bonus: Make reminder times adjustable	
	Bonus: Participants seemed aware there were no migraine accommodations built in to app	"...once I answered these questions and I'm answering, like, I have a migraine—if it stopped there, when I have a migraine. If it was like "Yes, I have a migraine." "Great! You're done with your s- with your diary for today.""

Participants overwhelmingly indicated impact on their day-to-day technology use due to light sensitivity from migraine, with all participants but 1 experiencing notable photophobia as a result of their migraine attacks. Over half of the participants also experienced visual aura with at least some migraine attacks.

Key themes that emerged from these interviews were: Impacts of visual disturbance in migraine; Coping with light sensitivity; Visual impacts associated with cognitive changes; Patients struggle to “work around” aura; Impacts of light sensitivity on diary; Improving accessibility for migraine (see Table 8). Broadly, participants reported significant impact on their behavior from light sensitivity during migraine, and most have already built migraine accommodations into their regular use of backlit technology (i.e. by using dark mode on their

phone; by setting up workspaces and work routines that allow them to compensate for discomfort due to migraine symptoms).

While participants did not indicate that the diary application was particularly inaccessible compared to other applications and devices they may have to use during migraine, their responses suggested significant opportunity to increase the app's accessibility during migraine. In particular, most participants reported using dark mode by default on their phones as a coping mechanism for visual changes and sensitivity due to migraine, a feature the diary application does not currently support as-is. Participant responses also indicated potential benefit from designing a "migraine mode" with customizable settings, cognitive adaptations for the application during the migraine (supporting brief, less complicated engagement with the application), and that the application might benefit from a lower-contrast migraine-friendly color scheme.

Results – Study 3 (Qualitative Interviews with Headache Providers)

20 providers participated in this study (45% male, 55% female). Most providers were physicians (65%), with the remainder divided between PA and NP providers. All completed qualitative interviews, approximately 35 minutes in duration (ranging 27-51 minutes) regarding the current landscape of digital headache diaries and their personal needs for a headache diary integration. Providers reported broadly that accessibility of the application, including cost and technological skillsets, were key considerations in their decisions around recommending or requesting patients' use such an application. While provider concerns around visual impact on migraine and diary usability were not explicitly or implicitly part of the interview guide, three providers spontaneously yielded content related to these themes. More specifically, these three

providers expressed concern around the impact of requesting digital headache diaries from patients who experience light sensitivity as part of their headache constellation.

Table 9. *Participant demographics – qualitative providers.*

Demographics	M (SD) or N (%)
Provider Type	
Physician	13 (65%)
NP or PA	7 (35%)
Number of years of clinical practice	
1-5	6 (30%)
6-10	5 (25%)
11-20	3 (15%)
21+	3 (15%)
Gender	
Woman	11 (55%)
Man	9 (45%)
Race	
White	14 (70%)
Black	0 (0%)
Asian or Pacific Islander	2 (10%)
Other	4 (20%)
Ethnicity	
Hispanic/Latino	3 (15%)
Not Hispanic/Latino	17 (85%)
Institution Type	
Large Academic	9 (45%)
Small Academic	3 (15%)
Large Private	2 (10%)
Small Private	6 (30%)
Fellowship Area of Study	
Cognitive Neurology	1 (5%)
Headache	12 (60%)
Did not complete a fellowship	7 (35%)

Note: M represents mean; SD represents standard deviation. N represents the number of participants and % the number accounted for of total participants.

Table 10. *Themes emerging from qualitative interviews with providers.*

Theme	Subthemes	Quote
Provider I: Concerns around light symptoms and cognitive ability during light sensitivity and digital diary completion	I.	Difficulty completing cognitively complex task
	II.	Negative impact of light sensitivity when
		“And then the second reason would be you know it's kind of hard to do electronic stuff in the middle of a migraine in

		completing assigned electronic diaries	general um you know the lighting the coordination the cognitive ability all those kinds of things so there's some people who would have even more trouble doing it if it's electronic and they have to you know send it or something like that..."
Provider II: has noted patients with light sensitivity so extreme they delay introducing applications when assigning them.	I.	During light sensitivity, good provision of care includes avoiding exposing patients to backlit technology, even when introducing apps.	"I would say younger population—I often times will have them download the app in the room pretty easily. If it's somebody who's really light-sensitive, I will give them a paper handout and not show them my screen because that would be pretty bright for them."
Provider III: Some patients cannot or will not complete diaries due to their light sensitivity	I.	Provider does not request digital diaries from all patients due to accessibility concerns	"I mean, some people have vision changes during the migraine attack or are too light sensitive cause they cannot use the phone. , that's another limitation, although I feel like the people who have a lot of issues with the vision, I also don't really write it on paper, oh I have a patient with crazy vision changes, she has a paper diary, but I cannot even read it because she scribbles, and then I don't know what the symptoms were, I just know something happened that day.... But yeah, the vision changes, the light sensitivity..."
	II.	However, their vision sensitivities may also affect their writing—in which case apps are helpful	
	III.	To cope with light sensitivity in migraine, patients reduce focus on bright devices (i.e. use things quickly, minimally, in read-aloud mode)	
	IV.	To cope with light sensitivity, patients withdraw entirely (dark room, lying down, eyes closed)	
	V.	Use of screen color filter or tinted lenses/sunglasses	

