MiCOAS UH3

QUALITATIVE STUDY FINAL REPORT: CONCEPT ELICITATION INTERVIEWS

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REVISION HISTORY

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1.0	5/5/2022	R. Mangrum	Incorporated feedback from the External Technical Advisory Committee to • Shorten the executive summary • Add a concise statement of study aims to Section 1 • Add content for missing symptom code, Pain-Other • Clarify details throughout the findings

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ABBREVIATIONS

Abbreviation	Definition
BIPOC	Black, Indigenous, and other People of Color
CHAMP	The Coalition for Headache and Migraine Patients
COA	Clinical outcome assessment
COI	Concept of interest
Einstein	Albert Einstein College of Medicine
ETAC	External Technical Advisory Committee
FDA	U.S. Food and Drug Administration
HIPAA	Health Insurance Portability and Accountability Act
IRB	Institutional Review Board
MBS	Most bothersome symptom
MiCOAS	Migraine Clinical Outcome Assessment System
PROM	Patient reported outcome measure
VPG	Vector Psychometric Group, LLC

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EXECUTIVE SUMMARY

There is a clear gap in published qualitative research on the health and well-being outcomes that are meaningful to people living with migraine. Addressing this gap is an essential step for prioritizing those clinical outcome assessments (COAs) that are most important to patients in migraine clinical practice or clinical trials of treatment. To develop an understanding of the outcomes that matter to people with migraine, a qualitative study was conducted with 31 people in the US who self-reported a clinical care diagnosis of migraine. Study participants completed in-depth interviews via telephone or web-conferencing between August and November 2021. The interviews elicited detailed accounts of individuals' experiences of migraine, including symptoms and cognitive, psychosocial, and physical impacts. Separately, interview participants completed a health and demographic survey to report relevant personal characteristics and health data.

The study resulted in a comprehensive catalog of symptoms and impacts of migraine and a detailed analysis of how migraine contributes to function limitations, disability, and changes in well-being and quality of life.

RESULTS

Interview participants were purposively sampled from eligible applicants to represent diverse demographic characteristics and average number of headache days per month.

Analysis identified 61 discrete concepts related to migraine symptoms or impacts that participants described as important or that impaired their ability to function. In addition, analysis explored participants' conceptualization of the bothersomeness and severity of their symptoms and impairments and characterized their perceived ability to recall migraine attacks over different periods of time, a component that is critical to the development of a useful patient-reported outcome measure. A synopsis for each broad area of study results is presented below.

The study results confirmed the patient-centered importance of symptoms and impacts that have previously been used as primary or secondary outcomes in migraine research. Examples include symptoms such as pain, nausea, and sensitivity to light, sound, and smell, and impacts such as impairment of ability to move around, take care of oneself and one's home, or to work. The study also identified symptoms and impacts that have not been systematically used in migraine research but are burdensome to many people with migraine. Examples include changed mental acuity and impacts on cognitive functioning, mood, and social roles and activities. Finally, the study results shed light on the factors people with migraine use to assess bothersomeness and how they describe levels of severity in their experiences.

1. *Symptoms*

Interviews detailed the following migraine symptoms, presented in order of prevalence:

- Head pain, face pain, or headache (31 interviews)
- Changed mental acuity (30 interviews)

- Sensitivity to sensory stimuli including
  - Light (30 interviews)
  - Sound (29 interviews)
  - Smell (14 interviews)
  - Touch (11 interviews)
  - Other stimuli such as motion (as distinct from movement making pain worse), room temperature, or weather conditions (11 interviews)
- Sensory changes or disturbances, including visual disturbances, skin sensations, tinnitus, or changes in taste or smell, and parasympathetic symptoms such as unexplained yawning, twitching, or eye watering (29 interviews)
- Nausea (28 interviews)
- Pain in other areas of the body (e.g., neck, back) (24 interviews)
- Fatigue or changes in level of energy (23 interviews)
- Change in mood (18 interviews)
- Dizziness or vertigo (17 interviews)
- Muscle tension or stiffness (e.g., in neck, shoulders, and back) (17 interviews)
- Muscle weakness (overlapped with fatigue) (10 interviews)
- Changes in appetite (12 interviews)
- Changes in sleep (8 interviews)
- GI symptoms other than nausea (6 interviews)
- Clumsiness (6 interviews)

Interviews demonstrated that participants experience migraine attacks as variable combinations of these symptoms. The way that symptoms combined and compounded each other during an attack affected both perception of individual symptoms and the attack as a whole. For example, attacks with many symptoms were generally described as more severe than attacks with only a few symptoms. Similarly, impairment of functioning often resulted from combinations of symptoms and was influenced by factors such as the individual's family or social roles and responsibilities, access to support systems, or the ability to respond to a developing migraine attack. Although most symptoms were experienced in ictal periods (i.e., during one or more phases of a migraine attack), participants also reported interictal symptoms (i.e., symptoms present between attacks) that occurred routinely or intermittently.

2. *Cognitive Function*

Interviews detailed the following concepts associated with migraine's impact on cognitive functioning:

- Ability to concentrate (29 interviews)
- Language, including speaking and understanding (28 interviews)
- Memory, including working memory and free recall (26 interviews)
- Ability to read (17 interviews)
- Information processing and reasoning (18 interviews)

- Ability to write (10 interviews)
- Cognitive flexibility and multitasking (10 interviews)
- Impulse and behavior management (9 interviews)
- Medication management (6 interviews)
- Problem solving (6 interviews)
- Money management (3 interviews)

Interview participants attributed cognitive functioning impacts to changes in mental acuity as well as to other symptoms, which could impair cognitive functions even when mental acuity was unchanged. For example, light sensitivity could interfere with someone's ability to read or severe pain could be so all-consuming that one cannot concentrate on anything else. Migraine's impact on cognitive function resulted in a variety of associated burdens for participants, including embarrassment, frustration, or anxiety; impairment of other functions or roles, such as work or leisure activities; and experiences of stigma or negative perceptions by other people. Impacts on cognitive functioning were experienced predominantly in ictal periods but could also occur in interictal periods.

3. *Physical Function*

Interview participants referenced the following concepts when discussing physical function:

- Ambulation, including the ability to move parts of the body or to walk (27 interviews)
- Mobility and transportation, or one's ability to move around the community or to travel (27 interviews)
- Ability to exercise (22 interviews)
- Ability to prepare and eat meals (22 interviews)
- General function and disability (21 interviews)
- Health maintenance, including ability to keep medical appointments, achieve health goals, and choose migraine treatments (21 interviews)
- Housekeeping (19 interviews)
- Basic self-care, such as bathing, eating, or dressing (15 interviews)
- Sleep (12 interviews)
- Shopping and running errands (13 interviews)
- Ability to use communications and information processing systems (10 interviews)
- Fine motor control (8 interviews)
- Lifting and carrying (7 interviews)

Impairments of physical functioning occurred primarily during attacks, but some functions were affected in interictal periods, particularly those that require advance planning. Capacity for physical functioning was related to the specific symptoms experienced during each attack as well as their severity and duration. For example, severe pain was usually described as completely disabling while even mild dizziness could affect a person's ability to walk. Impacts were also sometimes subject to contextual factors: a person may feel unable to go shopping or prepare a meal, but still keep a medical appointment because it is a key priority. Finally, physical functions could be impaired directly by symptoms, the way that symptoms impaired other functions (e.g., impaired concentration could make someone reluctant to drive a car), or by individual decisions about how to respond to an attack (e.g., a medication may prevent driving).

4. *Psychosocial Function*

Interview participants described a wide range of concepts related to migraine's effect on psychosocial functioning and the concepts in this psychosocial domain often overlapped or intertwined with each other. The impacts ranged from effects on people's emotional state of mind and sense of identity to impacts on their ability to carry out a variety of social roles or activities. Depending on the specific functioning concept, impacts from migraine could occur ictally, interictally, or both.

Psychosocial functioning concepts fell into three broad categories: role functioning, emotional and psychological experience, and migraine management.

a. *Concepts related to social role functioning*

- Work (31 interviews)
- Interpersonal relations (28 interviews)
- Social, community, and civic roles (28 interviews)
- Recreation and leisure (28 interviews)
- Family relations (26 interviews)
- Social support or isolation (22 interviews)
- Intimate relations (17 interviews)
- Care of others or pets (16 interviews)
- School (10 interviews)
- Spiritual life (5 interviews)

b. *Concepts related to the emotional and psychological experiences of migraine*

- Feeling heard, or the sense that people understand what one is going through (29 interviews)
- Well-being, or the general ability to achieve a state of being comfortable, healthy, and happy (27 interviews)
- Identity, or one's self-image and sense of individuality (26 interviews)
- Emotional states, including
  - Anxiety (25 interviews)
  - Anger or frustration (24 interviews)
  - Depression (19 interviews)
  - Irritability (18 interviews)
  - Feelings of relief or invigoration (18 interviews)
  - Feelings of increased/decreased energy or drive (16 interviews)

  - Skepticism, or mistrust of oneself or of medical care (15 interviews)
  - Guilt (12 interviews)
  - Happiness or euphoria (12 interviews)
  - Embarrassment (10 interviews)
  - Grief (3 interviews)
  - Other positive (5 interviews) or negative (10 interviews) thoughts, such as feeling hopeful about the future or having a negative outlook on the future
- Accepting or adapting to life with migraine (23 interviews)
- Stigma (23 interviews)
- Life satisfaction and meaning (16 interviews)

c. *Concepts related to management of migraine*

- Predictability or control of migraine (30 interviews)
- Coping, including
  - Cocooning, or withdrawing into a safe environment to wait out an attack (29 interviews)
  - Voluntary avoidance of activities (17 interviews)
  - Non-pharmacological therapies (12 interviews)
  - Lifestyle changes (11 interviews)
  - Sensory control, or practices aimed at reducing exposure to bothersome stimuli (10 interviews)
  - Maintaining, or practices aimed at preventing migraine symptoms or impacts from worsening, but not necessarily obtaining relief (5 interviews)
- "Pushing through," or the practice of continuing to function during an attack despite symptoms or impairments (26 interviews)
- Direct costs of migraine, including money and time spent seeking medical care (21 interviews)
- Self-sufficiency, including both ability and inability to be self-sufficient (21 interviews)

Interview participants with severe, prolonged, frequent, or treatment-resistant migraine described a range of profoundly constraining effects on their home, social, and work lives, as well as their emotional and general well-being. Those with less frequent, less severe, or treatment-responsive migraine described challenges and impairments, but were often able to maintain substantial psychosocial functioning. However, migraine's psychosocial impact was also greatly influenced by the level of support and understanding that people encountered in their social environments, irrespective of the severity of disease. Finally, psychosocial functioning was influenced by individual decision making, such as choosing to treat or push through an attack or decisions about lifestyle adjustments.

Psychosocial impacts from migraine were pervasive and often negative, as well as unpredictable. For example, the list of emotional states associated with migraine includes far more negative feelings than positive ones. Migraine's unpredictability was particularly problematic for social role functioning and often made people feel reluctant or unable to make plans, which then contributed to feelings of frustration, guilt, and isolation.

However, many participants were also quick to note that they still had joy and lived fulfilling lives. Some expressed concern about the narrow focus on symptoms and negative outcomes they encountered in healthcare, while acknowledging that these burdens are quite substantial and of profound concern to them. This focus may, however, serve to exaggerate the negative consequences of migraine at the expense of understanding broader nuances about life with migraine. For example, many participants talked about learning to accept and adapt to life with migraine, which brought some participants a sense of peace or greater control over their lives although this psychological transition appeared to do little to lessen the concrete burdens of the disease. Instead, comments about acceptance seemed to suggest that the fight to control migraine adds to the burden of illness. Accepting and adapting to migraine allowed participants to minimize or eliminate this added burden.

5. *Bothersomeness*

Interviews provided robust evidence that pain and the three symptoms used in the Most Bothersome Symptom (MBS) approach—nausea, phonophobia, and photophobia—are indeed identified as most bothersome by people living with migraine. In addition, interviews provided robust evidence that changed mental acuity, or the experience of “brain fog,” was an equally common symptom and was equally bothersome compared with the three MBS symptoms. The unpredictability of migraine was also frequently referenced as the most bothersome aspect of the disease. Interview participants described a very wide range of other symptoms and specific impacts or impairments from migraine that were most bothersome to them, with very few participants being content to select just one. However, many of these appeared infrequently across interviews, underscoring the highly variable and individualized experience of life with migraine.

In describing why specific symptoms were bothersome, participants referenced four primary concepts:

- Creates physical or emotional suffering or discomfort
- Impairs function or causes disability
- Worsens migraine experience overall, such as making pain or brain fog worse
- Perceived ability to tolerate the symptom, such as people who described a high tolerance for pain or a low tolerance for nausea

6. *Severity*

Overall, participants described four degrees of severity that can be loosely described as mild, bad, awful, and extreme. Degrees of severity applied to both symptoms and to an attack as a whole. However, although attack severity was often directly based on the severity of associated symptoms, people did also regard attacks as more severe when they were prolonged or included more or different symptoms than usual, even when those symptoms were not severe. When participants talked about the severity of an attack, they most frequently referenced pain; nausea and vomiting; mental acuity; sensitivities to light, sound, or motion; dizziness or vertigo; visual disturbances; and impairments of functioning.

7. *Recall of Attacks*

Participants varied in their perceived ability to recall attacks after 1-2 weeks. Many said they could not remember specifics and that experiences tended to "*blur*" or "*blend*" together. This blurring appeared to be more pronounced for participants with frequent attacks. Some participants said they could remember attacks clearly, although they also noted they might remember some details and not others. Participants noted they would remember attacks that were unusual for them, such as particularly mild, severe, or long-lasting attacks. Participants also remembered attacks more clearly when there were other events that prompted recall (e.g., a holiday). Multiple participants provided perspectives that fit into more than one of these categories. For example, one participant talked about being able to clearly remember nausea and emotional feelings, but also talked about being able to remember more clearly an attack that lasted for days and one that happened at work that resulted in embarrassment. Finally, participants who kept records of their migraine attacks noted that they would refer to those notes to help them remember. Participants used a variety of means to record their attacks, ranging from migraine apps on a smartphone to handwritten notes on a wall calendar.

INTRODUCTION

Migraine is a highly prevalent neurological disease that is associated with significant economic, social, and individual burden, including disability (Blumenfeld et al., 2011; Buse & Lipton, 2013; Hu et al., 1999). Migraine impacts people's ability to function across multiple roles and settings ranging from occupational or academic to social, familial, and personal (Buse & Lipton, 2013; Buse et al., 2016; Haut et al., 2006; Hu et al., 1999; Lipton et al., 2017; Lipton et al., 2001; Society, 2019). Although there are many subtypes of migraine, one important distinction is between episodic migraine, defined as migraine with ≤14 headache days per month over a 3-month period, and chronic migraine, with ≥15 headache days per month over a 3-month period, of which at least 8 are linked to migraine (International Headache Society (IHS), 2018). Episodic and chronic migraine are associated with different levels of impact on well-being, with studies demonstrating that chronic migraine conveys significantly higher burdens compared with episodic migraine and that burdens increase as the number of monthly headache days increases (Buse et al., 2010; Lanteri-Minet, 2014). Research has shown that people living with migraine experience headache-related impairments and disability, decrements in quality of life, higher rates of comorbidities, increased healthcare resource utilization, and higher direct and indirect costs (Buse, Reed, Fanning, Bostic, Dodick, et al., 2020; Buse, Reed, Fanning, Bostic, & Lipton, 2020; Ishii et al., 2021).

Treatments for migraine, which include both pharmacologic and non-pharmacologic therapies, are categorized as either acute or preventive (Haut et al., 2006; Society, 2019). Acute treatments aim to resolve migraine symptoms when an attack occurs and return individuals to a normal level of functioning as quickly as possible (Marmura et al., 2015). Preventive migraine treatments aim to reduce the frequency, duration, or severity of attack s(Silberstein, 2015). Both acute and preventive migraine treatments also aim to preserve or enhance individuals' health-related quality of life, and to reduce burden associated with migraine; these treatments can be used together to optimize burden reduction and improve function. In recent years, the US Food and Drug Administration (FDA) has approved many new acute and preventive migraine treatments and a significant level of interest in developing new treatments persists in headache medicine. However, there are significant limitations to the evidence regarding the meaningfulness and validity of current clinical outcome assessments (COA) used to assess the varied burdens of migraine in clinical trials of acute or preventive treatments (Houts et al., 2021; McGinley et al., 2021). These limitations include a lack of published qualitative evidence about people's experiences living with migraine.

In acute migraine trials, coprimary endpoints are typically pain freedom and freedom from the individual's designated most bothersome symptom, both often at 2 hours post-dose (Houts et al., 2021). For preventive treatment trials, the standard primary endpoint is reduction in mean migraine (or headache) days per month (McGinley et al., 2021). Although these endpoints are important and capture part of what patients with migraine value, reliance on these few outcomes may result in missed opportunities to assess the full array of symptoms and burdens that disrupt the lives of people with migraine and to understand how treatments address these impacts. This study sought to develop further empirical evidence about symptoms and burdens for use in identifying or developing supplemental measures that could assess these other impacts of migraine during clinical trials and allow for better understanding of how to assess treatment efficacy.

1. STUDY BACKGROUND AND AIMS

To assess and address current limitations in patient-reported outcome metrics for evaluation of therapies in migraine, Vector Psychometric Group, LLC (VPG), in collaboration with Albert Einstein College of Medicine (Einstein), was awarded an FDA grant to support the development of a patient-informed and publicly available standard core set of COAs for migraine. This project to develop the Migraine Clinical Outcome Assessment System (MiCOAS) focuses on incorporating data about the lived experience of people living with migraine and feedback regarding impacts and outcomes most meaningful to them.

To support this work, VPG assembled key stakeholders (i.e., patient advocates, healthcare professionals, COA development experts, psychometricians, regulators, industry, and payers) in an External Technical Advisory Committee (ETAC) that provides ongoing guidance in the implementation of the project and conducted a comprehensive systematic review of the migraine literature to fully understand existing outcomes and COAs used in both acute and preventive migraine trials (Houts et al., 2021; McGinley et al., 2021). The research team then partnered with Pharmerit (now called OPEN Health) to conduct an initial qualitative study to capture the perceived symptom, disability and impact experiences of persons living with migraine, with a specific focus on understanding (1) when symptoms occur across the phases of migraine (aura, prodrome, headache, postdrome) and (2) the treatment benefits that people with this disease value most. The initial study is referred to as UG3.