Providers' responses indicated that providers' willingness to recommend digital headache diaries for migraines may already incorporate concerns around the impact of light sensitivity on

the accessibility of migraine applications. These considerations may impact both how many migraine patients receive recommendations to use applications to track their headaches and suggests patients for whom light sensitivity is not significantly impairing self-select into settings in which they may use technology to track migraine.

Chapter 4. Discussion.

Interpretation

Clinical and Research Implications

This study showed that looking at backlit technology, i.e. phones and computers, is generally uncomfortable for individuals during migraine attack. Photophobia, which is among the sensory processing symptoms in the diagnostic criteria for migraine (Goadsby et al., 2017), was described by our qualitative study participants as being frequent and impairing. During data collection for headache, the most significant data collection occurs not between headache attacks, but during the attacks; headache-free days yield less-rich data for clinical diagnosis than do days on which headaches occur. Unfortunately, the results of our study suggest that on the days when data is most valuable—during the premonitory or the headache phase—participants living with photophobia or aura are in fact most likely to a) either not complete data collection due to the severity of their photophobia or aura, or b) force themselves to engage in data collection despite their symptoms, increasing both their errors in recording their data and their level of pain as a result of their efforts.

These results in aggregate suggest that participants during migraine attacks may not be completing headache tracking tasks as researchers or clinicians require. As missing data in a clinical or research headache diary may result in erroneous conclusions about patients' headache diagnosis and treatment efficacy (Seng et al., 2018), patient mistakes due to their discomfort looking at devices during a headache attack stand to create a cascade of ambiguity around their status. As the vast majority of persons diagnosed with migraine experience photophobia (estimates ranging between 82.5% (Choi et al., 2009) and 92.4% (Russell et al., 1996)), the

results of this generative qualitative study significantly undermine the validity of digital data collection completed by patients during premonitory and migraine attack phases. Additionally, as the headache phase itself may last 72 hours (Goadsby et al., 2017), and as most persons living with migraine are also living with photophobia, these results hint at the risk for significant unintentional research bias—results of incoming clinical and research data may be more inaccurate in persons experiencing more severe photophobia. Should data be more inaccurate in these persons living with more severe impact of photophobia, these biases risk significantly undermining therapeutic efficacy of interventions and resisting statistical corrections otherwise applied to non-systematically missing (or incorrect) data.

We did not find significant quantitative associations between the presence of migraine with aura, or real-time changes in photophobia, and diary day completion. Our study was not designed to solicit information on the real-time impacts of photophobia, and these null results are likely explained by study recruitment and participant self-selection. Participants who opted-in to completion of a digital diary study likely self-screened for their own ability to manage symptoms of photophobia and of aura as they related to headache diary applications before committing to such a study. Additionally, the application as established did not solicit any qualitative data around patient's experiences of using the application and would not have captured increases in discomfort due to light sensitivity or qualitative difficulty completing diaries due to light sensitivity or aura. In our qualitative data collection (Study 2), patients reported experiencing nausea when forcing themselves to engage with technology during migraine, difficulty focusing, heightened awareness of mistakes made during migraine, and feeling they had to force themselves through diaries; none of these elements would have been captured in our quantitative study, as the study predated large-scale awareness of these concerns around data collection

during migraine. Future quantitative studies should evaluate the questions related to app accessibility and photophobia and aura among migraine patients who were unwilling to engage in multi-month daily diary collection. Future mobile health diary studies should also begin to explicitly track information about rushing through, only partially completing, or making errors in completing diaries as much as is feasible.

Furthermore, these results suggest that even when individuals push through their increased pain to complete data collection as assigned, they experience secondary harm as a result of their efforts. While logic suggests that patients experiencing difficulty with visual sensory processing are more likely to experience adverse events when asked to engage with detailed, sensitive visual material during their symptoms (i.e., headache diary completion), this study is the first to confirm patients experience this minor secondary harm. Several of our participants noted challenges with focusing on visual material during migraine, both due to physical characteristics of the stimuli (i.e., looking at bright colors and looking at moving images was physically discomfiting) and due to challenges with attentional focus during migraine. Participants with aura in their primary field of vision similarly generally aligned on significant impairment with vision and visual attention during aura symptoms. Some participants further noted nausea when they sustain attention on backlit visual material during migraine. Providers qualitatively noted their own preference not to request digital diaries from patients with severe visual symptoms during migraine due to the discomfort digital stimuli cause patients during migraine attack. Several of the participants in this qualitative study indicated mild adverse events from forcing themselves to complete digital headache diaries, including increases in pain, cognitive fatigue, and nausea. These results therefore yield further concerns around the ethics of attempting data collection or digital therapeutics with persons who did not self-select into these

conditions. As the field of mobile health expands, we risk proportionately expanding the relative harm to these patients—unless sufficient accessibility changes are made.

This study significantly expands the characterization of visual disturbances during migraine as impairing, as photophobia reduces patients' ability to work in typical technology-driven settings or even participate in daily life under certain lighting conditions. Patients reported extensively on coping skills for migraine-related photophobia and aura that are explicitly violated by requests for patients to complete a digital headache diary during migraine attack. These included switching focus away from backlit technology, engaging in less cognitively demanding tasks, and other withdrawals from light and cognitive activity; consistent with the current literature, many of our qualitative participants reported managing their symptoms of photophobia and of aura by retreating from light and other stimuli into a dark room (Kikkeri, 2022). Others reported making significant accommodations in their day-to-day life in order to mitigate discomfort due to lights, including working in the dark at their workplace, installing dimmers on all their lights at home, needing to leave their car at work due to inability to drive facing other cars' headlights on the road, and changing their work schedules to that they can focus less on backlit devices during headache attacks. The intensity of the accommodations of these persons—all of whom considered their photophobia manageable enough to engage in several weeks of daily engagement with a digital headache diary—suggests significant pain and discomfort engaging in daily activities during photophobia.

Participants also reported baseline accommodations for their migraine light sensitivity that are violated by the present digital headache diary, which has a white background, no modifiable accessibility settings, and extensive use of fine print and sensitive sliders. Patients reported generally keeping their technology on the dimmest possible setting and using dark

mode. Based on patients' feedback around neutral colors, dark mode, low-contrast backgrounds, and desire for improved accessibility in the application, migraine-based color palettes, individualized migraine-based settings, and a cognitively less burdensome structure (i.e. to reduce time spent in the app and to reduce difficult cognitive tasks within the app) may also represent significant strides in migraine accessibility. As with many other accessibility considerations, implementation of these features is unlikely to detract from the application experience for people not experiencing light sensitivity. They are also unlikely to reduce the quality of data extracted from study participants. Indeed, as study participants reported forcing themselves to complete diaries, skipping diaries, or knowing they made mistakes in diaries when they had to complete the diaries during migraine, implementing these accessibility features may instead increase data quality collected during research and clinical use.

Our participants' self-report overall characterized this kind of diary completion—requiring extended focus on their phones, faithful reporting of details related to their migraine, and use of their phones during headache attack—as in-conflict with how they would typically manage their symptoms. Accordingly, patients reported associations of migraine, errors, discomfort, and diary skipping (missing data) when they were attempting to participate in data collection during photophobia and aura. Additionally, patients' report of cognitive difficulties that they associate with visual disturbance and light sensitivity—difficulty focusing and increased mistakes, in particular—is novel in this field of migraine symptom report.

Provider report suggests that some providers have already become aware of the potential risks associated with assigning digital diaries to patients with severe photophobia, but that these providers have extremely limited alternatives to solicit comparable quality data from these patients. Additional data collected with headache providers (Study 3, with permission of NYU

Grossman School of Medicine and Dr. Mia Minen) suggested that provider concerns around application usability during light sensitivity may also impact providers' decision-making around recommending headache diary tracking on digital devices. That this is an implicit consideration for so many providers and that this concern appeared in a study not designed to collect information on light sensitivity in migraine suggests that patients may have been communicating accessibility needs to providers informally for some time. The presence of this theme in provider interviews around the current landscape of headache diaries also validates that patients' light sensitivity is likely a consistent impact on their ability and willingness to engage in digital headache diary tracking.

Participants in this study offered extensive suggestions for how to improve application accessibility during migraine attack. Their suggestions highlighted several areas: avoiding white backgrounds, as these are uncomfortably bright for patients to focus on during photophobia; increasing font size, to aid readability and reduce effortful focus; and implementing dark mode in the diary application, to sustain patients' coping skills around brightness reduction across other applications used. Participants also suggested several accessibility aids to facilitate individual coping with headache symptoms, including adding a "Migraine mode" in which participants can indicate what they would need from a diary during migraine attack—whether this be light-based or attention-based accommodations. Finally, several participants requested support specifically around their cognitive changes during migraine, which may co-occur with vision-based changes. These accommodations included requests to streamline the application during migraine, by incorporating fewer questions, less stimulation, or requiring less time in the application. One participant encouraged study designers to support headache patients during migraine by simply terminating further tasks and questioning if patients indicated during their first engagement with

the app that they were experiencing migraine. If, as our results suggest, data collected during migraine attack is extremely likely to be compromised due to patient rushing, errors, or early termination of data collection, this “escape hatch” option may protect research and data collection, especially if paired with an opportunity for patients to record their migraine experience after the headache terminates (i.e. by adding a flow soliciting recent data after headache has ended).