Execution of these initial three project tasks provided substantial evidence of widespread physical, psychological, social, and cognitive burden associated with migraine. Participants in the UG3 study, for example, reported a broad array of factors associated with migraine-related functioning and disability. However, these initial investigations suggested that existing patient-reported outcome measures (PROMs) may not capture functional impairment or disability over all the domains identified as important by people with migraine. For example, existing measures vary widely in which functions are included, as well as how functions are conceptualized and measured with respect to timeframe or response scale. Additionally, the systematic reviews documented inconsistencies in the level of available qualitative evidence supporting the patient-centeredness and content validity of existing PROMs.

As a result, a major concern emerged regarding how to assess these functional outcomes reliably in a manner that is meaningful to patients with migraine and can be used to support valid claims regarding a treatment's impact on migraine-related functioning and disability. A second qualitative study, referred to as UH3, was conducted to assemble further evidence for use in developing a conceptual framework for migraine measurement and in selecting, developing, or validating migraine-related PROMs.

The aims of this study were to

1. Develop a comprehensive and detailed body of qualitative evidence about the impacts that migraine has on people's functioning and overall well-being

2. Develop an understanding of how people with migraine conceptualize and assess core concepts critical to measurement, such as levels of severity or bothersomeness

3. Develop an understanding of people's perceived ability to recall their attacks over different periods of time

1.1. STUDY DESIGN OVERVIEW

This was an observational, cross-sectional, qualitative study of people with migraine comprising one-time individual in-depth interviews via telephone or web-conferencing with 31 people who lived in the US and self-reported that they had been diagnosed with migraine by a health care professional. The interviews focused on understanding each individual's experiences of symptoms and the cognitive, psychosocial, and physical impacts that ensue. A health and demographic survey was also used to capture relevant personal characteristics and health data for all study enrollees.

Individual interviews were selected instead of focus groups to permit a detailed, comprehensive study of individual experiences of functioning and disability and provide clarity about complex, interrelated factors within illness experience (Britten, 2011; Brédart et al., 2014). Conducting one-on-one interviews provides the interviewer with more control over the conversation, allowing for greater personalization to each person, and eliminates group dynamics, such as a social desirability response bias, that may constrain individuals from sharing their genuine perspectives. Individual interviews offer participants a private, unhurried environment which makes it easier to share detailed experiences and address questions that may be sensitive or embarrassing (Carter & Henderson, 2005). Telephone/web-conference interviews were conducted in lieu of in-person interviews to minimize the logistical burden for study participants (i.e., not required to travel for the interview) and to allow maximum flexibility in accommodating participant availability and personal comfort.

Finally, the UH3 study included re-examination of interviews conducted during the UG3 study to identify, code, and analyze participant comments about bothersomeness; these findings were then used to establish an approach to inquiry and analysis of this topic for the UH3 interviews.

1.1. QUALITATIVE STUDY OBJECTIVES

The overall goal of the qualitative study was to support the development of person-centered COAs for the measurement of migraine outcomes and endpoints in therapeutic treatment trials by collecting data regarding people's experience of physical, cognitive, and psychosocial function impacts that result from migraine. Building on a previous round of qualitative work, concept elicitation interviews provided data to support understanding of the underlying concepts, content, structure, and scope of the functional impact or disability outcomes relevant for studies of both acute and preventive treatments for migraine. Secondarily, most bothersome symptom, severity of symptoms and impacts, and ability to recall migraine experience over a period of time were qualitatively examined. Across all study objectives, differences in symptoms and outcomes by ictal and interictal phases were also examined.

Data collection consisted of interviews with people with migraine focused on the following objectives:

1. **Develop deeper knowledge of the concepts related to impacts on functioning in migraine**. To elaborate on the list of concepts related to cognitive, psychosocial, and physical functioning developed during the UG3 study.
2. **Develop knowledge of relevant timeframes for experience and for recall**. To understand how interview participants conceptualize symptoms and function relative to ictal and interictal periods, and how they perceive their capacity to recall their experiences over short periods of time (e.g., a day, 1-2 weeks).
3. **Develop knowledge of the relevance of different outcomes to people with migraine.** To understand which impacts on functioning are the most bothersome, the most consequential in reducing overall quality of life, or the most desirable to address through treatment.
4. **Develop knowledge of severity as perceived by people with migraine.** To explore variation in the severity of symptoms, limitations on activities and functioning, or disability as experienced by people living with migraine, and to build knowledge of how people describe and judge the severity of their experiences.
5. **Develop knowledge of language.** To identify the specific language people living with migraine use to express concepts relevant to symptoms and functioning.

2. METHODS

2.1. STAKEHOLDER ENGAGEMENT IN THE STUDY

The study team engaged with two stakeholder groups to design and execute this study. These engagements provided opportunities for stakeholders to provide input into data collection and analysis procedures. The ETAC provided input on the interview guide and codebook and advised on the interpretation of results. Select members of the Coalition for Headache and Migraine Patients (CHAMP), an advocacy organization for people with headache, migraine, and cluster diseases, provided input on the interview guide and outreach protocols and participated in a mock interview to test and refine the interview guide. CHAMP disseminated outreach materials through their communication channels to support patient recruitment.

2.2. INSTITUTIONAL REVIEW BOARD DETERMINATION

The study protocol and all participant-facing materials were reviewed by WCG IRB, an institutional review board (IRB) registered with Office for Human Research Protections (registration number IRB00000533). The protocol and materials were approved on July 26, 2021 (study number 1313665).

2.3. RECRUITMENT AND ENROLLMENT OF STUDY PARTICIPANTS

Stratified purposive sampling (a type of non-probability sampling) was used to recruit people who self-reported that they were diagnosed with migraine by a health professional and who exhibited variation in self-reported headache frequency and other desired characteristics, such as age, sex, race, and ethnicity. Interview participants were selected to mirror the overall characteristics of patients who are eligible to participate in migraine clinical trials and to optimize the capture of variations across key cohorts such as age, sex, or employment status (Guest et al., 2006; Lasch et al., 2010; Patrick et al., 2011; Patton & Patton, 2002).

Participants were recruited through a collaboration between VPG and CHAMP. CHAMP distributed study announcements through their website, social media, and other distribution channels to reach potentially eligible individuals. These announcements directed individuals to a designated study webpage to access detailed study information and complete an electronic screening questionnaire. Eligible participants were then directed to an electronic informed consent form. Consented participants were directed to complete a confidential health and demographic survey and provide contact information through a secure study website. Interview participants were selected from among those individuals who completed all enrollment steps. Copies of the screening questionnaire and health and demographic survey are provided in **Appendix A**.

After the initial announcement of the study, 142 individuals completed enrollment. However, this sample included only 5 people who identified as male and 9 who identified as Black, Indigenous, and other People of Color (BIPOC). To improve enrollment, CHAMP conducted additional rounds of outreach using IRB-approved materials prepared specifically to target individuals from these backgrounds.

A member of the research team contacted each selected participant directly to schedule the telephone/web-conference interview. Interviews were scheduled at times that accommodated participants' availability, time zones, and preferences for time of day. Participants who completed interviewers were provided a $125 electronic Mastercard gift card as compensation for their time and expertise.

2.3.1. Eligibility Criteria

Individuals were eligible for the study if they were:

- Currently living in the US
- Between 18 and 75 years of age
- Reported being diagnosed with migraine by a healthcare professional
- Reported experiencing 4-26 headache days per month over the last 3 months
- Reported being able to distinguish between a day with migraine and other types of headache days
- Reported experiencing limitations on physical or cognitive activities on at least 1 day over the last 3 months because of migraine
- Reported being comfortable reading and speaking in English
- Consented to have their interview video/audio recorded for the purpose of transcription and data analysis (participants determined whether they preferred to be on camera or not)

Individuals reporting any of the following at the time of screening were excluded from the study:

- Self-reported diagnosis or any other clinically significant health condition that might interfere with the person's ability to provide non-confounded descriptions of their experience with migraine-related cognitive, psychosocial, or physical impacts
- Self-reported use of opioids or barbiturates more than 4 days during the past 30 days
- Self-reported alcohol or drug abuse over the past 3 months, using the CAGE Questionnaire (Ewing, 1984)
- Reported participating in an interview or focus group related to migraine experience in the past 12 months or participating in the MiCOAS UG3 study
- Reported being an employee or family member of an employee of FDA, VPG, or Albert Einstein College of Medicine/ Montefiore Medical Center

2.3.2. Informed Consent and Participant Incentives

All participants received and signed an informed consent document that described the study, provided study contact information, and emphasized that participation was voluntary at all times. Participants who completed interviews received an incentive of $125 in the form of an electronic gift credit card. Prior to starting the recording, interviewers reminded participants that the interview was being recorded and confirmed their consent.

2.4. DATA COLLECTION AND STUDY PROCEDURES

Guidance from the ETAC, results from the migraine literature review, and results of the qualitative study of migraine symptoms and meaningful treatment outcomes informed the development of data collection forms and the interview guide for this study. A patient stakeholder participated in a mock interview to test the interview guide and provide feedback on questions and conversational flow.

2.4.1. Data Collection

Study data consisted of two surveys and the in-depth interview. All survey data was collected through the flexCOA® survey platform, a proprietary electronic data collection platform. flexCOA® is compliant with the Health Insurance Portability and Accountability Act of 1996 and individual data collected within the system are encrypted and protected. Participant data, interview recordings, and interview transcripts were stored on secure, encrypted servers within VPG's information technology systems. Access to all data files was restricted to members of the research team who were directly engaged in data collection or analysis activities.

To optimize confidentiality, interview recordings were labeled with the participant's unique identification number before being securely transferred for transcription and analysis. Analysts reviewed each transcript and redacted potentially identifying information, such as references to places, occupations, or events. The de-identified interview transcripts were uploaded to NVivo Windows for analysis.

2.4.2. Interviews

The purpose of the interviews was to gather evidence relevant to study goals and objectives described in Section 1. Interviews invited participants to share their experiences with and perspectives on migraine regarding the following topics:

1) Migraine symptom experience and history
2) Impacts of migraine on physical, cognitive, and psychosocial functioning
3) Perceived relationships among migraine symptoms and impacts, including
    a. Bothersomeness of symptoms or impacts on function
    b. Timeframes, such as phases when symptoms occur, change in symptoms or functioning over time, or how often or how long symptoms or effects last
    c. Recall and severity judgment, such as ability to recall symptoms and functioning over different time frames or how participants perceived changes in severity

The interviews were conducted in English using a semi-structured interview guide (**Appendix B**). The interviewer began with broad questions intended to elicit spontaneous responses describing individual experiences with migraine and its impact on function. The interviewer then cultivated in-depth responses through open-ended questions focused on specific aspects of migraine and function as well as targeted probes to ensure consistent data collection on key symptoms, impacts, or functions. Interviews were conducted one-on-one by phone or web-conferencing system by trained interviewers (see Section 2.4.3) and lasted 50 to 90 minutes, depending on how many interview questions applied to the participant's individual lifestyle and experience with migraine.

2.4.3. Interviewer Qualifications

All participant interviews were conducted by members of the VPG research team who have training and experience in conducting interviews with patients and who have also been trained in qualitative data collection requirements for patient-centered concept elicitation and COA development. Prior to conducting interviews, all interviewers studied the study protocol and interview guide (**Appendix B**) until they were thoroughly familiar with the content.

2.5. DATA ANALYSIS

Data analysis included both descriptive and interpretive methods. Descriptive methods consisted of a quantitative summary of participant characteristics and stratified summary tables of quantitative patterns in the coded data. Interpretive methods included examining content for conceptual patterns or themes relevant to each domain and topic area.

2.5.1. Codebook Development

A preliminary codebook was prepared prior to beginning data collection. The codebook was developed using published literature and the results of the earlier UG3 study, which identified numerous concepts relevant to migraine experience. In addition, existing conceptual frameworks for functioning and disability, such as the International Classification of Functioning, Disability and Health (World Health Organization, 2001), were reviewed and integrated into the initial coding structure. Finally, the research team received input from clinical experts including a United Council for Neurologic Subspecialties headache expert neurologist, a headache psychologist, and ETAC members.

The codebook was designed to reflect phenomenological bracketing that distinguished between absolute aspects of a participant's experience (e.g., specific functional limitations, such as disruption of sleep) and their individual consciousness of that experience (e.g., non-absolute aspects, such as perceptions of how bothersome something is). In the codebook, absolute aspects of experience were captured under the parent code called Content Codes. These codes capture the concepts describing migraine experience that could be used in a PROM. Consciousness of experience was captured under the parent code called Context Codes, which included codes for ictal and interictal experience, bothersomeness, severity, and frequency. Context codes were used only for dual coding (i.e., applied to text already coded with a Content code) and used to help discern patterns in content data. With the exception of bothersomeness and severity, content from these codes is not summarized separately in this report. Findings for ictal and interictal experience, for example, are reported for each Content code in Section 3.5. In coding for ictal and interictal periods, analysts considered specific temporal identifiers in each participant's answer as well as the question-as-asked in the transcript. For example, a participant might be responding to a question that asked about experiences in between migraine attacks and this response would be coded as interictal. However, within their response, a participant might also reflect on contrasts with ictal experiences and that content would be coded as ictal.

After transcript analysis began, the codebook was revised to add and modify codes to reflect the actual content of interviews. For example, new codes were added to capture comments about "*pushing through*" and the practice of withdrawing to wait out an attack, which analysts ultimately referred to as "cocooning." The code for Cocooning was later moved to serve as a subcode of Coping, in recognition that it is a major mechanism by which people cope with their migraine attacks. Many codes were further divided into subcodes to support identification of themes and interpretation of results. For example, the cognitive function code Read/Write was subdivided into separate subcodes to better reflect the substantive differences in data about these two functions: many participants (n=17) experienced migraine-related challenges with reading, but not with writing. Rather, numerous participants talked about using writing to help during attacks, for example through written notes or lists that supported memory or concentration, or about preferring written to verbal communication when their speech was affected. As new codes were created, the research team reviewed them to establish agreement on code definition and scope. Coders used an audit trail of decisions to track additions and modifications to the codebook.

In addition to Concept and Context coding, case classifications were applied to all transcripts. Case classifications included demographic and health data collected during participant enrollment, such as age and sex. The classifications were used to stratify coded data, examine differences among groups of participants with similar characteristics, and test assumptions.

The final codebook (**Appendix C)** is hierarchical, including 61 parent codes identifying discrete concepts found in interviews, along with numerous subcodes that reflect themes or subsets of content. The final codebook served as the basis for both saturation analysis and stratification of results.

2.5.2. Analysis of Concept Elicitation Data

Interview recordings were professionally transcribed and uploaded to NVivo Windows for analysis. The following data reduction and analysis procedures were used.

Coding and assessment of inter-coder agreement. All coding was completed by two researchers who conducted a line-by-line review of each transcript to identify portions of text expressing relevant concepts. Coders met several times per week to review coding, raise questions and concerns, and reach agreement on new codes or interpretation of code definitions. Consistency of coding and case classification was assured through assessment of inter-coder agreement and resolution of inconsistencies. Three transcripts were independently coded by both researchers, who then met to compare coding and discuss the addition of new codes to the codebook. Intercoder agreement on the first three transcripts was analyzed using the embedded NVivo interrater reliability function and showed high per-code agreement ranging from a low of 84% (for the severity code) to a high of 98% (for multiple codes). Differences of opinion were resolved through consensus. Thereafter, interview transcripts were coded by the researcher who had not conducted the associated interview and the coders reviewed each other's work through periodic cross-checks to assess level of agreement. When discrepancies were found, the coders resolved them through consensus.

Thematic and descriptive analysis. Thematic and descriptive analysis was conducted for all Content codes. Analysis entailed developing a summary description of how participants described the scope of experience captured by the code, what terminology they used, and what disconfirming examples were present. In developing summary reports, analysts considered

- The number of participants represented by the coded data
- The dominant and minor themes found in a code; coders also made decisions about the value of applying subcodes to reflect themes and allow more granular stratification of results
- Whether the code captured ictal or interictal experiences, or both
- How the coded content was related to content in other codes
- Whether there were disconfirming cases (Roller & Lavrakas, 2015) (i.e., people whose experience was different compared to most participants, for example a person who did not experience head pain)

Summaries were illustrated with extensive verbatim quotes that reflected both the typical content and the range of variation in content found for each concept. Analysts also developed summaries that discussed how participants talked about bothersomeness and severity.

2.5.3. Assessment of Saturation

Saturation was assessed by documenting which interview constituted the first instance of each concept as well as the number of interviews endorsing each concept. The saturation assessment followed prevailing best practices and the FDA's Guidance to Industry regarding evidence of saturation in qualitative research carried out to support PROM development (United States Food and Drug Administration, 2009). The standard approach to saturation analysis involves comparing each interview to those that preceded it and, when several interviews have passed with no new content, data collection often ceases. However, given the breadth and variation in possible impacts and experiences of disability that were found in this study, the level of saturation among interviews with participants with similar characteristics was also considered. For example, a concerted effort was made to ensure that the data set represented a substantial number of male and non-white participants to obtain a balance of perspectives and enhance the opportunity to observe any differences in experiences based on sex and race. An analysis of concept prevalence, or the percentage of transcripts coded to each code, was also conducted to complement the saturation analysis. Prevalence was also examined to understand whether there was sufficient data for concepts (which is needed to adequately describe and understand them) and to assess whether coding was overly broad or applied inconsistently, which would be signaled by substantial numbers of high- or low-frequency concepts.

2.5.4. Secondary Analysis of UG3 Interview Data

This report includes one section that describes findings from a secondary analysis of interviews conducted for a prior round of data collection during the MiCOAS UG3 study. These interviews included participants' spontaneously offered perspectives on the bothersomeness of symptoms. These perspectives were most often mentioned in the context of the outcome prioritization exercise included in the UG3 interview. Using the same approach to coding and analysis used in the present, transcripts from the previous study were examined for relevant content as a way to further enrich the findings on this topic. Findings from the secondary analysis were used to establish subcodes for the Context code for bothersomeness.

3. STUDY RESULTS

This report presents results for all analyses conducted with the study data.

3.1. SAMPLE AND PARTICIPANT CHARACTERISTICS

A total of 153 participants enrolled in the study, completed the demographic and health survey, and provided valid contact information. Interviews were conducted between August and November 2021, with 31 individuals purposefully selected to reflect diversity across personal and migraine/headache characteristics. Aggregate demographic characteristics for participants are provided in Table 1. Overall, participants with episodic migraine constituted 58% of the sample while those with chronic migraine constituted 42%. A total of 14 participants, or 45% of the sample, self-reported membership in a racial minority. Hispanic individuals made up 16% of the sample and represented a diversity of Hispanic origins.

In enrolling participants, three age groups were used to reflect younger adults (ages 18-40), middle aged adults (ages 41-60), and older adults (ages 61-75). These categories reflected broad assumptions about the ages at which adults typically transition in both lifestyle and age-related general health; these transitions can affect the way illness affects functioning. During participant selection, a minimum of 5 and a maximum of 16 per age group were included in the sample so that the data would include content from people of different age categories. Table 1 provides both traditional, decade-based age groups and the age groups used in the sampling framework for this study and shows that the sample was skewed towards middle-aged individuals, with nearly one third being ages 55-64. This distribution, however, is similar to that found in large panel studies, where respondents also tended to be older.(Lipton et al., 2016)

Table 1. Participant Characteristics

Characteristic	No. Interview Participants	Percent of Sample
Number of self-reported headache days per month		
4-8 days	8	26%
9-14 days	10	32%
15-20 days	8	26%
21-26 days	5	16%
Age group for enrollment		
18-40 years old	10	32%
41-60 years old	16	52%
61-75 years old	5	16%
Age		
18-24 years old	1	3%
24-34 years old	4	13%
35-44 years old	8	26%
45-54 years old	6	19%
55-64 years old	10	32%

Characteristic	No. Interview Participants	Percent of Sample
65-75 years old	2	6%
Male	9	29%
Hispanic	5	16%
Colombian	1	
Puerto Rican	1	
Uruguayan	1	
Xicanx	1	
Cuban/Mexican	1	
Race (multiple selections permitted)		
Asian	1	3%
Black or African American	6	19%
American Indian or Alaskan Native	3	10%
Native Hawaiian or Pacific Islander	*	*
White	18	58%
Other	4	13%
Self-reported years since diagnosis is 5 years or less	8	26%
Reported using treatments to address migraine attacks when they occur**	30	97%
Reported using treatments to prevent or reduce the severity of migraine**	28	90%
Reported current use of opioids or barbiturates to treat migraine	5	16%
Reported using a medication with known cognitive toxicity (for any reason)	10	32%
PHQ-8* score >10	10	32%
MSSS* > 24	20	64%
Employment status (multiple selections permitted)		
Paid employment	20	64%
Student	2	6.5%
Homemaker	2	6.5%
Retired	3	10%
Not working	1	3%
Disabled (or on disability or leave of absence)	10	32%
Education		
High school or some college, technical school, or apprenticeship	7	22%
Completed college, technical school, or apprenticeship	12	39%
Attended or completed graduate school	12	39%
Income		
Under $30K	7	23%
$30-59K	6	19%

Characteristic	No. Interview Participants	Percent of Sample
$60-90K	5	16%
Over $90K	11	35%
Did not answer	2	7%
Married	17	55%
Have children	8	26%
Reported having aura symptoms	13	42%
Reported clustering of migraine attacks	4	13%
Reported menstrual migraine	5	16%
Geographic location based on time zone		
Eastern	16	52%
Central	4	13%
Mountain	2	6%
Pacific	9	29%

**PHQ-8: Personal Health Questionnaire, a widely-used depression scale. MSSS: Migraine symptom severity score.*
***Treatments included therapies other than pharmaceuticals, such as vitamin or dietary supplements*

3.2. SATURATION AND PREVALENCE OF MIGRAINE EXPERIENCE CONCEPTS

Examination of concept saturation was conducted at the end of each 10-interview wave of coding. Saturation of concepts, or the determination that no new concepts were being added to the coding scheme, initially occurred at interview 14 during the second wave of analysis, at which point there were a total of 92 codes and subcodes for migraine concepts. Because the 20 completed interviews at that time did not include a sufficient percentage of male participants and did not achieve reasonable balance among other key individual characteristics, interviewing continued until 31 interviews were completed. This procedure resulted in a data set that included enough data to permit stratification to examine possible meaningful variations by participant characteristics, such as number of headache days, sex, or income. After thematic analysis and axial subcoding was conducted, saturation of concepts was reviewed and showed that no new concepts were added to the expanded code structure after interview 24 (see Table 2 for a summary and **Appendix D** for the detailed saturation table showing per-interview occurrence of codes). The final codebook contained a total of 193 codes, including both Content and Context codes. There were 160 unique Content codes organized hierarchically into 61 concepts in 4 domains (see **Appendix C**). Analysis also showed that 94% of all concepts were identified within the first 12 interviews.

Table 2. Concept Saturation Summary

Interview Number	No. Concepts and Sub-Concepts First Identified
1	68
2	31
3	24
4	7

Interview Number	No. Concepts and Sub-Concepts First Identified
5	6
6	3
7	4
8	0
9	2
10	0
11	2
12	4
13	2
14	2
15	0
16	0
17	3
18	0
19	0
20	0
21	1
22	0
23	0
24	3
25-31	0

Prevalence analysis was conducted after initial saturation of concepts was established and then repeated with the complete dataset. Analysis showed there were:

1. **A limited number of low-frequency concepts.** This analysis indicated that the interviews likely captured a robust amount of descriptive data for identified concepts. The dataset reflects a limited number of low-frequency concepts, defined as items referenced in fewer than 20% of interviews (6 or fewer participants). There were 40 low-frequency concepts, or 25% of the 160 codes and subcodes. Examination of the low-frequency concepts showed that many were either (a) sub-codes denoting alternate or related expressions of concepts (e.g., specific terms for mental acuity symptoms, specific aspects of self-care such as toileting or dressing), or (b) concepts reflecting activities that may be generally less commonplace (e.g., unpaid volunteer work was referenced by 19% of the sample, which is in line with estimates that roughly 20-25% of US adults volunteer each year (Bureau of Labor Statistics, 2016)).

2. **A limited number of high-frequency concepts.** This analysis indicated that the interviews likely captured a wide variety of experiences and that coding avoided overly broad conceptual groupings. The dataset reflected a limited number of high-frequency concepts, defined as items referenced in more than 80% of interviews (25 or more participants). There were 27 high frequency codes, or 17% of

the 160 codes and subcodes. These high-frequency codes reflected concepts that were expected to be frequent in the data, such as migraine symptoms (8 concepts, or 30% of the high-frequency codes), parent codes such as Coping (which has 6 subcodes), or concepts reflecting areas of function known to be commonly affected by migraine, such as ambulation or concentration.

3.3. LEVELS OF PROBED AND SPONTANEOUS DATA

To understand saturation more fully, tables were generated illustrating the degree to which information was offered spontaneously versus in response to a broad open-ended question (see **Appendix D**). Overall, 78% of all coded data was spontaneously offered by participants and 22% resulted from interviewer probing. Among codes, the percentage of data resulting from probing ranged from a low of 0% (for 10 different codes) to a high of 83% (for the concept of grooming). Just 12 codes reflected 50% or more of probed content and many of these codes are narrow, reflecting a small amount of data (Table 3). Note that this analysis excluded the code for Recall of Attacks because this topic *only* arose because interviewers asked about it and was never raised spontaneously by participants. .

Table 3. Codes with High Percentages of Probed Data

Code	Not Probed (number of references coded)	Probed (number of references coded)	Percent of total that is Probed
Physical\Basic self-care\Grooming	1	5	83%
Physical\Mobility Transport\Driving a car\Medication prevents driving	1	3	75%
Cognitive\Language\Comprehension	3	6	67%
Physical\Ambulation\Stand-sit prolonged	4	8	67%
Physical\Basic self-care\Bathing	5	9	64%
Cognitive\Concentrate-Focus\Divided attention\Multiple inputs	3	5	63%
Cognitive\Money management	2	3	60%
Cognitive\Language\Numbers	4	5	56%
Physical\Basic self-care	16	18	53%
Cognitive\Flexibility, multitasking	9	10	53%
Cognitive\Language\Speech\Slurred, mumbled	3	3	50%
Psychosocial\Pushing through\Maintain self-image	3	3	50%

3.4. VARIATION BY DEMOGRAPHIC AND HEALTH STATUS

To support understanding of the potential influence of participant characteristics on study findings, coding was stratified to look for patterns that might illuminate differences linked to participants' demographic or health characteristics. These quantified differences can be valuable in several ways (Dey, 2003; Sandelowski, 2001). First, they can be used to contextualize the conceptual thematic results, either to underscore the validity and rigor of findings or to identify places where the evidence is thin or conflicting. This process can be important for avoiding common biases and fallacies in qualitative research, such as over-reliance on dramatic or compelling examples or underweighting of data that does not conform to existing theories or assumptions (Miles et al., 2018). Second, stratified and quantified results can be used to test conclusions drawn from a study, particularly if these conclusions are anchored in assessments of prevalence or the broad applicability of findings to groups of people. Finally, the stratified results may permit new themes in the data to be identified.

Because the total sample size was small, and enrollment of individual participants was purposive, quantified stratification must be interpreted with a high degree of caution. In addition, observed differences can also be confounded by the coding: differences may appear for subcodes, for example, but not for parent codes. Thus, observed differences in coded data from a small purposive sample can be coincidental even when the observed differences among groups are large. To mitigate these risks, this report uses a relatively high bar when highlighting observed differences in the percentage of interview participants coded to a particular Concept code. Specifically, a threshold of ≥40% difference in the percentage of coded cases was used to identify potentially meaningful differences among groups of participants, while a threshold of less than 15% was used as an indication that there may be no meaningful differences (complete stratification results for all codes are provided in Appendix D). These thresholds were selected on the basis of their capacity to identify persuasive, compelling variations that could enhance the descriptive, interpretive, and theoretical validity of the results (Maxwell, 1992). Indeed, the relatively small number of potentially meaningful differences found through stratification underscores the fundamental qualitative focus on exhaustive, detailed description of experience, as opposed to seeking causation or association among variables. Nevertheless, when substantial differences are found, they may illuminate important variations in the ways that groups of people experience burdens of illness or articulate concepts related to living with migraine. These differences may be helpful when writing or selecting items. Additionally, observed differences may suggest hypotheses or avenues for further investigation, such as quantitative study to examine whether subgroup variation found in qualitative data is reflected in larger-sample statistical analyses.

3.4.1. Stratification by sex

Stratification by male or female sex demonstrated that there was minimal variation (defined as less than 15%) in rate of endorsement for 101 concept codes (see Appendix E for a complete table of results). Further, there were only 7 codes (see Table 4) that showed substantial sex-based variation, defined as a difference of ≥40% in endorsement rate. More female participants discussed jumbled speech, memory—free recall, feeling heard by friends and family, accommodations/adjustments at work, missed work, and sensitivity to touch compared with male participants. More males described mental acuity symptoms in terms of feeling “not as sharp or clear.” Notably, several concepts were unique to female participants, who described speech as “jumbled” or mixed up (males used terms like slurred or stuttered) and talked about feeling heard by friends and family (males tended to talk about people in general, without identifying specific groups) and sensitivity to touch. The uniqueness of these findings was confirmed by keyword searches and re-review of coded material.

Table 4. Differences Among Participants by Sex

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female	Percent Difference
Cognitive\Language\Speech\Jumbled	0	0%	9	41%	41%
Cognitive\Memory\Memory free recall	3	33%	17	77%	44%
Psychosocial\Feeling heard\Friends-family	0	0%	12	55%	55%
Psychosocial\Work\Work for pay\Accommodations-adjustments	2	22%	14	64%	42%
Psychosocial\Work\Work for pay\Missed work-leave	2	22%	15	68%	46%
Symptoms\Mental-Foggy or Clear\Not as sharp, clear	6	67%	3	14%	53%
Symptoms\Sensitivity\Touch	0	0%	11	50%	50%

3.4.2. Stratification by age

Because of the relatively small number of study participants, stratification by the standard, decade-based age grouping resulted in sub-groups too small to employ percentage-based assessments of variation (Sandelowski, 2001). Age of interview participants also skewed older, with significant concentration in ages 55-64 (n=10). Stratification was therefore conducted only with the three age group categories used during participant selection. These categories reflected broad assumptions about when adults typically transition in both lifestyle and age-related general health. For example, individuals aged 41-60 are transitioning out of prime parenting and working years but may have to care for elderly relatives, and they are more likely to have a variety of age-related chronic health conditions, such as heart disease or arthritis.

As Table 5 shows, 20 codes demonstrated a difference of ≥40% in the percentage of participants in any two groups that referenced the concept. These concepts included several aspects of concentration and feeling heard, as well as word finding, problem solving, immobility, missed work, and tension—stiffness. For 14 of these concepts, the difference reflected higher rates among 18-40 year-olds compared with 61-75 year-olds, and in all but one code the rate among 41-60 year-olds fell in between the other two groups, suggesting a possible age-related progression.

Table 5. Differences among Participants by Age

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75	Largest Absolute Difference
Cognitive\Concentrate-Focus\Divided attention	8	80%	9	56%	1	20%	60%
Cognitive\Read Write\Read\Visual disturbances	6	60%	4	25%	0	0%	60%
Symptoms\Tension-Stiffness	8	80%	8	50%	1	20%	60%
Symptoms\Dizziness	9	90%	5	31%	3	60%	59%
Cognitive\Concentrate-Focus\Divided attention\Sensory-distraction	5	50%	5	31%	0	0%	50%
Physical\Basic self-care	7	70%	7	44%	1	20%	50%
Psychosocial\Feeling heard\Friends-family	7	70%	4	25%	1	20%	50%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75	Largest Absolute Difference
Psychosocial\Feeling heard\Work-school-society	7	70%	7	44%	1	20%	50%
Psychosocial\Care of others or pets	4	40%	11	69%	1	20%	49%
Psychosocial\Emotion States\Energy and drive	8	80%	5	31%	3	60%	49%
Symptoms\Sensitivity\Other	7	70%	4	25%	4	80%	45%
Cognitive\Concentrate-Focus\Divided attention\Pain-distraction	4	40%	7	44%	0	0%	44%
Cognitive\Language\Word finding	8	80%	8	50%	2	40%	40%
Cognitive\Problem solving	8	80%	11	69%	2	40%	40%
Physical\Ambulation\Immobility	4	40%	3	19%	0	0%	40%
Physical\Mobility Transport\Public transportation	4	40%	1	6%	0	0%	40%
Psychosocial\Well-being	8	80%	16	100%	3	60%	40%
Psychosocial\Work\Work for pay\Missed work-leave	8	80%	7	44%	2	40%	40%
Symptoms\Mental-Foggy or Clear\Brain not working, migraine brain	4	40%	2	13%	0	0%	40%
Symptoms\Sensitivity\Touch	6	60%	4	25%	1	20%	40%

3.4.3. Stratification by race and ethnicity

To identify differences based on race, participants were divided into two groups: BIPOC and White. Because there were only 5 Hispanic participants, they were treated as a single group; however, the Hispanic participants included two that identified as White, one that identified as Black, and two that identified as multiple races. Differences in the percentage of participants in each of the three groups that endorsed each concept was then examined.

Because only two concepts showed a ≥40% difference in level of endorsement by White and BIPOC participants, Table 6 includes 8 concepts that met a lower threshold of ≥30%. Higher percentages of White participants discussed life satisfaction and meaning and lifestyle changes as a coping strategy. All six participants who referenced problem solving were White. A higher percentage of BIPOC participants discussed a number of concepts, including impairments of concentration related to dividing one's attention, housekeeping activities, reading, and memory. BIPOC participants also discussed toileting, which no White participants did.

Table 6. Differences among BIPOC and White Participants

Code	BIPOC (n=13)	BIPOC Percentage	White (n=18)	White Percentage	Percent Difference
Psychosocial\Life satisfaction and meaning	4	31%	12	67%	36%
Psychosocial\Coping\Lifestyle changes-adjustments	2	15%	9	50%	35%
Cognitive\Problem solving	0	0%	6	33%	33%

Code	BIPOC (n=13)	BIPOC Percentage	White (n=18)	White Percentage	Percent Difference
Physical\Basic self-care\Toileting	4	31%	0	0%	-31%
Symptoms\Sensory disturbance\Other	5	38%	1	6%	-33%
Cognitive\Memory\Memory free recall	11	85%	9	50%	-35%
Cognitive\Read Write\Read	10	77%	7	39%	-38%
Symptoms\Appetite	8	62%	4	22%	-39%
Physical\Housekeeping	11	85%	8	44%	-40%
Cognitive\Concentrate\Divided attention	11	85%	7	39%	-46%

As shown in Table 7, some differences between White and Hispanic participants were found. Hispanic participants did not discuss several concepts at all, including multi-tasking and the use of non-pharmaceutical therapies as part of coping. Similarly, all Hispanic participants discussed several other concepts that were referenced by half or less of White participants, including sensitivity to touch, feeling heard, and working through attacks. Given the small number of Hispanic participants, these variations may be coincidental. However, the potential for some cultural differences in perceived experiences should be noted, particularly in light of the fact that two Hispanic participants identified as White.