While our participants offered us a rich landscape of informed experiential accommodations for the application, research in the field also suggests further possible accommodations that headache patients may not be aware of (and therefore may not be able to independently suggest). Perhaps the most significant of these in the context of digital data collection for migraine is the potential therapeutic benefit of green light during headache attack (in contrast with red, blue, and yellow lights, all of which appear aggravating during headache) (Burstein, Nosedá, & Fulton, 2019). Clinical studies into light wavelengths have yielded preliminary findings that through neurobiological activation, specifically via production of comparatively less activation in the visual pathways of the brain, certain green lights may be therapeutic during migraine instead of painful (Burstein et al., 2019). This may offer opportunities for commercial clinical intervention both through specific therapeutic lights and through production of therapeutic light through other light-emitting devices—specifically, it raises questions of whether we might use light filters on phones to offer light-based intervention during migraine. This is one such accommodation that we would not expect our participants to suggest but offers a rich opportunity for future research. As our digital data collection for migraine stands currently, our efforts at data collection risk creating secondary harm and incomplete, inaccurate data, especially in our persons most in need of accurate and timely

headache treatment (i.e. those with more severely impairing symptoms). The opportunity to test green light interventions in this context represents a reversal of this current standing: to turn our presently impairing and inaccurate data collection into a genuinely therapeutic intervention. Many more such opportunities may be discovered as this generative research is expanded on in wider populations who did not opt-in to digital research already.

The value of increasing accessibility of mobile health for persons living with photophobia and/or aura extends significantly beyond the immediate population of persons pursuing diagnosis of or participating in research for headache conditions. Visual disturbances and impairments are associated with several conditions beyond migraine, including non-hereditary conditions like concussion and meningitis (Burstein et al., 2019). The accommodations suggested by study participants (and hinted at by broader research around therapeutic interventions for migraine) do not yield any evident risks for persons not living with these symptoms—that is, increasing access to dimmer screens or dark mode for persons with photophobia in no way negatively impacts the app experience for someone not living with photophobia. Accordingly, design accessibility modifications stand to benefit any living person engaging with smartphone technology, regardless of current headache diagnosis.

The strengths of this study are significant. By conducting complementary research in two different patient populations—the 63 patients who completed quantitative data collection for analysis, and 7 further participants across two different studies who provided qualitative data—a wide range of patient experiences are accessed. This wider range of patients stands to yield broader insights than a small patient pool or a patient pool limited to only one study, in which the study itself might then have limited possible findings. Furthermore, this study is innovative in its inclusion of both patients who have been asked to complete diaries and of providers responsible

for asking patients to complete diaries. By including both stakeholder groups in this analysis, this study's contributions to understanding the landscape of headache diary impacts is significantly increased over including only a single group.

The overall picture painted by this research is one of severe and disabling sensitivity to light and visual disturbances due to aura, even in patients who are willing to engage in digital data collection. Paired with this expanded landscape of understanding the severe discomfort, both physical and cognitive, of using of backlit technology in these patients during the actual symptom occurrence, is an undeveloped field of extensive technological accommodations for migraine-related light sensitivity and aura. This research yielded several initial such accommodations to further explore for their benefits.

Limitations and Future Directions

One relevant limitation is that in two of the three studies contributing to this body of work, light sensitivity and app usability were not primary considerations or even explicitly incorporated into the studies as designed. Especially in the case of the quantitative analysis, this may have contributed to the lack of significant results.

A second relevant limitation is that in patient data collection (Study 1 and Study 2), participants were predominantly white women who were highly educated. This population is therefore likely not representative of the population of people living with migraine worldwide, as it omits many people from the global majority as well as men. Furthermore, as all patient-participants in this study explicitly understood that they would complete daily data collection in a mobile application, this population may have lower levels of light sensitivity or visual disability due to migraine than is representative; patients who self-select into the studies may be presumed to know they are physically capable of managing the study demands of backlit device use. However, this population is representative of which patients tend to participate in these studies

and offers us good insight into how significantly digital data collection during migraine impacts even patients who self-select into studies.

An additional limitation is that in our study, the patient populations providing qualitative and quantitative data were two distinct populations, i.e. no participants from this secondary quantitative data analysis also participated in our qualitative analysis. Future studies would benefit from a true mixed-methods model in which the same population pool provided qualitative insights to complement quantitative statistical insights.

Finally, qualitative interviews revealed consensus that patients prefer to use dimmer lighting and dark mode on their phones. As the study application did not facilitate or permit use of dark mode, it is possible patients focused on the need for accessing this feature that is otherwise available across apps and across their devices. Interviews conducted on identical themes after the application is “caught up” to patients’ baseline technology considerations (dark mode) may reveal significantly more accessibility considerations.

Future research should incorporate more participants and more diverse participants. Additionally, interviews should be conducted to test the proposed accommodations named here, including integrating dark mode, a customizable migraine mode, and/or migraine-friendly color palettes and cognitive simplification to evaluate what impact these accommodations have on migraine patients’ experiences.

Appendices

Appendix A. Qualitative Interview: Migraine Mobile Application Usability (MMAU)

Existing interview (parent study)

I'm going to ask you some questions about the application you used to track your headache for the study you did before. There aren't any right or wrong answers to these questions. I'm hoping to get your honest feedback on how well the application worked for you, and how you felt using the application when you were having migraine symptoms. I didn't design the application; I'm really looking for any thoughts you have on it, good or bad.

User Interface

Describe how you interacted with the application. What did you try to do with the application?

What pieces of the application were difficult to figure out, or were annoying? Where did you get stuck? What operated smoothly?

Symptom-based questions

How do your migraine symptoms affect when you're willing or able to use backlit technology—things like your phone, computer, or TV?

Did you ever notice difficulty or discomfort looking at your phone or reading your phone while completing the diary?

Was this related to your migraine symptoms?

Do you ever experience physical discomfort looking at your phone:

During migraine attack?

Between migraine attacks?"

Do you ever experience visual migraine aura, like spots, wiggly lines, or holes in your vision?

Describe your experience of aura.

"Does this ever affect how you use do things in your day to day life?

...with your phone?

...with other technology, like your TV or computer?"

...with reading fine print?

How do you manage needing to use your phone or computer when you have either aura or pain looking at light?

“Did you ever use any of these methods when using our app?”

Did you ever need to wait to complete a diary due to something like what we’ve talked about?

What about ending a diary early or just skipping a whole diary?

[Follow-ups, as needed, on UPSIS-12 responses indicating photophobia]

I noticed on your UPSIS-12 you said...Tell me more about your experience with that.

Usability questions

How usable is the app, in general, for someone with migraine?

On a scale of 1 to 5, if 1 is not at all usable and 5 is the best user experience possible, how would you rate it?

Why?

How usable is the app when light is painful?

On a scale of 1 to 5, if 1 is not at all usable and 5 is the best user experience possible, how would you rate it?

Why?

What would you change?

How usable is it/would it be during aura?

On a scale of 1 to 5, if 1 is not at all usable and 5 is the best user experience possible, how would you rate it?

Why?

What would you change?

What’s an example of an app that you think is very usable?

While light is painful?

During aura?

[Follow up on low scores on MAUQ]

I noticed on your MAUQ you said...Tell me more about your experience with that.

Overall Satisfaction

Would you use this application?

How satisfied were you overall with this application?

On a scale of 1 to 5, if 1 is not at all satisfied and 5 is the most satisfied possible, how would you rate it?

Why?

Appendix B. Data Dictionary for Qualitative Interview: Migraine Mobile Application Usability (MMAU)

Table 11: Data Dictionary - Qualitative Patient Interviews

Theme/Code	Sub-Codes
Goals for app use	<ul style="list-style-type: none"> A. Identify triggers (x2) B. be proactive, not reactive C. Track migraines D. Track migraine severity E. Track migraine quantity F. Track migraine symptoms G. Completed app as directed (no goal) (x4)
App broad difficulties	<ul style="list-style-type: none"> A. Redundant questions B. Neutral (no problems) x3 C. Positive (app easy to use) x2 D. One cognitive evaluation task annoying (x2) E. Annoyance with reminders (x2) F. App difficult to figure out: selecting study from home screen, G: Annoyance: one cognitive measure reads instructions aloud, H: Annoying: had to click through instructions every time for cognitive evaluations I: Annoying: app felt homegrown, J: Difficult to figure out: reminders stopped suddenly K: Difficult to figure out: not sure if completed study, L: Annoyance with reminders: could not change reminders M. Annoyance: confused by cognitive test instructions (1 task) N. Annoyance: Bug evident in slider O: Annoyance: Couldn't go back if unintentionally skipped cognitive test
Light Sensitivity	<ul style="list-style-type: none"> A. Light sensitivity (X7) B. So severe, light painful through eyelids C. Blue light intolerable: computer, phone D. light exacerbates migraine (x4) E. Light triggers headache: bright lights, backlit devices (x2) F. Felt had track despite light sensitivity in migraine G: App tolerable: only a few minutes looking at light H: App tolerable: Not as bad as looking at light all day I. App tolerable: backlit technology not bright enough to be troublesome J. Everything more effortful during visual disturbance in migraine K. everything more painful during visual disturbance in migraine L. Light sensitivity in severe migraine/worst when pain is worst (x2) M. IGHT DISUTRANCE: problem reading print, (all migraine)