Table 7. Differences among White and Hispanic Participants

Code	White (n=18)	White Percentage	Hispanic (n=5)	Hispanic Percentage	Percent Difference
Psychosocial\Coping\Non-pharmaceutical therapies	9	50%	0	0%	50%
Physical\Basic self-care\Bathing	7	39%	0	0%	39%
Psychosocial\Coping\Sensory control	7	39%	0	0%	39%
Cognitive\Flexibility, multitasking	6	33%	0	0%	33%
Cognitive\Problem solving	6	33%	0	0%	33%
Psychosocial\Work for pay\Accommodations	8	44%	4	80%	-36%
Psychosocial\School	4	22%	3	60%	-38%
Symptoms\GI-Other	4	22%	3	60%	-38%
Cognitive\Concentrate-Focus\Divided attention	7	39%	4	80%	-41%
Psychosocial\Social Community Civic roles\Friends-family	9	50%	5	100%	-50%
Psychosocial\Feeling heard\Work-school-society	8	44%	5	100%	-56%
Psychosocial\ Work for pay\Work through attacks	8	44%	5	100%	-56%
Psychosocial\Feeling heard\Friends-family	6	33%	5	100%	-67%
Symptoms\Sensitivity\Touch	5	28%	5	100%	-72%

Finally, as shown in Table 8, several differences between BIPOC and Hispanic participants were found. As was found when comparing with White participants, BIPOC participants discussed toileting, but Hispanic participants did not, and larger proportions of BIPOC participants talked about topics like housekeeping, care of others or pets, and ability to enjoy life. Smaller percentages of BIPOC participants referenced concepts such as identity, anxiety, or working through attacks.

Table 8. Differences Among BIPOC and Hispanic Participants

Code	BIPOC (n=13)	BIPOC Percentage	Hispanic (n=5)	Hispanic Percentage	Percent Difference
Cognitive\Read Write\Write	6	46%	0	0%	46%
Physical\Housekeeping	11	85%	2	40%	45%
Physical\Ambulation\Walk	8	62%	1	20%	42%
Psychosocial\Care of others or pets	8	62%	1	20%	42%
Psychosocial\Well-being\Enjoy life	7	54%	1	20%	34%
Cognitive\Flexibility, multitasking	4	31%	0	0%	31%
Physical\Basic self-care\Toileting	4	31%	0	0%	31%
Cognitive\Language\Speech	9	69%	5	100%	-31%
Psychosocial\Emotion States\Anxiety	9	69%	5	100%	-31%
Psychosocial\Identity	9	69%	5	100%	-31%
Symptoms\GI-Other	2	15%	3	60%	-45%
Psychosocial\Feeling heard\Work-school-society	7	54%	5	100%	-46%
Psychosocial\Feeling heard\Friends-family	6	46%	5	100%	-54%
Psychosocial\ Work for pay\Working through attacks	6	46%	5	100%	-54%
Symptoms\Sensitivity\Touch	6	46%	5	100%	-54%

3.4.4. Stratification by level of education

Three education strata were created to group participants who had completed some college or less, those who had completed college, and those who had attended or completed graduate school. Analysis identified 19 concepts with a difference of ≥40% in the percentage of participants across any two groups (see Table 9). However, it appears that many differences are likely coincidental. For example, it is hard to theoretically justify how education level would precipitate large differences in experiences with sensitivity to smell or ability to walk. This, in turn, makes it harder to credit those differences that may seem aligned with traditional thinking about the relationship between education and health-related quality of life, such as the higher a percentage of college- and graduate-level participants who referenced making coping lifestyle adjustments or the higher percentage of participants with less education who referenced depression.

Table 9. Differences by Level of Education

Code	Some college or less (n=7)	Percent Some college or less	Completed college (n=12)	Percent college	More than a college degree (n=12)	Percent More than college	Largest Difference (absolute value)
Symptoms\Sensitivity\Smell	3	43%	9	75%	2	17%	58%
Physical\Exercise	2	29%	10	83%	10	83%	55%
Psychosocial\Care of others or pets	6	86%	4	33%	6	50%	52%
Psychosocial\Emotion States\Embarrassment	0	0%	4	33%	6	50%	50%

Code	Some college or less (n=7)	Percent Some college or less	Completed college (n=12)	Percent college	More than a college degree (n=12)	Percent More than college	Largest Difference (absolute value)
Symptoms\Fatigue	5	71%	12	100%	6	50%	50%
Physical\Ambulation\Walk	2	29%	9	75%	5	42%	46%
Psychosocial\Social Community Civic roles\Civic roles-events	5	71%	6	50%	3	25%	46%
Psychosocial\Well-being\Enjoy life	5	71%	8	67%	3	25%	46%
Psychosocial\Work\Work for pay\Productivity-performance at work	2	29%	9	75%	5	42%	46%
Psychosocial\Coping\Lifestyle changes-adjustments	1	14%	3	25%	7	58%	44%
Psychosocial\Emotion States\Depression	6	86%	8	67%	5	42%	44%
Symptoms\Appetite	1	14%	7	58%	4	33%	44%
Symptoms\Pain-other	4	57%	12	100%	8	67%	43%
Physical\Lift carry	0	0%	5	42%	2	17%	42%
Psychosocial\Emotion States\Guilt	3	43%	7	58%	2	17%	42%
Psychosocial\Work\Work for pay\Accommodations-adjustments	3	43%	9	75%	4	33%	42%
Symptoms\Sensory disturbance\Other	0	0%	5	42%	1	8%	42%
Physical\Basic self-care\Bathing	4	57%	3	25%	2	17%	40%
Physical\Sleep impacts	4	57%	2	17%	6	50%	40%

3.4.5. Stratification by employment status

In comparing participants who were employed with those who were not, two work-related concepts showed expected large differences (see Table 10): 75% of employed participants discussed productivity or performance at work, compared with 10% of those who were not currently employed. Similarly, 80% of those not currently employed endorsed the concept of job-career loss, compared with 25% of employed participants. Feelings of relief and invigoration were endorsed by 70% of employed participants, compared with 30% of those who were not employed, suggesting a possible link between employment and finding effective treatment.

Table 10. Differences by Employment Status

Code	Employed (n=20)*	Percent employed	Not employed (n=10)*	Percent not employed	Percent Difference
Psychosocial\Work\Work for pay\Productivity-performance at work	15	75%	1	10%	65%
Psychosocial\Work\Work for pay\Job-career loss	5	25%	8	80%	55%
Psychosocial\Emotion States\Relief-invigorated	14	70%	3	30%	40%

**Total number of participants does not sum to 31 because one participant declined to answer this question*

3.4.6. Stratification by income

When stratifying by income, the distribution of participants across income groups resulted in small numbers in most groups. When these groups were then further subdivided by Concept codes, the resulting very small numbers made comparison difficult. For this analysis, two larger groups of approximately equal size were made, one for individuals with household income of less than $60,000 per year and one for household income of $60,000 and up. This division aligns roughly with the median US household income of $67,521 for 2020 (US Census Bureau, 2021). For the 142 of the concepts, the percentage difference between groups was less than 25%. Only two concepts reflected a difference of ≥40% between the two groups: Exercise, endorsed by 46% of lower income participants and 88% of higher income participants, and the sub-concept of writing, endorsed by 54% of lower income participants and just 13% of higher income participants (see Table 11). Note that writing included references to impairment as well as preferences for writing to communicate during attacks. One additional concept approached the 40% difference: the Well-being subcode for Enjoy life was found in 10 interviews for participants in the lower income group (77%) and 6 interviews in the higher income group (38%), a difference of 39%.

Table 11. Differences by Income Level*

Code	Lower income (<$60K/year) n=13	Percent lower income	Higher income ($60K or more) n=16	Percent higher income	Lower to Higher diff
Physical\Exercise	6	46%	14	88%	41%
Cognitive\Read Write\Write	7	54%	2	13%	41%

**Two participants did not disclose income*

3.4.7. Variation by use of medications with known cognitive toxicity

During participant selection, the number of interviewees who reported using medications with known[1] cognitive toxicity (Table 12) was restricted to 10 individuals (32% of the sample). This ensured that data collected from participants who currently used such medications did not outweigh data collected from those who did not, but that sufficient data was collected to understand how these treatments might affect the performance of PROM items capturing cognitive concepts.

Table 12. Medications with Known Cognitive Toxicity Included in Health Survey

Medication (Brand Names)
amitriptyline (Elavil, Vanatrip)
amoxapine (Asendin)
clomipramine (Anafranil)

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[1] Known indicates known side effect of the medication; the survey did not indicate that these medications could cause cognitive impairments and participants were not asked if they were aware of these possible side effects

desipramine (Normpramin)
divalproex sodium (Depakote)
doxepin (Sinequan)
eletriptan (Relpax)
imipramine (Tofranil)
lasmiditan (Reyvow)
nortriptyline (Pamelor, Aventyl Hydrochloride)
protriptyline (Vivactil)
topiramate (Topamax, Trokendi XR, Qudexy XR, Topiragen)
trimipramine (Surmontil)

All participants who used one or more of the medications (100%) reported impacts on cognitive function, compared with 68% of participants who did not (see Table 13). Across the 34 hierarchical codes for cognitive function, 24 concepts were endorsed by a higher percentage of participants using the medications compared with participants who did not. However, most of the differences in rate of endorsement were small. For just 8 concepts, the difference in percentage between groups of participants was 20% or more, with the largest differences occurring in memory (especially recall of attacks) and concentration. There were no concepts unique to individuals using medications with known cognitive toxicity. Indeed, several low-frequency cognitive concepts were only endorsed by people who did not use these medications.

Table 13. Differences in Coding Among Participants Who Do or Do Not Use Specific Medications

Code	Use Cog Toxic Meds	Percent Use Cog Toxic Meds	Do Not Use Cog Toxic Meds	Percent Do Not Use Cog Toxic Meds	Percent Difference
Cognitive (any code)	10	100%	21	68%	32%
Memory	10	100%	21	68%	32%
Recall of attacks	9	90%	19	61%	29%
Memory free recall	6	60%	14	45%	15%
Memory working	6	60%	15	48%	12%
Concentrate-Focus	9	90%	20	65%	25%
Divided attention	5	50%	13	42%	8%
Sensory-Distraction	3	30%	7	23%	7%
Multiple inputs	2	20%	4	13%	7%
Pain-distraction	2	20%	9	29%	-9%
Sustained attention	3	30%	10	32%	-2%
Critical thinking	0	0%	5	16%	-16%
Flexibility, multitasking	4	40%	6	19%	21%
Language	8	80%	20	65%	15%
Speech	7	70%	15	48%	22%
Slurred, mumbled	2	20%	4	13%	7%
Slowed	1	10%	1	3%	7%
Jumbled	2	20%	7	23%	-3%
Avoiding speaking, not able to speak	1	10%	5	16%	-6%
Word finding	6	60%	12	39%	21%
Numbers	2	20%	6	19%	1%
Comprehension	1	10%	3	10%	0%
Expression	0	0%	5	16%	-16%
Impulse-Behavior	3	30%	6	19%	11%
Info Processing/Reasoning	5	50%	13	42%	8%

Problem solving	2	20%	4	13%	7%
Money management	1	10%	2	6%	4%
Read Write	5	50%	15	48%	2%
Write	4	40%	6	19%	21%
Assistive writing	2	20%	3	10%	10%
Technology	0	0%	3	10%	-10%
Read	5	50%	12	39%	11%
Concentrate	2	20%	8	26%	-6%
Visual disturbances	0	0%	5	16%	-16%
Medication management	1	10%	5	16%	-6%

3.4.8. Variation across episodic and chronic migraine strata

To better understand how experiences may vary by type of migraine, coding results were stratified by the four groups for average number of headache days per month selected by participants during screening (see **Appendix A**). The accuracy of participants' screener answers was verified through comparison with information shared during the interview.

To compare the coding results, the minimum and maximum differences among percentages of participants in each group referenced in each code were computed. This process permitted identification of those concepts that exhibited the most and least variation across headache-day strata. A table providing detailed results for all concepts and all strata is provided in **Appendix E**.

Overall, most codes (n=75) exhibited a moderate level of variation. Variation often, but not invariably, exhibited an expected difference between lower numbers of headache days and higher numbers of headache days. For example, 80% of people reporting 21-26 headache days/month reported difficulties with word finding, compared with 25% for 4-8 headache days. Similarly, 80% of participants reporting 21-26 headache days reported impacts on self-care activities, such as bathing, compared with 38% for 4-8 headache days. However, for some concepts, endorsement was lower for 21-26 headache days compared with other groups, perhaps because these participants tended to avoid certain activities or tasks. For example, 40% of participants with 21-26 headache days/month endorsed impacts on ability to divide attention, compared with 63% of participants at 4-8 days and 70% of participants at 9-14 days. Similarly, 40% of participants in the 21-26 headache day stratum discussed impacts on exercise, compared with 100% of participants at 4-8 days, probably because people with frequent headache days are less inclined to exercise at all.

Finally, it is worth noting that a simplified approach comprising analysis of the differences between participants with episodic vs. chronic migraine would have resulted in a very different result: using an aggregated approach would have greatly increased the number of concepts exhibiting minimal difference (112 Concept codes in contrast to 27 when comparing across the four subgroups) and greatly reduced the number of concepts showing a substantial difference (3 Concept codes instead of 32). This observation suggests that although the episodic/chronic division is useful in many contexts, it could also obscure nuanced differences in people's experience based on their exact number of headache days.

3.4.8.1. Concepts exhibiting the least variation by headache days

Table 14 provides a list of the 27 Concept codes where the maximum difference between any two headache-day strata was less than 15%. This analysis demonstrates that, across headache day categories, endorsement rates are uniformly high for symptom concepts like pain, mental fogginess, and light sensitivity, as well as function concepts like work, coping, or concentration. Similarly, endorsement rates are uniformly low for some concepts, such as lifting and carrying; these concepts represent highly specific experiences that may be expected to be less prevalent.

Table 14. Codes Showing Least Variation Across Headache Day Strata

Code	Minimum Percent	Maximum Percent	Percent Difference
Cognitive\Concentrate-Focus	88%	100%	13%
Cognitive\Concentrate-Focus\Divided attention\Multiple inputs	13%	25%	13%
Cognitive\Language\Speech\Slowed	0%	13%	13%
Cognitive\Read Write\Write\Technology	0%	13%	13%
Physical\Mobility Transport\Driving a car\Medication prevents driving	0%	13%	13%
Psychosocial\Feeling heard	88%	100%	13%
Psychosocial\Intimate relations	50%	63%	13%
Symptoms\GI-Nausea	88%	100%	13%
Symptoms\Mental-Foggy or Clear	88%	100%	13%
Symptoms\Mental-Foggy or Clear\Confusion	0%	13%	13%
Symptoms\Mental-Foggy or Clear\Spaced out	0%	13%	13%
Symptoms\Sensitivity\Smell	38%	50%	13%
Symptoms\Sensitivity\Sound	88%	100%	13%
Symptoms\Sensory disturbance	88%	100%	13%
Psychosocial\Coping	90%	100%	10%
Psychosocial\Predictability-control	90%	100%	10%
Symptoms\Sensitivity\Light	90%	100%	10%
Cognitive\Language\Comprehension	10%	20%	10%
Psychosocial\Pushing through	80%	88%	8%
Physical\Lift carry	20%	25%	5%
Symptoms\Pain-other	75%	80%	5%
Symptoms\Pain-head and face	100%	100%	0%
Cognitive\Memory	100%	100%	0%
Psychosocial\Emotion States	100%	100%	0%
Psychosocial\Work	100%	100%	0%
Symptoms\Sensitivity	100%	100%	0%
Symptoms\Symptoms- General	100%	100%	0%

3.4.8.2. Concepts exhibiting the most variation by headache days

Table 15 shows the 32 codes that exhibited the most variation across any two headache day strata. The greatest differences were found for concepts such as bathing, direct costs, and care of others, where high percentages of participants with 21-26 headaches per month were represented, but also concepts like work productivity and mood change, where very low percentages in these chronic participants were observed.

Table 15. Concepts Showing the Most Variation Across Headache Day Strata

Code	Minimum Percent	Maximum Percent	Percent Difference
Physical\Basic self-care\Bathing	0%	80%	80%
Psychosocial\Direct costs	25%	100%	75%
Psychosocial\Work\Work for pay\Productivity-performance at work	0%	75%	75%
Physical\Communication systems	10%	80%	70%
Psychosocial\Care of others or pets	13%	80%	68%
Psychosocial\Emotion States\Irritable	13%	80%	68%
Symptoms\Mood change	20%	88%	68%
Cognitive\Memory\Memory working	38%	100%	63%
Psychosocial\Feeling heard\Healthcare providers	38%	100%	63%
Physical\Exercise	40%	100%	60%
Psychosocial\Emotion States\Other negative thoughts	0%	60%	60%
Psychosocial\Emotion States\Skepticism	20%	80%	60%
Symptoms\Mental-Foggy or Clear\Brain fog	40%	100%	60%
Cognitive\Language\Word finding	25%	80%	55%
Physical\Basic self-care	25%	80%	55%
Psychosocial\Coping\Cocooning\Voluntary avoidance	20%	75%	55%
Psychosocial\Emotion States\Embarrassment	0%	50%	50%
Psychosocial\Emotion States\Relief-invigorated	25%	75%	50%
Psychosocial\Social Community Civic roles\Friends-family social	38%	88%	50%
Psychosocial\Work\Work for pay\Accommodations	38%	88%	50%
Psychosocial\Work\Work unpaid-volunteer	0%	50%	50%
Cognitive\Concentrate-Focus\Sustained attention	13%	60%	48%
Cognitive\Read Write\Read\Concentrate	13%	60%	48%
Physical\Sleep impacts	13%	60%	48%
Psychosocial\Social Community Civic roles\Civic roles-events	30%	75%	45%
Symptoms\Dizziness	30%	75%	45%
Physical\Shopping errands	20%	63%	43%
Psychosocial\Life satisfaction and meaning	38%	80%	43%
Psychosocial\School	20%	63%	43%
Psychosocial\Well-being\Enjoy life	38%	80%	43%
Psychosocial\Work\Work for pay\Working through attacks	20%	63%	43%
Symptoms\Tension-Stiffness	38%	80%	43%

3.4.9. Variation in ictal v. interictal experience

Designations for ictal and interictal periods within this study were based on how participants perceived them, with ictal designating experiences during pre-headache, headache, and post-headache phases, or by other concepts that participants used to delineate a migraine attack. Participants who did not always experience headaches or experienced constant low-level head pain used other symptoms (e.g., nausea, increase in pain intensity) to delineate a migraine attack. When participants indicated that they thought an experience was related to migraine, it was coded accordingly as ictal, interictal, or both. When participants expressed uncertainty about whether to attribute an experience to migraine, coding included the statement of uncertainty so that it could be incorporated in concept analysis. For example, some participants noted that some memory difficulties could be due to aging, and this is highlighted in the summary for the memory concept in Table 20.