Light Sensitivity Coping Mechanisms	<ul style="list-style-type: none"> A. drapes B. eye mask/eyes closed (x2) C. treat migraine early (x2) D: Technology in low battery mode E. Technology in night mode (x2) F. everything black, G. Avoid light (x3) H. Technology brightness down I. Lie down and check out (2) J. ice pack K. avoids backlit technology (x2) L. Minimally activity/streamline M. withdraw from activities O. visual disturbance: pain already severe during visual disturbance (blurry vision), P. visual disturbance: no workaround because pain already too severe to do anything Q. Avoids overhead lights R. Takes breaks when have to use technology
Impacts of completing diary with light sensitivity	<ul style="list-style-type: none"> A. Discomfort while using this diary x2 B. Belief made mistakes in diary due to discomfort C. Nausea while using app/nausea due to extended focus on app D. light sensitivity coping: looking away from phone, app negative: couldn't look away from phone, app negative: would miss something or perform worse if coped with light by looking away E. No pain (x3)/neutral/Always able to complete diary despite light sensitivity/visual disruptions, F. Hard to concentrate on diary during migraine G. Blurry vision while completing diary H. Cognitive fatigue I. Eye fatigue J. Finished early accidentally due to cognitive fatigue + time out
Phone use during light sensitivity	<ul style="list-style-type: none"> A. Discomfort looking at phone during migraine attacks (x4) B. Coping: dark mode C. Pain when not in dark mode D. Coping: lie down and close eyes E. Coping: don't look at anything F. Coping: avoid light at all costs G. coping: turn off tv, computer, phone, H. coping: does not use phone during migraine I. skipped diary days due to need to shut off phone J. visual stimulation exacerbates migraines K. using backlit technology exacerbates migraines (x2)
General Migraine Codes	<ul style="list-style-type: none"> A. everything difficult during migraine B. Slowed down during migraine
Discomfort looking at phone between attacks	<ul style="list-style-type: none"> A. None (x3) B Coping: Phone brightness all the way down C. Coping: phone in night/dark mode D. Light sensitivity if extended focus E. light sensitivity if reading long text F. light sensitivity causes feeling of sea-sickness

Symptoms of Aura	<ul style="list-style-type: none"> A. blurry vision x2 B. halo around light aura-associated nausea C. unable to work during aura D. unable to work during migraine E. most severe episode had aura and nausea F. No aura (x2) G. Spots H. Spots when trying to concentrate I. Spiderwebs through periphery of visual field J. Feeling of second self
Impacts of aura	<ul style="list-style-type: none"> A. No impact of aura day to day B. Aura disrupts life: difficult to do daily tasks C. Aura disrupts life: can't look at light D. aura disrupts life: can't concentrate visually E. Hard to work during migraine generally (pt with aura) F. hard to work on computer during migraine (pt with aura) G. Hard to work during migraine-related visual impairment H. Physically slowed down due to aura
Impacts of aura: backlit technology	<ul style="list-style-type: none"> A. aura affects daily use of phone/hard to concentrate on phone (x2) B. aura difficulty: can't use apps for social media during aura C. can't use apps for social media during visual disturbance D. aura difficulty: hard to read in dark mode because letters still white E. No impact of aura day-to-day F. Yes aura affects daily use of computer G. aura difficulty: cannot turn down brightness on TV H. aura difficulty: aura blocks fine print I. Visual disturbance reduces ability to read J. visual disturbance increases errors in writing AURA PROBLEM: reading print,
Coping with Aura	<ul style="list-style-type: none"> A. aura coping: dark mode B. aura coping: force self to endure C. light sensitivity coping: force self to endure D. light/aura coping: take medication E. light/aura coping: go to sleep (x2?)

Coping with Light Sensitivity	<p>A. No coping skills for light sensitivity (impacts too severe)</p> <p>B. shut down completely during light sensitivity</p> <p>C. lie down during light sensitivity</p> <p>D. coping with light sensitivity: minimal activity</p> <p>E. coping with light sensitivity: if must use phone use minimally and quickly</p> <p>F. coping with light sensitivity: not very necessary as not generally heavy technology user</p> <p>G. coping with light sensitivity: lower brightness on screen (Light sensitivity coping: dim monitor, light sensitivity coping: dim phone) x3</p> <p>I. light sensitivity coping: schedule activities with less focus</p> <p>J. light sensitivity coping (meetings): avoid computer and phone completely</p> <p>K. Coping with light sensitivity: dark sunglasses,</p> <p>L. F. coping with light sensitivity: changed workplaces for gentler light</p> <p>M. COPING WITH PHONE LIGHT: blue filter on all devices,</p> <p>O. Coping when light is painful: dark mode reduces pain.</p> <p>P. Coping when light is painful: reduced lighting in house</p> <p>Q. Coping when light is painful: work in dark room</p> <p>R. Coping when light is painful: use technology as required for work only</p>
Coping with Light Sensitivity During Diary	<p>A. Coping with this diary: brightness turned down on screen (maybe x3)</p> <p>B. DID NOT COPE USING: sunglasses</p> <p>C. app coping: had to stop app due to aura/light sensitivity</p> <p>D. app coping: had to force self to engage with app due to aura/lights sensitive</p> <p>E. App coping: took break from app (re-engaged)</p> <p>F. Used in dark room, turned brightness down</p>
Delaying or skipping app	<p>A. Never waited due to headache: completed early during headache because feared headache would worsen;</p> <p>B. never waited due to headache: medication takes minimum 1 hour to work, would miss window</p> <p>C. always completed diary quickly due to anxiety would miss</p> <p>D. Skipped diary due to headache (x2)</p> <p>E. (did not need to end early due to headache symptoms, needed to end early for social/activity reasons)</p> <p>F. Paused to take break from light</p> <p>G. Accidentally stopped early due to cognitive fatigue from migraine</p>

Light Sensitivity Impacts Technology	<p>A. light sensitivity: burning searing pain in eyes</p> <p>B. light sensitivity: all input painful</p> <p>C. stress provokes headaches</p> <p>D. strong/fluorescent lights provokes headaches</p> <p>E. exhaustion provokes headaches,</p> <p>G. phone light exacerbates headaches, computer light exacerbates headache</p> <p>H. phone light not trigger new headache, computer light not trigger new headaches,</p> <p>J. light sensitivity: cannot drive at night safely</p> <p>K light sensitivity: car lights too impactful to drive, light sensitivity</p> <p>L. have to leave car at work if light sensitivity</p> <p>M. light sensitivity coping: avoid phone/computer completely</p> <p>N. sensory changes in migraine</p> <p>O. Avoids bright light because known trigger</p> <p>P. Bright light rarely triggers headache due to avoidance</p> <p>O, light does no t trigger migraine</p> <p>P. coping with light: lowest brightness that can still see</p> <p>Q. COPING WITH ALL LIGHT: wear blue filter on rx lenses, (x2)</p> <p>R. COPING WITH ALL LIGHT: diary made her more aware of triggers including light</p> <p>S. dimmers on all home lights, work in darkness</p>
App Usability: General	<p>A. App negative: questions redundant</p> <p>B. app neutral: suitable for research</p> <p>C. app negative: improve usability before commercial use</p> <p>D. app questions short</p> <p>E. app easy to use</p> <p>F. , app is not high in utility commercially for people with migraine</p> <p>G> App negative: can't go back if unintentionally skip cognitive task</p> <p>H. App negative: does not return data output</p>

App Usability: Light Sensitivity/Aura	<p>A. Problem with app: white background</p> <p>B. Problem with app: bright background,</p> <p>C. Fix for app: fonts for visual impairment or neurodivergence</p> <p>D. Fix for app: consultant to increase accessibility and reduce pain</p> <p>E. Fix for app: dimmer lighting, -- APP STRENGTH: if dimmer lighting, would be 4 or 5</p> <p>F. Fix for app: darker colors</p> <p>G. Fix for app: larger font</p> <p>H. usable app during migraine</p> <p>I. E. app neutral: not worse than other apps</p> <p>J. APP STRENGTH: nothing aggressive to headache x2</p> <p>K. APP STRENGTH: neutral colors</p> <p>L. APP STRENGTH: no bright colors</p> <p>M. app not inherently difficult during light sensitivity</p> <p>N. no usability accommodations for light sensitivity in app</p> <p>O. Cognitive assessment more difficult when light is painful</p> <p>P. app is painful too look at when light is painful</p> <p>Q. APP STRENGTH: Absent strobe lights</p> <p>R. APP STRENGTH: absent bright flashing lights</p> <p>s. APP WEAKNESS: no dark or soft lighting,</p> <p>t APP WEAKNESS: had to look at</p> <p>u. APP WEAKNESS: too bright,</p> <p>v. does not recall specifics</p> <p>w. irritation tolerance lower for app during light sensitivity</p> <p>x. increased irritation for voiceover instructions during light sensitivity</p> <p>y increased irritation for clicking through instructions during light sensitivity</p> <p>z. coping with light sensitivity: turned down audio during light sensitivity due to annoyance</p> <p>aa. app usability problem: thinks would be hard during obstructive aura</p> <p>bb. app usability neutral: own aura does not disrupt app use</p> <p>cc. app usability problem: app too bothersome during aura</p> <p>dd. app usability problem: not at all usable during aura</p> <p>ee. app usability problem: no coping skills help with aura and app</p> <p>ff. all apps unusable during aura</p>
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Participant suggestions to improve app (general)	<p>A. APP WEAKNESS: reminders did not go off</p> <p>B. difficulty using app: window should be open longer than one hour</p> <p>C. difficulty using app: establishing routine logging symptoms</p> <p>d. app dislike: 5 times a day</p> <p>e. app dislike: reminder beeps</p> <p>f. app dislike: during social settings disrupted,</p> <p>g app dislike: couldn't easily reset reminder times</p> <p>h. app dislike: reading instructions aloud,</p> <p>I. app negative: perceived app took a long time due to irritation,</p> <p>j. app suggestion: eliminate things unnecessary to repeat users,</p> <p>k. not a healthcare access app</p> <p>l. APP USABILITY PROBLEM: white background,</p> <p>m. APP USABILITY PROBLEM: white background hard to see with aura,</p> <p>o. APP USABILITY PROBLEM: hard to read during aura,</p> <p>p APP USABILITY SUGGESTION: read questions aloud</p> <p>q. APP USABILITY SUGGESTION: reading in migraine mode</p> <p>r. gg. Data collection should stop after pt indicates migraine</p> <p>s.</p>
Participant suggestions to improve app (visual disturbance)	<p>A. app suggestion: dim app screen (comparable to phone dim) (x2)</p> <p>B. app suggestion: remove some cognitive assessments during migraine</p> <p>C. app suggestion: add dark mode, app suggestion: dark mode easier when lying in dark due to migraine,</p> <p>D. CHANGE APP SUGGESTION: migraine mode,</p> <p>E. CHANGE APP SUGGESTION: option to make all darker,</p> <p>F. CHANGE APP SUGGESTION: customizable</p> <p>G. CHANGE APP SUGGESTION: larger font option</p> <p>H. CHANGE APP SUGGESTION: darker colors option</p> <p>I. CHANGE APP SUGGESTION, fewer questions</p> <p>J. APP USABILITY SUGGESTION: read questions option</p> <p>H. Kindle screen preferable - contrast easier to read</p>
Would use app again	<p>A. Yes x2</p> <p>Aa. (app gave insight into triggers, sleep trigger, menstrual trigger, stress trigger)</p> <p>B. Probably</p> <p>C. No</p> <p>Ca. no utility (would need to get data back if going to use app again) x3</p> <p>D. App neutral - research only x2</p>