Analysis of which concepts were dual-coded for ictal or interictal experience showed that numerous concepts were only or primarily referenced in discussions of ictal periods (see Table 16). Only a few concepts were referenced primarily in discussions of interictal periods, including life satisfaction and meaning, civic roles, and stigma (see Table 17). There were some additional concepts where the number of individuals referencing interictal phases was slightly higher (i.e., 1-3 more) than those referencing ictal periods. However, since individual participants might discuss the same concept in both ictal and interictal periods, these concepts are not highlighted here. Overall, findings in this section demonstrate that overall experience of migraine is largely comprised of ictal experiences, but that migraine also affects interictal life.

There were 24 codes that were only used in the context of discussions of ictal experience. These ranged from codes for symptoms such as visual disturbances, mental acuity, to functioning concepts such as ambulation-immobility and impairments of language such as slowed, jumbled, or slurred speech. There were an additional 35 codes that primarily arose in discussions of ictal experience. These codes were applied in fewer than 3 interviews (less than 10% of the sample) in the context of discussions of interictal experience. These 35 codes captured additional symptoms, such a muscle weakness and clumsiness, and functioning concepts such as aspects of concentration, memory, mood, self-care, and mobility, including many concepts that align with traditional activities of daily living (ADLs) and instrumental activities of daily living (IADLs). In addition, these 35 codes included many concepts relevant primarily to migraine attacks, such as aspects of 'pushing through' or the use of medication that prevents driving.

Table 16. Concepts Associated With Ictal Experiences

Codes associated with ictal experience only	Codes primarily associated with ictal experience
Cognitive	

• Concentrate-Focus:
  ▪ Divided attention\Pain-distraction
• Language:
  ▪ Expression
  ▪ Numbers
  ▪ Speech:
    ▪ Avoiding speaking, not able to speak
    ▪ Jumbled
    ▪ Slowed
	• Concentrate-Focus:
	  ▪ Critical thinking
	  ▪ Divided attention
	    ▪ Multiple inputs
	    ▪ Sensory-distraction
	• Flexibility, multitasking
	• Language:
	  ▪ Comprehension
	  ▪ Word finding

Codes associated with ictal experience only	Codes primarily associated with ictal experience
▪ Slurred, mumbled • Medication management • Money management • Problem solving • Read Write: ▪ Read\Visual disturbances	• Memory\Recall of attacks • Read Write: ▪ Read\Concentrate ▪ Write: ▪ Assistive writing ▪ Technology
Physical	
• Ambulation\Immobility • Basic self-care: ▪ Grooming ▪ Toileting	• Ambulation\Head-limb movements • Basic self-care: ▪ Bathing ▪ Dressing ▪ Eat drink • Fine motor • Lift carry • Mobility Transport: ▪ Driving a car\Medication prevents driving ▪ Public transportation ▪ Travel • Sleep impacts
Psychosocial	
• Coping\Maintaining	• Emotion States: ▪ Grief ▪ Other positive thoughts • Feeling heard\Healthcare providers • Pushing through: ▪ Care for others ▪ Desire to live life ▪ Maintain self-image ▪ No choice-no other alternative • Work\Work for pay\Working through attacks
Symptoms	
• Mental-Foggy or Clear: ▪ Brain not working, migraine brain ▪ Confusion ▪ Spaced out • Sensory disturbance: ▪ Eye symptoms ▪ Other ▪ Taste or smell symptoms ▪ Yawning	• Clumsiness • GI-Other • Sensitivity\Touch • Sensory disturbance: ▪ Skin sensations ▪ Tinnitus, aural disturbances • Weakness

For 8 codes, the number of participants discussing the concept in the context of interictal experience was substantively greater than the number of participants discussing it in the context of ictal experience (see Table 17). All of these concepts fell into the psychosocial domain and encompassed principally social interactions (e.g., interpersonal relations, civic roles) or general well-being (e.g., stigma, life satisfaction and meaning).

Table 17. Codes Associated Primarily with Interictal Experiences

Code	Interictal (# interviews)	Ictal (# interviews)	Difference (# interviews)
Psychosocial\Life satisfaction and meaning	16	4	12

Code	Interictal (# interviews)	Ictal (# interviews)	Difference (# interviews)
Psychosocial\Stigma	11	4	7
Psychosocial\Intimate relations	12	6	6
Psychosocial\Social Community Civic roles\Civic roles-events	11	5	6
Psychosocial\Well-being\Enjoy life	12	6	6
Psychosocial\Social Community Civic roles\Community life	7	2	5
Psychosocial\Interpersonal relations	21	17	4
Psychosocial\Social support-isolation	15	11	4

As shown in Table 18, there were 25 codes that demonstrated both high frequency across cases (i.e., appearing in 15 or more cases, or roughly 50% or more of the sample) as well as a very large difference (i.e., 12 or more cases, or roughly 40% or more of the sample) between ictal and interictal reference rates. These codes included the hallmark migraine symptoms of pain, nausea, mental acuity, and sensory sensitivities or disturbances, as well as a variety of core functioning concepts related to mobility and cognition. These 24 codes also included two major methods of managing migraine: pushing through and cocooning.

Table 18. Codes Showing High Frequency and Large Difference in Ictal/Interictal Experiences

Code	Interictal (# interviews)	Ictal (# interviews)	Difference (# interviews)
Symptoms\Sensory disturbance	5	29	24
Cognitive\Language	5	27	22
Symptoms\Sensory disturbance\Visual disturbances	3	23	20
Cognitive\Concentrate-Focus	10	28	18
Symptoms\GI-Nausea	9	26	17
Symptoms\Mental-Foggy or Clear	12	29	17
Symptoms\Pain-head and face	15	31	16
Physical\Mobility Transport\Driving a car	6	21	15
Symptoms\Pain-other	8	23	15
Cognitive\Concentrate-Focus\Divided attention	3	17	14
Cognitive\Memory	9	23	14
Cognitive\Memory\Memory free recall	4	18	14
Cognitive\Read Write	4	18	14
Physical\Ambulation	11	25	14
Physical\Mobility Transport	10	24	14
Symptoms\Dizziness	3	17	14
Cognitive\Info Processing\Reasoning	4	17	13
Psychosocial\Coping\Cocooning	14	27	13
Psychosocial\Pushing through	10	23	13
Symptoms\Mental-Foggy or Clear\Brain fog	6	19	13
Symptoms\Sensitivity\Sound	15	28	13
Physical\Housekeeping	4	16	12
Psychosocial\Emotion States\Anger-Frustration	7	19	12

Code	Interictal (# interviews)	Ictal (# interviews)	Difference (# interviews)
Psychosocial\Work\Work for pay\Productivity-performance at work	4	16	12
Symptoms\Tension-Stiffness	3	15	12

3.5. CONCEPTS IN MIGRAINE

Participants described the broad impact of migraine through a variety of terms, phrases, and analogies that illustrated the profound range of ways that migraine burdens, disrupts, or redirects life. Some participants emphasized ways in which "*migraine has changed the whole course of my life*" (2693) and were skeptical that they would ever be cured. Other participants focused on their desire to "*get my life back*" (2711) even when that simply meant being able to "*pretty well count on feeling well enough to follow through*" on planned activities (2711), or as another participant described it: have a life that is "*a little more bearable*" (2940). Other participants pointed to specific disabling experiences, such as one participant who said, "*for, like, the day before the migraine, I am a useless pile of overwhelmed crying jam*" (2830), and another who described times when "*I haven't left my home for three days, and I'm still in pain after taking all the medication*" (2909). Finally, many participants used epithets and expletives to describe how much they disliked living with migraine. For example, one participant commented, "*You spend the whole day in bed, and then you feel hungover the next day. You're just like, well, that's [expletive redacted]*" (2850). However, many participants also described times when they pushed through their migraine attack to prevent disruptions to their life or the lives of others. The practice of pushing through hinged on how important specific activities were in the context of the individual's day-to-day life, the severity of a given attack, and whether the act of pushing through might itself contribute to an exacerbation of symptoms.

Although all participants described migraine symptoms as unpleasant and referred to the impacts of migraine in negative terms, some also noted that adaptation and attitude could result in a better quality of life within the constraints of a life with migraine. For example, one participant commented, "*I try to keep what I'll call my head on straight, and I try to remain – you know. I like being a realist, but I try to keep a positive kind of spin. Like, I ask myself, instead of "what can't I do," what can I do?*" (2709). This participant was retired and acknowledged that this left them in a better position to create a lifestyle that accommodated migraine. Other retired participants echoed that sentiment, as did participants who had started their own businesses (e.g., 2689, 2640) or who had found humor in their situation, like the participant who created personalities for their migraines named Hal, Suzanne, and Felicia (3005). By creating these personalities, this participant found an effective way to make sense of their situation as well as to communicate quickly and effectively with others about migraine severity, which made life easier. Finally, numerous participants reflected on how much easier it would be to live with migraine in a society that was better informed and more understanding of chronic illness. As one participant commented, "*But in a more tangible sense, I think people with disabilities and with migraine, which is pretty invisible, are somewhat punished for not fitting into the mold of, like, being able to be in a bright 200-person classroom or pump out the productivity that I'm being asked for with jobs.*

And so I think just lessening some of the expectations around productivity in general in society would be a huge help to folks with disabilities in general" (2691).

In the sections that follow, results of the coding and analysis of interview participant perspectives on symptoms of migraine and the impacts migraine has on life are presented in detail.

3.5.1. Symptoms of Migraine

Interviews confirmed the prevalence and impact of migraine symptoms already described in the literature. A summary of participant perspectives on migraine symptoms is provided in Table 19.

Although symptoms are described as separate concepts in Table 19, the interviews demonstrated that participants experience migraine attacks as variable combinations of symptoms. The way that symptoms combined and compounded each other during an attack in turn affected both perception of individual symptoms and of the attack as a whole. For example, pain could be exacerbated by sound sensitivity or dizziness could be worsened by pain, and attacks with a multitude of symptoms were generally described as more severe than attacks with only a few symptoms. Similarly, impairment of functioning was often the result of various symptoms and participants often emphasized that head pain was not the only important or disabling aspect of migraine. For example, one participant recounted, "*Sometimes I will even have the head painless migraines where I'll go into an attack and I can – it'll last however long it wants to last, and I'll get either minor to no head pain, so I can have all the other symptoms…but also not being able to function, whether that be because I was so nauseous that I couldn't go get dinner with my friends, or I was so tired that I couldn't finish my work properly during the day…I feel like it's probably all a combination of things because there is just so many – at least with me – so many symptoms that accompany. It's not just head pain. Yeah, just a combination of everything. It's a triple/quadruple whammy, I feel like.*" (3104)

Impairments resulting from symptom combinations could also be profoundly affected by individualized factors, such as the participant's family or social roles and responsibilities, access to support systems, or ability to respond to a developing migraine attack. For example, a person who has a job and family to care for might describe greater impairment either because (a) they were having a severe migraine attack accompanied by many symptoms or (b) they were having a milder attack with fewer symptoms but had a great many things to do that day. Participant interviews also showed that people with migraine viewed the notion of functional impairment in two ways: impairment could mean either (a) an actual reduced ability to function (e.g., unable to move, slowed reading due to change in mental acuity) or (b) an ability to function that requires enduring exacerbated symptoms or taking risks (e.g., can move normally but must endure increased nausea, can drive a car but concentration impairment makes it riskier). This dichotomy in how impairment occurs was further underscored by participants who no longer worked or whose children were grown: these participants talked about how life with migraine was now easier because they had less responsibility and more flexibility.

Table 19. Summary of Concepts for Symptoms of Migraine

Symptom	Summary	Quotations
Pain in the head or face / Headache	Found in all 31 transcripts, with 287 references coded. Participants described pain that occurred primarily in ictal phases of migraine but may linger during migraine recovery. Several participants had experience with periods of continuous headache lasting weeks, months, or years. Participants described experiencing pain that varied in type, location, and intensity; was unpredictable; and could interfere with functioning. Variations in pain experience could occur during the course of a single attacks, as well as over months or years. Interference from pain ranged from minimal to profound depending on pain severity, frequency, and duration, as well as individualized factors such as lifestyle or roles and responsibilities. Several participants who used Aimovig reported having migraine attacks with no head pain.	• There is pain. Rarely is there significant pain, I would say. It's almost always one-sided, right-hand side. And there's the occasional icepick headache. That hurts. (2672) • I'm on a CGRP, Aimovig, and I noticed I still have the prodromes. I don't have the pain. (2689) • I have some level of head pain every other day, I would say, and have for a long time. … the migraine is concentrated on one side of my head, and it's also in my jaws and my teeth and at the top of my head. (2691) • Like, right now I could feel the throbbing without paying particular attention. But when I say the background, unless, you know, it's like unless you look for something, I don't find it. Like, if I'm out doing something, it doesn't really bother me, but - let's call it if I'm slightly distracted. (2709) • After I started taking Aimovig, where I would just get really nauseous but have no head pain. … It wasn't till later in life that I realized that, hey, this kind of head pain has really shaped my life in a way that I wasn't aware of until I did a little retrospecting on it. And I think it didn't help my marriage. I don't think it helps raising my kids the way I like sometimes. It definitely didn't help my job. (2744) • The pain. Yeah, that's the big thing, is the pain. Yeah. Because I feel like if the pain were less, then things would change, because I wouldn't feel that irritability, I wouldn't feel anxious about things, I wouldn't be as moody, because I'd be able to get up and just do things. (2882) • I feel pressure, but, like, it feels like - the best thing I would say, it's like, you know these, like, a fist or, like, a helmet, or something that's, like, squeezing my head, trying to crush it. … So when it's severe, it always be flames. Like, it feels like my head is burning. And I have pressure in my ears, pressure in my eyes. I'm sensitive to everything around me. And so the crushing skull I told you about, like, as if my skull is being crushed. But when the headache is mild, I don't get the flames. I get pressure in my ears, but I don't get these intense flames. (2913) • A migraine, you definitely have throbbing on the one side, and it varies on what side the headache's going to be in. It could be on the left for a month and then on the right for two months, so it all is different. (3013) • I wake up to a splitting headache or fear of one. It's one of the two always. (3214)
Change in mental acuity	Found in 30 transcripts, with 253 references coded. All 30 participants referenced mental acuity changes in ictal phases of migraine,	**Brain Fog** • I feel like my brain is still like - it's foggy but I'm not tired, if that makes sense. (2798) • I don't know how to describe it. You're kind of in a fog. … And then, like I said, I also have the brain fog from medicines, so there is that. (2813)

Symptom	Summary	Quotations
	and 13 participants also reported symptoms during interictal periods. In the remaining interview (2940), the participant described cognitive impairments without explicitly mentioning a change in mental acuity. Changes in mental acuity were challenging for participants to describe. Participants often used descriptive metaphors or described resulting changes in function. The most common description was brain fog (n=21), followed by slowed or delayed thinking (n=12), and feeling less sharp or clear than usual (n=9, all males). Other descriptions included 'my brain is not working' (n=6), feeling stupid or less smart during interictal periods (n=6), and feeling spaced out (n=2) or confused (n=1). Mental acuity symptoms were associated with all forms of cognitive functioning impacts experienced by participants and were also linked to a variety of psychosocial impacts. Participants acknowledged that mental acuity changes could be affected by medications they used to treat their migraine or by other factors, such as level of fatigue or normal aging. Finally, some participants believed repeated attacks over many years had created permanent cognitive impairment.	• Well, with the brain fog, it's a question of does stuff start to make sense and how easy it is for me to understand things. I've had brain fog so severe that I've actually sat at my computer when I've been working, trying to do something that I've done a hundred times before and looking and it and going, "I have no idea what I'm supposed to be doing here. (2997) • I get brain fog more. I feel like I'm more scatterbrained. (3104) **Slowed Thinking** • Just in general, I just feel slower. Like, everything feels like it takes more effort and has a bigger cognitive load than it should, if that makes sense. (2915) • I just get - like, feel like you're getting slower. That one I don't like. I'm like, my brain wants to go faster, and it's like, okay, it's not really doing it. (3018) • My brain just feels slow. (3248) **Not as Sharp or Clear** • I wish that I could have, like, my same clarity. I do feel dumber now, so I definitely wish I could be sharper back like I was before. (2692) • You know, it's just, you're not as mentally sharp, you don't have the acuity (2797) • My head's not clear. It's almost like thinking is hard. (3214) **Other Descriptions** • Well, the cognitive impairment. That seems to be - some days I'm less stupid now, but that's one of them that I still experience. I'm never as smart as I used to be, let's put it that way. (2689) • My brain is just not okay (2850) • I also felt like, kind of like I wasn't even there, because there was no pain, but I was, like, dead on the inside. I don't know how to explain it. I have that feeling a lot. Like, phased-out feeling. (2909) • If my brain's not working properly, I might as well not try and make it do anything. (3104)