What makes an app usable	<p>A. COPING WITH LIGHT SENSITIVITY: apps on dark mode, x3</p> <p>B. USABLE APP: twitter,</p> <p>C. USABLE APP REASON: dark mode,</p> <p>D. USABLE APP REASON: tone down brightness and colors</p> <p>E. other apps: trouble with all of them / all unusable in headache x2</p> <p>F. app with good usability: weather app,</p> <p>G. other app usability: information clear,</p> <p>H. other app usability: good use of symbols,</p> <p>I. other app usability: information right there,</p> <p>J. other app usability: background is dark color and not white x3</p> <p>k. other app usability: big font,</p> <p>L. other app usability: simple,</p> <p>M. other app usability: consistent/easy/simple,</p> <p>N. also likes animation</p> <p>O. coping with light sensitivity: dimness all the way down</p> <p>P. app more usable when light is painful if reduced visual stimulation, more usable when light is painful if few visual details</p> <p>Q. Kindle screen - improved readability</p>
Benefits of App	<p>A. Benefit of app: helped with symptom management</p> <p>B. benefit of app: trigger insight</p> <p>C. benefit of app: more proactive</p> <p>D. detractor of app: not user friendly during migraine,</p> <p>E. detractor of app, 3 times a day bad</p> <p>F. negative: really unsure whether finished study</p> <p>G. negative: uncertain if was helpful</p> <p>H. negative: app could not deal with time zones,</p> <p>I. suggest for app: allow people to miss some surveys,</p> <p>J. negative on app: felt guilty when missed surveys</p> <p>K. had to force self to use/endure diary during light sensitivity,</p> <p>L. skipped diary elements due to lights sensitivity</p> <p>M denies problem with app and blames migraine</p> <p>N denies problem with app and says needs to rest to cope</p> <p>O coping with light sensitivity: close eyes,</p> <p>P. negative: picked surveys at poor times</p> <p>q. negative: more pain than gain</p>
What makes app usable when light is painful	<p>a. usable during aura: minimal visual interaction,</p> <p>b. app usable during aura: meditation app</p> <p>c. app difficulty during light/aura: small screen,</p> <p>d. app difficulty during light/aura: having to look at and read app</p> <p>r. app usability during aura/light: needs to be minimal</p> <p>s. app usability during aura/light; no bright colors,</p> <p>t. app usability during aura/light: no flashing,</p> <p>u. app usability during aura/light sensitivity:</p> <p>v. high utility only app usability during aura/light sensitivity: no motion from video/games</p> <p>w. difficulty completing diary: sensory changes during migraine</p> <p>x. usable during light painful: app that actively mediates pain (headspace),</p> <p>y. usable during light painful: minimal visual interaction,</p> <p>z. app usable during light painful: meditation app</p>

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