Symptom	Summary	Quotations
Nausea	Found in 28 transcripts, with 139 references coded. 26 participants described ictal nausea and 9 reported nausea during interictal periods. Nausea that progressed into vomiting was only reported during ictal phases and interictal nausea was described as manageable because it was mild or because the participant had grown accustomed to it. Participants described nausea ranging from mild stomach discomfort to severe nausea with vomiting. Participants associated nausea with dizziness, sensitivity to motion or smell, and the use of migraine medication. Impacts from nausea included distress, anxiety, and impairment of activities and daily functioning. Participants had mixed experiences with medication to control nausea and effective treatment was a clear priority for those who experienced nausea severe enough to cause distress or loss of function.	• So, when I'm in a migraine attack, I don't know, I'll throw up three, four times a day, and it's just, it's awful. It's just constant. I can't keep anything down, and then I get dehydrated and that just makes my migraine even worse. (2798) • I think the primary focus that I have as far as symptom remedy is usually just nausea, because once I get nausea, that's the one that kind of shuts everything down. Like, when I'm nauseous, I don't really feel capable of doing anything because I feel like if I'm going to throw up at any point in time, you obviously can't leave the house, you can't stray too far from where you would need to be if you were throwing up. And so, I feel like the key thing would be if I can find the perfect remedy for that, it would be a little bit easier to function normally, even with migraines constantly. (3022) • And nausea is like – you know, you can't do anything for nausea. It's the worst feeling. And since then, I think nausea has always been the – I've always been sort of anxious to get nauseous with migraines because you can't take anything, or there's nothing really that works for it. (2830) • That's the only migraine that took me to the hospital and that was because I couldn't stop vomiting, not because of the pain. I can deal with the pain. I can deal with pain that would put other people into the hospital. I didn't go to the hospital, the emergency room, with those three migraines because of the pain, I went because I couldn't control the vomiting. (3184) • Sometimes I'll get nausea. That's usually in just like the more extreme cases. (3022)
Sensitivity to sensory stimuli	Found in 31 transcripts, with 433 references coded. Participants reported sensitivity to: • Light, 30 transcripts • Sound, 29 transcripts • Smell, 14 transcripts • Touch, 11 transcripts • Other sensitivities, 11 transcripts	**As an ictal symptom** • I'm very susceptible to motion sickness, particularly when I'm in the middle of an attack. So that affects if I want to go anywhere. (2689) • It's more my clothing. I have to change – sometimes I'll be wearing something and I'll have to change into something really loose, because my clothes feel like they're touching my skin too closely. (2692) • If I'm around somebody that's talking very loud or I'm smelling somebody's food or cologne or perfume, it can intensify from there. (2703)

Symptom	Summary	Quotations
	Other sensitivities included motion, room temperature, and weather conditions. All 31 participants reported experiencing at least one form of sensitivity during ictal phases of migraine, and 24 participants also reported experiencing sensitivity during interictal phases. Sensitivity to light and sound were the most common forms of sensitivity reported in both ictal and interictal migraine phases. Sensory sensitivities also varied in intensity from mild to severe both within individual attacks and across different attacks. Some participants talked about sensitivities together, essentially as a single symptom of sensitivity to any sensory stimuli. Others discussed them separately, for example because they were migraine triggers, occurred in different phases, did not occur in all attacks, or resulted in exacerbations of other migraine symptoms. Light and sound, for instance, was described as triggering or worsening pain, while smell sensitivity could trigger or worsen nausea. Sensory sensitivity affected functioning in all domains by affecting the environments, activities, and interactions that participants could tolerate. Extreme sensitivity could be disabling, prompting	• If it's a rainy day, it could affect my migraine. … I think I have a sensitivity to the barometer, to changes in the barometer, because I seem to feel worse when it's raining than when it's not raining. (2711) • I know this sounds bizarre because we're always around people and noise – it feels physical. The noises just – it almost makes my skin feel too tight. But it feels both like noises are too loud and like they are too close in my head, and like they're distorted. (2830) • And I get super sensitive to sun, to light, to even movement. Like, I just – I don't move, I don't want anyone around me to move, because it just makes me more dizzy. (2913) • The one that bothers me the most is the smell, the sensitivity to smell. And that's the only one I can't plug up, cover up, or hide, to prevent or to kind of taper down. So, that's the one. And you can't escape smells. (2940) • Light, sound, movement occasionally. Cannot absolutely bear to have somebody touch me. Even the lightest touch could feel like just somebody smacking you. Occasionally even just like the touching of fabrics. (2997) • So, I just start off photosensitive. It's that when I start getting an actual migraine attack, everything starts getting amplified. I get even more photosensitive and I get even more queasy. … And temperature, very, very sensitive. And I can't have a breeze blowing on me because then it will – it hurts. (3184) **As an interictal symptom** • There's always – most of the time, there's some minor symptom there, whether it's minor sensitivity to light or sound, that's almost always there. (2672) • Pretty much every day. Like, me getting annoyed by looking at the light. It's not even a blinking light. It's always there. Just looking at that – waking up first thing in the morning and looking at that and getting annoyed and irritated and feeling that pain in the eye and the forehead. I have it all the time. (2909) • I'm very sensitive to smells. Like, I can smell stuff my husband doesn't smell. I get bothered by smells he can't even smell at all. (2913) **As a migraine trigger** • I'm super sensitive, sometimes even to touch, with migraines, but with the light and sound especially. Like, sometimes I can be having a pretty good day and not in pain at all, and it's a very quick shock, almost, when there are very loud noises or a light catches me in a certain way. (2691) • I can't stand being around anything perfumy or chemically smelling. That will give me a migraine. (2711)

Symptom	Summary	Quotations
	participants to self-isolate and cease functioning. These impairments in turn contributed to anxiety and a reluctance to make plans or commitments.	• I still have not managed to eliminate the single trigger that affects my migraines, and that is drops in barometric pressure. If there is what a weatherman would normally call a slow-moving low pressure cell, 100%, I will get a migraine. (2997) • One of the reasons I'm looking for getting employment at home - part-time, remote work - is that I can control the lighting here. I don't have any lights here that will trigger my migraine. (3184)
Dizziness or vertigo	Found in 17 transcripts, with 68 references coded. All 17 participants reported experiencing dizziness symptoms in ictal phases. 3 participants reported interictal dizziness but described it as milder and less incapacitating. Some participants distinguished between dizziness and vertigo, but others used the terms interchangeably. Dizziness/vertigo was also described as loss of balance or lightheadedness. Dizziness/vertigo resulted in substantial impairment and disability, including loss of basic mobility, requiring assistive devices or help from other people, and having to avoid specific motions or movements. Some participants also described dizziness/vertigo as more bothersome than other symptoms because treatment did not improve it and no participant had identified effective coping strategies other than ceasing to move around (e.g., 2709, 2850, 2940, 3104).	• While I consider migraine to be very disabling, vertigo is a situation in which I feel almost incapacitated. … sometimes it'll start off I'm dizzy and then it'll get worse. Sometimes it starts off worse than other attacks, but usually I'm dizzy, and also the vertigo comes later. (2691) • I'm dizzy, I'm lightheaded, I can't even get up. If I try to get up, I'm going to go back down. (2813) • I mean, the dizziness kind of comes and goes all the time. Like, I feel a little dizzy right now, but it's not so much that it affects my ability to go about my day. I guess it's kind of like the dull headache that just sort of is there. … Honestly, the dizziness [is most bothersome]. Even though it's usually not as severe as the headache, it's harder to treat. You know, like, a headache you can throw pain medicine at and eventually you can get rid of it, but dizziness is a lot harder to treat with acute medication. … So yeah, the dizziness is worse. Even though the pain is usually more intense, it seems. (2850) • I also get really bad vertigo. I get very dizzy spells, I feel very lightheaded. (3104)
Sensory change or disturbance	Found in 29 transcripts, with 98 references coded.	• I'd have the eye watering, the yawning. (2689) • I get this ringing in my ear like the swooshing of the ocean when I'm beginning to get one (2703)

Symptom	Summary	Quotations
	All 29 participants reported experiencing sensory symptoms in ictal periods, especially in terms of aura and prodrome, but a few participants (n=5) also experienced them during interictal periods. Participants reported experiences with visual disturbances (n=24), skin sensations such as numbness or tingling (n=10), tinnitus (n=4), changes in taste or smell (n=2), and unexplained yawning or eye symptoms such as twitching or watering (n=3). A few sensory disturbances were unique to one individual, such as one person who experienced a sensation of electrical shocks (2703) or another who experienced hand tremors during ictal phases (3018).	• I lose my peripheral [vision] pretty quick. My vision gets foggy. I'll think my glasses are dirty and I'll clean them, and still my vision is still foggy. (2744) • That's where aura comes in. So it may be – I have occasionally what I call "spiking," and that can be anywhere from a needle prick to it feels like somebody's hitting me with a railroad spike – that severe. So it could be that. It could be the tingling in the face, yawning. (2797) • The squigglies. And when it's really bad, the tunnel vision will close in and sometimes it'll just black out, but it only blacks out for a second. It's not black for a long time. And then I'll get the pinpoints of light. So yeah, visually, it's bad. (2798) • And sometimes, I get like this weird taste in my mouth of whether it's metal or sometimes it feels like I can almost taste like sweat. It's just very weird. This really strange taste in my mouth. And I've noticed that that kind of pre – I forgot what it's called, the pre-migraine symptom. (2915) • Occasionally I'll have what people call the migraine bug hallucination, which is like you think you see a bug out of the corner of your eye. I've talked to other migraine people and they say, "Oh yeah, that happens to me too." So, you'll think you'll see a big fat bug out of the corner of your eye, and when you look, there's nothing there. (2997)
Fatigue or changes in level of energy	Found in 23 transcripts, with 69 references coded. 17 participants described ictal fatigue and 11 described interictal fatigue. Participants associated fatigue during headache and post-headache with pain, weakness, and mental fogginess, as well as physical tiredness or sleepiness. Post-headache fatigue could last for hours or days and could also depend on the duration of an attack, the severity of	**Ictal fatigue** • You're really just feeling like you're not a functioning human being, like everything is an effort. Like left foot, right foot, left foot, right foot. The fatigue I remember was just incredible. (2997) • I'm either way fatigued and need to go to bed. … It's kind of like after you've been really sick, you've gotten over what you were sick with, but now you have to do recovery. You still have to spend an extra day or two in bed to let your body recover enough to actually be up to snuff. (3184) • I sit at my computer and it's like – it's not that I'm not motivated. I guess lethargic. So I'm certainly much less productive and kind of ambivalent about a lot of things. (2689) • I don't know even know how to – when you have all that sound sensitivity, and especially if you take an Imitrex in the middle of the day, and keeping your energy up enough to do the work that you have to do, that by the time you get – by the time I got home, I was so tired. (2830) • And then, when you get them a lot of days in a row, the recovery, the fatigue, what they do to wipe out my body. (3214)

Symptom	Summary	Quotations
	symptoms, and other individualized factors (e.g., work and lifestyle, decisions about pushing through attacks, etc.). A few participants linked their fatigue to medication taken during the attack, while others were unsure whether their fatigue was due to migraine or caused by medication.	**Interictal Fatigue** • I feel like the only thing I want to do is just stay in bed and sleep. And it's really hard to motivate myself as well – like, to tell myself, "No, today is a shiny day. Let's get out the bed and do stuff." It's really difficult for me to do that. So yeah, between headaches I just want to sleep. It feels like my body – it feels like I hiked a mountain, like, I climbed a mountain, and I just want to sleep, if that makes sense. (2913) • Like I said, the symptoms have started to happen in between migraines. Fatigue is one I didn't mention, sorry. I also have a lot of exhaustion, even when I'm not in migraine, and that could just be chronic pain. (3005)
GI symptoms other than nausea	Found in 6 transcripts, with 18 references overall. Several participants described gastrointestinal symptoms such as gastroparesis, constipation, or diarrhea. These symptoms occurred in both ictal and interictal periods.	• Gastroparesis right now, where my digestion tract is just not moving, which is normal for me during an attack, but it's happening outside of attacks. (3005) • There can be some digestive upset. Sometimes, there's some diarrhea, just to be very blunt about it. Sometimes, there is also just having to pee like every 15 minutes. So, there's that on the digestive end. (2997) • There for a while I was using MiraLAX every single day, drinking MiraLAX every single day just to get things kind of going because sometimes – and that also affects me. And it's not so much diarrhea unless it's like something bad that I ate, but I definitely lean more towards the stopped up side. (3104)
Change in appetite	Found in 12 transcripts, with 36 references coded. Participants reported symptoms of increase, decrease, or loss of appetite or thirst, as well as food cravings. These symptoms occurred during both ictal and interictal periods. Some participants attributed appetite loss to nausea or gastroparesis. A few participants were unsure whether appetite symptoms were related to migraine or to medications.	• I'll get really hungry for no reason. I mean, literally, I'll eat dinner and then I'll just be hungry again five minutes afterwards. It's like the body's kind of prepping itself, storing food for when you will be unable to get up from bed and eat. So, it's kind of an increased appetite. (2997) • I will have bouts of time where I physically can't eat, like I'll get very nauseous, I lose all my appetite. Even if I do eat something, I feel full within a few bites. Sort of that thing where – and that could be either related to migraine or that could be the medication that I'm on. I'm not exactly sure. I'm still trying to figure that out. (3104) • Now, the only time I crave donuts and pancakes is when I'm about to have a migraine. And it's sort of like, okay, so I know that's a clue on a migraine. (3184) • [During a migraine] I usually don't have much of an appetite anymore. I can't imagine going through the process of actually preparing food, and then the mechanics of eating it. It's just probably the least – it's so unappealing that it's never even occurred to me to try to eat. (3225)
Changes in sleep	Found in 8 transcripts, with 12 references coded.	• I can fall asleep for a good two hours and think I slept for six, and I wake up and look at the clock and it's only been two hours. And then I'll fall back asleep, and then I'll wake up again, and then I fall

Symptom	Summary	Quotations
	Participants described a variety of symptoms such as insomnia, restless sleep, and sleepiness. Participants also described sleep interference when awoken by migraine symptoms. Sleep symptoms lingered into interictal periods because sleep habits were disrupted.	back asleep. So I definitely it's attributed to the migraines because I am tired and I don't get enough sleep. I'm lucky if I get maybe four or five total hours of sleep. (2703) • Sometimes, I do feel sleepy with migraines (2915) • I started sleeping terribly. I used to never have problems with sleep and I still do now. I take melatonin every single night just to make sure. Because I would go to sleep and then I would wake up and be in pain or I would wake up and feel nauseous or have a hot flash or my face was tingly or whatever, and I could never stay asleep during the night. (3104) • Most of the time, if I'm going to have a migraine day, I wake up kind of in the middle of the night with it, like at 4 am, and then that's kind of the beginning of, you know, that migraine day. (3233)
Change in mood	Found in 18 transcripts, with 52 references coded. Participants reported mood changes during ictal phases that involved emotions such as anxiety, depression, anger or frustration, and irritability. Some participants described pre-headache mood changes as abrupt or unexplained and they were not always aware that the mood change signaled an upcoming attack. A few participants also reported experiencing depression as a mood change during post-headache or interictal periods. All reported changes in mood were shifts to a more negative mood. This included rapid shifts from positive to negative mood and amplification of an existing negative mood. Discussion of mood change symptoms often included references to identity. For example, some participants described their mood changes as feeling and acting like a completely different	• Because it affects your mood, it affects – I try so hard to hide it, but you get frustrated. You don't feel as – I don't want to say you don't feel as loving, but you feel less tolerant or more frustrated or something. And you know in your head that it's chemical, kind of. You know, it's, my brain isn't firing the way it should, kind of thing. It's not me. And I keep telling myself that over and over. But you still have the feelings, but you just try to understand that it's chemical, it's not real, if that makes any sense. So that's a lot. Yeah, that's huge. (2689) • Irritability, get angry, frustrated. Almost a sense of doom. … Most of them, I experience before the attack and during. If it's – I'll use a moderate attack. I get this feeling of like the sense of doom with the bad ones, like the 8 or the 9s. (2693) • I feel guilty that I'm yelling at someone or, you know. Yeah, because I've always, always been very happy-go-lucky, you know, but not with migraines. It's just kind of changed me in that aspect. (2882) • And overall my mood depresses versus elevates. I start to think about what if I died from this. It gets to that point. So, it's a very negative headspace, I think, during a migraine. (2997) • I'd say anxiety can happen in the prodrome or a panic attack can be triggered, or maybe not quite a full panic attack, but definitely heightened anxiety. … I definitely have felt anxiety spikes and, like I said, anger or irritability that's not my nature normally, my personality. And then the depression in the postdrome. (3005) • It can intensify how you're feeling, so if you're already a little sad, it'll make it, like, you're more sad. Very seldom that I get too angry, but it can cause me to get angry at times." (3018) • It definitely makes me more irritable and less patient with everything around me, like people or objects or noise. So, I feel like it makes me more irritable as a person because I'll start to have that slow onset that I'm not really realizing I'm starting to get a migraine and then I'm all of a sudden kind of switching mood. (3022)

Symptom	Summary	Quotations
	person from who they normally are. These experiences then contributed to feelings of guilt or frustration.	• I get another type of migraine where I just suddenly, out of nowhere, I'm talking to you like this and I'm talking about successes and how I did great here, there, and yonder, and all of a sudden, I'm just bawling my eyes out and depressed. (3184)
Pain in other areas of the body	Found in 24 transcripts, with 94 references coded; this code also includes references to pain when the location was not specified. Participants described experiencing pain in other areas of the body, including the neck, back, and limbs. Participants usually described these symptoms during ictal periods (n-23), but some also reported interictal experiences (n-8).	• Sometimes when it gets really bad - and this is not all the time but when it does get really bad - my hands will hurt at the pressure points here. I'll get sharp pains. (2798) • I would have this horrible head pain, but my neck pain would be worse. (2813) • And then pain that goes all the way down to my thighs and that lasts for a couple of days, just on left side. Like, my left side is awful weird for two days. (2909) • But at the same time, I start feeling pain in my body. Like, it's triggering a physical interaction for some reason. (2913) • I've also experienced pain in the back, in the stomach, in the legs, in the jaw, in the neck. I don't think there's an area of the body that at one point or another hasn't been affected by migraine pain during the time that I've had migraine. (2997)
Muscle tension or stiffness	Found in 17 transcripts, with 37 references coded. Participants described experiencing muscle tension or joint stiffness, typically in the neck, shoulders, and back. Most participants (n=15) reported these symptoms in ictal phases, while 3 reported lingering or interictal tension/stiffness. Some participants thought this tension resulted from bracing against pain during an attack, while others described it as a trigger or an ongoing, interictal experience. Several participants noted that this symptom was least bothersome to them.	• When I'm not having head pain. Just the tension in my neck and shoulders. I have that all the time, but anything that I'm not - like, right now, I'm sitting here and like I said, it's about a 3 but I feel it in the back of my neck that it could be getting worse at some point. (2703) • I still have to get a massage at least every two weeks, otherwise my body starts really stiffening up and hurting and things like that. (2813) • The least bothersome would be the tightness in the neck. That would be the least. It's there, it's noticeable, but it's not like I can't manage it. A heat pack, ice pack, massaging something ball, something. You can kind of work with it. (2940) • I also have - for the more intense, I have a prescription for baclofen which is a muscle relaxer, which helps incredibly. Especially, like I said, sometimes I get very tense in my neck and shoulders just from bracing for pain. (3104)
Muscle weakness	Found in 10 transcripts, with 12 references coded.	• I don't know if it's - my muscles are more weak probably from the migraine and the fatigue and just not being able to really exercise in a while. (2813)

Symptom	Summary	Quotations
	Some participants described feeling weak during or after an attack. Some described this symptom as muscle weakness while others described it as fatigue. Two participants experienced hemiplegic migraines and described weakness or paralysis on one side of the body.	• I'm physically – I feel weak. There's not the strength in my limbs. Things that I can normally open, like a jar or something, I can't open during a migraine. I can't lift as much weight during a migraine. (3184) • Then I feel weak and fatigued like immediately. It's like I weigh 500 pounds. It's a heaviness. (3214) • I get like physically weak. And then basically I stay physically weak until pretty much the end of it, for the most part (3225)
Clumsiness	Found in 6 transcripts, with 11 references coded. Participants referenced clumsiness, such as tripping or dropping objects during attacks. Clumsiness was linked to muscle weakness and balance impairment.	• The migraine makes me clumsy sometimes. I sometimes have clumsiness, muscle weakness. (2813) • It's like if you're reaching for something, you miss it by an inch. If you're walking along, you trip where you've walked there a hundred million times, and you've never tripped there before. … I remember standing at the sink and I was looking at my hand holding the toothbrush and it just fell out of there. And I didn't tell my hand to release it, it just went boop. (2997) • I become a total klutz because of my migraine. … I'm a super klutz. I'll trip over my own feet. I don't have any balance. (3184)

3.5.1.1. Implications Of Symptoms Findings for Measuring Migraine

Currently utilized concepts of interest (COIs) are robustly validated by the findings. Interviews provided clear, spontaneously-offered evidence that participants ascribe importance to the same symptoms that are already widely evaluated in clinical trials, including pain, nausea, photophobia, phonophobia, and aura. The evidence also underscores the desirability of expanding symptoms consistently used in clinical trials to include other concepts, such as mental acuity, osmophobia, sensitivities to weather or to motion, and level of energy or fatigue, as well as an assessment of number of symptom-free days (which may be different than headache-free days).

Change in mental acuity is a central symptom that should be measured. The evidence indicates that change in mental acuity is a widely experienced symptom, most often referred to as “brain fog,” that has uniform characteristics. Further, although participants viewed altered mental acuity as a cause of cognitive impairment, it was not the only perceived cause, thus cognitive impairment may not be exclusively reflective of brain fog. Participants described impairment of concentration, for example, that they linked to pain interference. Some participants also described cognitive effects of migraine that occurred in the absence of symptoms, such as difficulties with memory. These findings support the conclusion that capturing change in mental acuity as a symptom, independent of asking about cognitive function, could be of value in understanding patient experiences with migraine and migraine treatments.

Additional sensory sensitivities may be valuable to measure in order to better understand functional impairments. Sensitivities to weather and to motion perhaps do not, on face value, seem like good concepts for a PROM or for a clinical trial. Weather conditions vary immensely from place to place and the conditions that are problematic for each specific person may not occur regularly throughout the year. Sensitivity to motion, as described by participants, encompassed an inconveniently heterogenous variety of scenarios that ranged from motion that occurs around a person (e.g., a crowd of people, a fast-paced car chase in a movie) to motion sickness (i.e., increased nausea, dizziness, or pain due to body movement, whether self-propelled or in a vehicle). What participants did make uniformly clear is that both weather sensitivity and sensitivity to motion were very bothersome, resulted in substantial and wide-ranging impacts on functioning, and could trigger or worsen migraine symptoms. Including these concepts in a PROM may thus provide value for patients and clinicians alike when evaluating treatments.

Measuring fatigue and level of energy may provide useful information about interictal experiences. Although it is somewhat unclear whether participants experienced reduced energy or fatigue as a symptom or as an impact resulting from other symptoms, changes in level of energy or fatigue were commonplace experiences that also carried through to interictal periods for many people. Capturing data about energy/fatigue may provide an opportunity to improve understanding of the somatic burden of migraine in interictal periods when other symptoms have resolved but people do not yet feel ‘normal.’

Inconsistencies in the way that patients think about impairments may have important implications for PROM item phrasing. The interviews provide considerable, nuanced evidence that the relationship between migraine symptoms and functioning is complex. As noted earlier, impairments were often the result of different combinations of symptoms and were affected by individualized factors, such as level of demand for function during a given time period. Furthermore, although symptoms like severe pain or nausea were universally distressing, the severity of such symptoms did not alone explain varied perceptions of functional impairment. Duration and frequency of symptoms also played central roles. For example, participants with many migraine days per month referred to a constrained life, in which they limited all manner of functioning to fit into the 'good' hours or days they had between attacks and the level of functioning they could maintain during attacks. By contrast, numerous participants described being able to function and simply enduring increased distress from symptoms during attacks.

These observations may have implications for PROM development because they highlight an inconsistency in whether people think of impairment as the *level* of difficulty in undertaking a specific function, the *duration* of experiencing any level of impairment, or the *frequency* of experiencing an impairment. This inconsistency will make item phasing crucial and could potentially affect the validity and specificity of items intended to capture functioning concepts that are subject to these inconsistent perceptions of impairment.

3.5.2. Cognitive Function Domain

Participants described a variety of impairments of cognitive function that occurred primarily during ictal phases of migraine but could linger into the interictal recovery period after symptoms have resolved. Participants who experienced lingering cognitive impairments sometimes attributed them to post-attack fatigue. Some participants noted experiencing some level of cognitive impairment interictally, but a few of these individuals were also unsure whether these impairments could be attributed to migraine or to something else. For example, individual participants sometimes noted that they might be experiencing changes in cognitive function associated with aging or medication use.

Impacts on cognitive function arose due to changes in mental acuity but were also associated with other symptoms (e.g., light and sound sensitivity, pain) that could interfere with cognitive functions even when mental acuity was unchanged. For example, light sensitivity can interfere with someone's ability to read. Similarly, participants reported that severe pain occupied so much of their attention that they could not concentrate on anything else.

Migraine's impact on cognitive function resulted in a variety of associated burdens for participants, including embarrassment, frustration, or anxiety; impairment of other functions or roles, such as work or leisure activities; and experiences of stigma or negative perceptions by other people. However, some participants reported that impairments of cognitive function operated as a "tell," which included other people being able to recognize that a migraine was occurring, thus enabling understanding or accommodation rather than added burden.

Coding and analysis identified 11 overarching concepts related to migraine’s effect on cognitive function. These concepts are described in detail in Table 20. Interviewers also asked participants to comment on their ability to recall specific migraine attacks after a week or two, inquiring about recollection of both symptoms and impacts experienced. Because this topic arose only because interviewers asked about it and was intended solely to inform decisions about PROM recall periods, this topic is treated separately in Section 3.5.3.

Table 20. Summary of Cognitive Functioning Concepts

Cognitive Function	Summary	Quotations
Ability to concentrate	Found in 29 transcripts, with 155 references coded. 28 participants discussed impacts on concentration during ictal phases and 10 referenced impacts in interictal periods. All the participants reported that migraine symptoms negatively affected concentration by • Interfering with cognitive processes or functions necessary for paying attention or sustaining concentration • Dominating thoughts, or causing distraction or interruption of thoughts • Making it easier to feel overwhelmed by any level of demand for attention Some participants did use terms for concentration and mental acuity interchangeably, suggesting that difficulty with concentration is a principal way that people identify mental acuity symptoms. This blurring of symptom and function impairment makes it appealing to see these concepts as identical. However, it is important to note that participants did make a distinction: changed acuity expressed as 'brain fog' was perceived as the cause of multiple cognitive impairments and was not synonymous with concentration. For	**Interference** • I have to really concentrate in short spurts versus doing a project for an hour. I'd have to break it up in 15 minute things so I don't get overwhelmed and too tired. Concentrating is more difficult. Focusing on the task at hand without getting overwhelmed is difficult. (2693) • It makes it difficult to pay attention to things, and depending on the task, how much—You know, if I'm watching a TV program, who cares if I miss the plot? That's what they made the record button for. But depending if I want to do something where my att-, it's like, lately I've wanted to take an artisan bread course and baking course - a professional-level one. But unfortunately, migraine, on different levels, has precluded me from moving forward, because, you know, this is once again a professional-level thing where they're expecting your attention. (2709) • I don't have as much concentration and I can't focus for as long. … I can't focus even long enough to follow a stupid commercial on the TV let alone enjoy a TV show. (3184) **Dominating or distracting attention** • When your head is throbbing, it's really hard to concentrate on anything. It sort of demands your full attention. (2850) • If I can limit the number of background noises, then I can optimize my brain and what I get done, being efficient and effective. So, if I'm not getting all that hearing and conversations I'm trying not to listen to, so I'm not having to spend brainpower not listening to what I'm hearing. And I don't have to spend the brainpower trying to deal with the lights that are flickering over my head trying to give me a freaking migraine, I do better. (3184) • So, it's really the physical symptoms, especially with respect to the throbbing, the pain - well, the throbbing itself, it's like a heartbeat throbbing that spikes the pain and it causes me to cringe, coupled with the nausea, makes it very hard to focus really on anything but the pain. I mean, I could probably muddle through most of the stuff that I have to do. There's no - it's not like a cognitive impediment. I wouldn't say that I become not as intelligent or anything like that. It's just that the pain becomes so severe that it's not worth it. It takes me twice as long to read a sentence between the throbbing and the visual problems, and then I'm not able to process it because so much of my brain is focused on the pain itself. (3225) **Feeling overwhelmed** • Focusing on the task at hand without getting overwhelmed is difficult. The completion of a task can be overwhelming, or like a deadline. … Getting overwhelmed easily is very bothersome. Not being able to focus and concentrate is very bothersome. Not multitasking, bothersome.

Cognitive Function	Summary	Quotations
	example, participants talked about difficulties with memory or word finding that they connected with mental acuity but not with concentration. In addition, concentration was affected by symptoms other than mental acuity, including pain and sensitivities to light or sound. Concentration was also affected by other cognitive impacts from migraine (e.g., impairments of short-term memory) and was referenced as a contributor to other cognitive impairments. For example, impaired concentration could affect a person’s ability to read. Consequences of concentration impairments included • Inability to undertake tasks or activities, or doing them with difficulty • Making errors, having to double-check or re-do things • Requiring assistive methods (e.g., lists) • Impairment of social functioning, including family, social, and work roles • Feelings of frustration, or embarrassment • Impacts on sense of identity/self-worth	Interviewer: And could you please tell me a little bit about why you choose these things as being bothersome? 2693: Well, I guess because it's hard to think about the old me and what I was able to do versus what I'm able to do now. I find that very frustrating that I'm not the same person I was before I fell. And it's taxing. Life seems to be more taxing now. (2693) • Interviewer: Do you find that your migraine affects your ability to focus or concentrate on what you're doing? 2798: Oh yeah. Especially now that I'm in lingerie to where if I have to help like three or four people with bra fits and say I have someone who's a 34D and a 34DD, and across the hall, they're a 32DDD and a 32C, and I've just measured all of them. And now I have to go in the back and I have to go pull things for them and make sure I have four bras for each of them and go deliver them to the right rooms. … It's a lot to keep track of, you know? But most people should be able to figure that out. And, I do. Like, I have to function. I have to figure out a way. But I get away with it by trying to be endearing. By like, "oh, sorry. I'm sorry I sent you the wrong one. Here you go. Oh, I grabbed you the wrong one, here you go. Blah, blah, blah. Now, we're having a party, woo hoo." Just try to find ways to compensate, you know? It's stressful and I want to be perfect all the time, and I don't like not being able to pull it off. And it's my brain that's not working. (2798)
Language	Found in 28 transcripts, with 235 references coded. The overwhelming majority of participants described language impacts that occurred in ictal phases (n=27) and	**Ability to speak** • You're talking to a new client and your words come out all jumbled up or you just stop talking, and they don't know what's going on. So that's one of the most embarrassing ones. (2689) • Sometimes I combine words that don't make sense. I'll put one word together with another part of a word and it comes out and nobody knows what I'm talking about. (2693)

Cognitive Function	Summary	Quotations
	the small number of participants (n=5) who described interictal language effects could not be sure this was due to migraine, rather than factors like age. The most common language impairments were • Impaired ability to speak (n=22), a concept that included avoidance of speaking as well as experiences like slurred, slowed or jumbled speech • Difficulty with word finding or word recall (n=18) • Difficulty with numbers or math (n=8) • Difficulty expressing thoughts (n=5), which was closely related to word finding • Difficulty comprehending language (n=4) Participants sometimes connected language impacts to level of mental acuity, but this was not true for speech. Speech impacts, such as slurring or jumbling words, were largely described as an independent phenomenon, not directly linked to specific symptoms or to other impairments of function. The second most-common language impact, word finding, was typically described as related to mental acuity and to memory impairments.	• For me, it's really mixing up the letters and syllables in particular, where I'm completely mispronouncing. (2798) • I'm slurring and it won't come out. (2813) • If it's a severe migraine, I'll start stumbling over my words or I'll start stuttering (3022) • It's almost like I have peanut butter in my mouth to where words - it's like molasses that's coming out of my mouth. I feel like I'm physically talking slow, when in reality even somebody who knows me well may not even spot a difference. But to me, it's like my brain is working overtime just to physically form the words, structurally and grammatically, the sentences. (3104) • And I don't talk. There are times when I just won't participate in the conversation, because I know I'm going to have problems. (2689) • I recorded myself talking because I really wanted to go back and see if it was actually physically noticeable, and it really wasn't. And that to me, was proof enough that a lot of this may be psychological. I hate the phrase it's all in your head. … but as far as my speech goes, I was not - like maybe I was talking a bit slower, but I didn't have a slur or I didn't have any sort of speech impediment or anything, so it was just a nice reassurance that no, it's not as bad as you think it is. It feels really bad but that doesn't mean it is really bad. (3104) **Word finding** • When I can't find the word at all. That's the worst. … Nothing. There's nothing there. And no matter how hard I try, it's not going to be there. And how far back I go, how far back I reach, it's not there. It's just not. That is the most concerning to me because where did that word go? (2798) • It feels like having to find one word sort of among a thicket of words in other languages, almost. And you know the word is in there somewhere and you just can't get at it. (2830) • The other thing is in my house, it's a joke with my family because I will misname something in a minute. I will run through every appliance in my home to say something as simple as the microwave or the air fryer. (2940) **Numbers / Math** • I end up doing, unfortunately, fuzzy math, or I use a calculator, even for simple things. And again, I get irritated and annoyed, because, you know, something that used to come like snap to me is like, "Ugh, God, 27 plus 5. What is that?" You know. And this should be [audio cuts out]. This is simple stuff, you know? (2797) • I've looked at columns of figures in the past, and I don't even know what they're trying to tell me, and then the next day when I don't have a migraine, it's boom and we're good to go.

Cognitive Function	Summary	Quotations
	Difficulties with language contributed to other burdens described by participants. These included • Slowed general functioning or lost productivity • Concerns about being judged by others, including judgment by health care providers • Making errors, or having to double-check or re-do tasks • Feelings of embarrassment, irritability, or frustration • Interference with sense of identity, or having the sense that one's identity has changed In one notable exception, participant 3104 described recording themselves speaking during an attack and then finding little evidence of their perceived speech difficulties in the recording.	Numbers would be very challenging because they're a very abstract concept and I think that's one of the first things a migraine - or at least my migraines - drop is that those abstract concepts, you're not going to have them. (2997) **Expression** • Having difficulty expressing myself. I mean, it's - I'm talking to a doctor, I'm trying to explain why I'm not feeling good, right? Because of the migraine attack, I can't even come up with the words to describe the migraine attack that I'm experiencing. It's kind of ironic. And yeah, because it's one of those symptoms that, even at mild attacks, it's there. So, it seems to have the biggest impact to everyday life. (2672) • The speech stuff in particular, when I'm communicating, especially at work, it can make it difficult for me to get my point across. … I prefer to communicate in writing, because I feel like it communicates better what I am thinking or intend to say when my speech is all messed up because of a migraine. (2691) **Comprehension** • I either can't understand what you're saying, or I can't get any words out. And that was very troublesome, and still is. And until I really explained it so my husband understood it, he'd get very frustrated with me. And I finally explained it, and he said - because he would say, "Why are you staring at me like that?" "It's because I don't know what you're saying. I can't process it." (2689) • Yeah, it's too much. Where I would have been able to do that before. My job was being a [occupational title redacted], so it was really hard. And I didn't have the cognitive abilities to keep doing it. And also government paperwork is like that, where it's just all these words and repeating and stuff like that, that takes a lot of complex thought to figure out what they're really saying. (2813)
Memory	Found in 26 transcripts, with 117 references coded. Most participants referenced memory in ictal migraine phases (n=23) and some referenced interictal effects (n=9). Participants described impairments of both working memory and free recall and	**Free recall** • So I feel like I'm letting people down when I don't follow through with what I say I'm going to do, and that's big for me because I like to remember … now they have this perception of me that I'm forgetful and I can't remember to do something, and I don't want people to think that of me. (2703) • If you had to ask me, well, what bothers you, that kind of bothers me, because I used to have really excellent recall, and now it just doesn't seem. So is that migraine? You know. Is it normal aging? Is it something else yet to be determined? (2709) • Sometimes I feel like my brain is just like mushy, like I can't recall things (2711)

Cognitive Function	Summary	Quotations
	made little distinction between the two. 20 participants described impacts on free recall, or the ability to retrieve information from memory, including • Difficulty recalling information or past events, even when prompted • Remembering more slowly or remembering only after an attack 21 participants described impacts on working memory, or the ability to retain information, including difficulty • Remembering what they have just said or been told • Remembering what they are doing • Learning or forming new memories Some participants were uncertain how much impact on memory to attribute directly to migraine. Other possible origins of memory difficulties included medication side effects or age. Finally, discussion of memory was often intertwined with other concepts, such as brain fog, concentration, and word finding. Consequences of memory impairments included • Slowed or impaired ability to undertake activities that require memory • Worry about negative perception by others and feelings of frustration or embarrassment • Relying on behaviors to support memory function, such as list-making	• I have a PIN to my house, and I use that PIN to my house every day for my deadbolt. And I'll be looking at that, I'll be like, [expletive redacted], I can't remember that four-digit code. (2744) • It just takes longer, I guess, to get to things. You remember them eventually, but your brain is just moving slower. (2850) • Yeah, stuff like that happens often, and it makes me really angry at myself. … I write down everything and leave it in my desk, because otherwise I wouldn't remember. (2913) • The unfortunate side effect of having too many migraines is that it has really jacked up my short term memory. So, I can't recall it right then and there, but I can recall it later on. (2940) • I've actually sat at my computer when I've been working, trying to do something that I've done a hundred times before and looking and it and going, "I have no idea what I'm supposed to be doing here." (2997) • If I'm recalling a specific memory, I don't remember what happened. It's just really hard to recall stuff when I'm in the middle of a migraine. (3022) **Working memory** • Yes. Absolutely. Ask my family. Yes. There's no doubt about it. They get very with frustrated me. "I just told you that. Don't you remember?" "No, I didn't." It makes you – I'm sure it gives the impression that you're not listening to them. But yes, absolutely, positively affects it. (2689) • You know, sometimes I'm, like, going into a room, and then I have no idea why I'm there. (2691) • Sometimes, I do forget. Or, I'll repeat myself. That's something my family tells me, like, "You just said that 10 minutes ago." (2703) • And even remember why am I doing something, or why am I talking about it, or where was I going with this answer, and where did it start from. You know, like I couldn't even remember halfway through what I was explaining to you, why was I doing that. (2711) • My short-term memory has been affected, I feel like, also, especially this last few weeks – like, when I'm migraining a lot, I just won't know where I put something that I just put down. It's kind of disturbing. (3005) • I've always been kind of absent-minded professor, so a little bit of it is just kind of ingrained, but when I'm having a bad migraine – so – so, for example, if I'm lying on the couch and then I know, right, oh, ok, so six hours have gone by or whatever, I need to go take another naproxen or another ondansetron or whatever, right, to manage symptoms, I sometimes will get up, go in the kitchen, pour a glass of water, and then I can't remember like why I – why – like, I know vaguely like I was supposed to take medicine, but I can't remember, like, oh, what – wait -which medicine was I supposed to take? (3233)

Cognitive Function	Summary	Quotations
Information processing & reasoning	Found in 18 transcripts, with 41 references coded. Impairments were experienced primarily during ictal phases of migraine, but a few participants reported experiencing a permanent change in learning or reasoning capacity. Participants discussed impairments of information processing and reasoning, which are functions critical for decision-making and learning, as directly related to mental acuity, ability to concentrate, and memory. Changed mental acuity and impaired memory or concentration made it challenging for people to assemble the information to be processed and complete the complex thinking needed for decision making or learning.	• So maybe I won't make a decision, let's say, as quickly as I - I don't know that's necessarily true, but I won't, you know, make a decision prematurely if I don't feel like making a decision (2709) • As one [migraine attack] would get worse, sort of my cognition and just sort of logical reasoning and functioning does sort of degrade somewhat. (2753) • If you're going to play chess even as a novice chess person, you're looking at two, three moves, or four to five moves, depending on what range you are. Well, if I'm having a migraine, I'm not able to really look at two or three moves ahead. I'm doing good to be looking at one move ahead. (2797) • I feel like I can't choose between a purple marker and a blue marker. Everything overwhelms me. (2830) • But as far as being engaged or interested or applying any kind of thought to exactly what is happening, that is kind of off limits. (3225)
Ability to read	Found in 17 transcripts, with 45 references coded. All these participants described impacts on reading during interictal phases. The 4 participants who referenced reading during interictal phases mentioned its potential to trigger migraine or noted a habit of catching up on reading on migraine-free days. Migraine affected all forms of reading, such as reading for school, work, or pleasure. Participants consistently linked	• With reading, I'll read the same paragraph over and over, or I'll read five pages in, and I don't have the slightest idea what I just read. (2711) • Well, I do love to read, so sometimes I can do it, sometimes I just - I can't. I can stare at the page and can't do it, so yeah. (2882) • I have trouble reading, like, a book as well, [unclear, probably: so both]. But then, yeah, just reading, just using my eyes, focusing, I've been having issues with my eyes during attacks lately a lot. (3005) • Schoolwork is a struggle with trying to read stuff. Like, concentration. So if it's real bad, then I'm reading it seven or eight times, and I'm like, I used to not have to do this. I could read it once and it was in my head, and if the headaches are there, then I'm reading it over and over again, and I'm like, really? (3018) • So, it does impact my ability to kind of absorb the information that I'm reading, so it feels like I'm doing a lot of repetitive – like reading the same sections over and over again, so it takes

Cognitive Function	Summary	Quotations
	reading challenges to concentration, language comprehension, working memory, visual disturbances, and light sensitivity (particularly when using a lighted screen). Consequences of impacts on reading included • Slowed or impaired ability to undertake activities that require reading • Exacerbated pain or light sensitivity	three or four times as long for me to absorb the information because my brain just won't focus on it. (3022) • My vision becomes a little bit blurry, so I have to focus harder to actually read the words that are printed on the page. And at the same time, the heartbeat throb that I get means that I am basically squeezing my eyes shut every time that heartbeat comes, so it's like an ultralong blink. And so, those two things, coupled with general distractors like the pain and the nausea means that it's incredibly hard to read. (3225) • I can't read the words on the screen - not that I can't understand them - but the light sensitivity is terrible. (3248)
Ability to write	Found in 10 transcripts, with 36 references coded. Many participants were able to write during migraine attacks and reported using written notes as a means of supporting function (e.g., writing notes and lists to support memory). Some participants reported preferring written to verbal communication during an attack because it allowed them to gather their thoughts or find the desired words. One participant pointed out that computer apps may provide helpful technological support for writing function, but these are not available in all programs. Impairments of writing were linked to light sensitivity and impairments of language function more broadly, including misspelling or difficulties with sentence grammar.	• Unless I'm unable to look at a screen or write down on a piece of paper, I prefer to communicate in writing, because I feel like it communicates better what I am thinking or intend to say when my speech is all messed up because of a migraine. (2691) • I would say I am a little more forgetful now with the migraines, and I'm trying to like just do some process recalling of - that's why I write sticky notes everywhere, so I don't forget things. And at the end of the week, I'll be like, what didn't I accomplish. That'll go on for next week. And I use calendars and I try and write things down in there as well. (2703) • I hate it when I have to write in front of - like if I'm copying down someone's information and I have to write in front of somebody and they'll spell something out, and I just flat out write down the wrong words or wrong letters. Like I hear you, I just can't compute. I just can't make it work. Or I write down the wrong numbers. And it's numbers and letters. It's not specific for that. But no, I just can't make it work. (2798) • I have actually noticed myself writing not totally backwards, but writing some of my words backwards, if the headache's real bad. … And I didn't start taking note of that until, you know, when you're in healthcare and you're working on electronic stuff, you have to write it in there right, just because, you know, you may have spell check on a few things, but you don't have it when you're in a system program. I mean, no. You gotta write it correctly or they're like, "What's wrong with this patient again?" [laughs] It's like, well, I've come up with some new disease. (3018)

Cognitive Function	Summary	Quotations
	Impairments were also linked to the general disabling effects of pain and nausea.	• So, if I'm typing or something, I completely forget how to spell words. I'm typing something and I think that, I'll look at it, and it looks like gibberish to me, but it's not. Or, not knowing how to structure a sentence. (3104)
Cognitive flexibility, multitasking	Found in 10 transcripts, with 20 references coded. Some participants noted challenges with being cognitively flexible and able to multi-task during ictal phases of migraine. These abilities were linked to mental acuity and impairments of concentration.	• Absolutely. I used to be a great multitasker. No more. That was one of my favorite things. I could do 10 things at once. Now, I'm lucky if I can chew gum and tie my – you know what I mean. (2693) • Definitely. Anything that requires you to go on and off. So when you have multitasking, you're not doing it at the same time. What you're doing is your brain is switching from one task to the other task, one task to the other task, back and forth – the same thing you do when you have multiple people that you're having a conversation with. You're shifting from this person to this person to that person. And migraine, that shifting from one to the other doesn't work. It doesn't work as well. (2797) • I've always been a multitasker … but then I'm thinking too, like, yesterday I was making dinner and I had to melt butter and I put it in the microwave, and then I got sidetracked and had to do something else, came back, turned the microwave on, and realized that I'd already taken the butter out and put it on the counter, so the microwave was just going for no reason. So, you know. So yeah, so maybe sometimes. Most of the time I can still multitask. (2882) • Yeah. Yeah. And I like multitasking. When I'm having a good day, I can do multiple things, and a bad day, it's like, nope, not today. (3018)
Impulse & behavior management	Found in 9 transcripts, with 18 references coded. A few participants described impacts on their ability to manage impulses and reactions that overlapped heavily with related topics such as irritability and acceptance/tolerance. Participants also noted engaging in practices like meditation to help manage their impulses, although these techniques were typically directed at broader needs for stress-management and wellness.	• I try to keep what I'll call my head on straight, and I try to remain – you know. I like being a realist, but I try to keep a positive kind of spin. Like, I ask myself, instead of "what can't I do," what can I do? (2709) • Like, I cannot get humor or irony or satire. Like, that'll happen a lot lately, and I just, like – it's beyond my processing capability. So that's, like – yeah. And emotion regulation can be hard. (3005) • I'll just, out of the blue, oh god, my language turns bluer than ultraviolet. I mean, it's flaming blue. I'm dropping F-bombs and all kinds of other crazy language for no good reason. I'm not angry at anything, but all of a sudden, I'm dropping all kinds of ultraviolet, flaming blue language. (3184)

Cognitive Function	Summary	Quotations
Medication management	Found in 6 transcripts, with 8 references coded. A few participants referenced challenges in deciding how to treat an attack, which may include considering how much medication one has available. A few participants expressed concern about making medication errors during an attack, for themselves or others.	• And with insurance, I only get maybe - I get like 10 pills a month. And when you're diagnosed with chronic daily migraines, you have to rationalize: Is this bad enough for me to take one? Or do I take it later and wait? (2703) • [Related to medication for the participant's father] I was so afraid of making mistakes, even though I know these medications. Everything I checked three times - not that I would be careless to begin with, because these are such important medications, but … I was also in pain, but I couldn't take a chance on myself remembering things properly. (2909) • I have to question my judgment because I know I can't think clearly enough to actually make sound decisions. I'm not even sure, should I use a heating pad or an ice pack, or either one of them. What medications do I need to take? When is it time to take more medications? Did I take this medication? (3184)
Problem solving	Found in 6 transcripts, with 7 references coded. A few participants noted that migraine symptoms and cognitive impairments affected their ability to solve or manage problems.	• [Describing work responsibilities that involve solving staffing management] It's I'm struggling to deal with what I'm going through, the symptoms and whatnot, just to be functional. And then - [occupational description redacted], so dealing with the day to day personality issues that may come up, it's like, "I really don't want to deal with this." (2672) • Because you know, like I said, on the outside some people may not even recognize these sort of things, but on the inside, inside of your brain, you feel like you're losing your mind. … And of course, the more you think about it, the harder it is to come to any sort of solution, I guess if you're looking for a solution. (3104)
Money management	Found in 3 transcripts, with 4 references coded. Most participants avoided financial activity during migraine attacks, but a few participants referenced ictal challenges with handling money.	• I still have to write down checks occasionally, and some people - so I need to really have it - but I end up doing, unfortunately, fuzzy math, or I use a calculator, even for simple things. (2909) • The other thing is during an attack, I can't do basic things like count money, so I always make sure I have a debit card. Like, I can count the small change, but once we start getting higher and higher into the numbers or the bills, my brain gets confused and I can't count it. So, I don't keep a large amount of cash. I don't keep more than 30-40 bucks on me. (2940)

3.5.2.1. Implications of Cognitive Domain Findings for Measuring Migraine

Cognitive impairments are commonplace and burdensome; thus, a patient-centered measure should capture these important experiences. Interview results provided considerable evidence regarding cognitive functioning impairments that are widely experienced and consequential for people with migraine, including impairments of concentration, memory, and speech. In addition to direct consequences, such as making errors or being unable to communicate, these impairments were also associated with psychosocial consequences, such as feelings of embarrassment and reduction or loss of ability to work. To fully capture a patient-centered conceptualization of illness experience, a PROM for migraine must address these important aspects of life with migraine.

Patients' ability to accurately report their experiences may be affected by whether they notice or pay attention to their symptoms; this may create particular challenges for capturing milder symptoms and impairments. Participants also described an interesting dimension of concentration as the ability to distract oneself from symptoms, in which "*noticing*" and "*paying attention*" play a mediating role in symptom experience. If one can focus on something other than symptoms—by getting absorbed in some task or activity, for example—then perception of pain or other symptoms is reduced. Participants talked about being able to get on with life and not *noticing* their migraine symptoms. However, when symptom experience becomes too great, it interferes with concentration: people can pay attention to nothing else and they begin to report cognitive limitations (e.g., participant 3225 who described how their symptoms "*makes it very hard to focus really on anything but the pain. I mean, I could probably muddle through most of the stuff that I have to do. There's no – it's not like a cognitive impediment. I wouldn't say that I become not as intelligent or anything like that. It's just that the pain becomes so severe that it's not worth it*"). This suggests that symptoms can burden cognitive functions without the presence of cognitive symptoms or direct cognitive impairments, such as memory loss or aphasia. These observations suggest that PROM development must consider whether it is important to capture the perceived cause of cognitive impairment and, if so, how to do so concisely. These findings also suggest that "*noticing*" of symptoms could impact study participants ability to accurately report low levels of severity for symptoms.

Perceived impairment of concentration may be confounded by context; therefore, it may be better to ask about concentration in general rather than about specific tasks that require concentration. The perception of severity of concentration impairment and its associated burdens appeared to be contextual in some cases, principally in terms of the perceived challenge of mental tasks, as well as potential risks associated with completing a task in an impaired state and the necessity of doing the task. Driving a vehicle with even mildly impaired concentration is dangerous, for example, while bringing a customer the wrong size garment is not. Similarly, individual participants shared experiences of switching to easier tasks or developing strategies that allowed them to avoid specific cognitive challenges during migraine attacks. For example, one participant said, "*during an attack, I can't do basic things like count money, so I always make sure I have a debit card. Like, I can count the small change, but once we start getting higher and higher into the numbers or the bills, my brain gets confused and I can't count it. So, I don't keep a large amount of cash. I don't keep more than 30-40 bucks on me.*" (2940) These observations suggest that wording of items intended to capture impairment of concentration (or specific burdens that result from this impairment) must either be general—allowing the respondent to decide which specific experiences and functions to consider and how—or take into account these potential nuances.

3.5.3. Recall and Tracking of Migraine Attacks

Interviewers asked participants about their ability to recall attacks, including specific probes about recalling symptoms and impairments. Participants were asked about their ability to recall specific symptoms or impairments after 1-2 weeks and, depending on their answer, were also asked about how long they could recall these details. Additionally, because a few initial participants spontaneously provided opinions about migraine tracking systems, an interview probe was added to ask about the use of apps, daily diaries, or calendars.

Ability to recall attacks. Participants varied in their perceived ability to recall attacks after 1-2 weeks (see Table 21). Many said they could not remember specifics and that experiences tended to "*blur*" or "*blend*" together. This blurring appeared to be more pronounced for participants with frequent attacks. For example, one participant who had transitioned from episodic to chronic migraine said, "*Well, growing up, when I was episodic, I remember them vividly. Like, I can still remember attacks that happened, like, 20 years ago and more. But they happened so seldom, and now they do blend together.*" (3005) Some participants said they could remember attacks clearly, although they also noted they might remember some details and not others. Participants noted they would remember attacks that were unusual for them, such as particularly mild, severe, or long-lasting attacks. Participants also remembered attacks more clearly when there were other events that prompted recall (e.g., a memorable event in their community, a holiday, or having to miss a planned activity). One participant acknowledged that attack recall might be based on extrapolation rather than direct memory: [Recall is] "*Not very challenging. You know, I can either remember or extrapolate that, hey, this was one that was only sort of a two or three, and I used my abortive and it went away within an hour.*" (2753) Multiple participants provided perspectives that fit into more than one of these categories. For example, participant 2691 talked about being able to clearly remember nausea and emotional feelings, but also talked about being able to remember more clearly an attack that lasted for days and one that happened at work that resulted in embarrassment. Finally, participants who kept records of their migraine attacks noted that they would refer to those notes to help them remember.

Use of migraine trackers. Participants reported using varied methods for tracking migraine-related information. Some used purpose-built commercial software products, such as Migraine Monitor or Migraine Buddy; some used office software programs, such as a spreadsheet; some used commercial products intended for general health or fitness tracking; some used paper or virtual calendars, charts, or diaries of their own design; and some used paper forms obtained from health care providers. Most participants said they had tracked their migraines on a consistent basis at one or more points in time, such as right after diagnosis or when their symptoms changed, but there were mixed views on its usefulness. Some participants had learned a great deal from tracking their symptoms and lifestyle factors, permitting them to identify triggers or understand whether medication was effective, while others had not been able to detect any useful patterns.

Some reported long-term, ongoing tracking habits, but this was not common among participants; participants who tracked consistently often noted that it was helpful for self-monitoring their medication use. A few reported that they had never engaged in any consistent tracking. Participants who were not currently tracking their migraines gave various reasons, including difficulty remembering to do it, not feeling well enough to do it during an attack, finding it "*too much of a burden to actually sit there every night and fill it out*" (2915), and not finding it useful because they were not learning anything new. Some participants also linked tracking to negative perspectives: "*It's hard enough living with migraine disease without thinking about it all the time. I find that if I'm tracking every day, it makes everything one dimensional*" (2693). Despite these varied practices and perspectives, all participants noted that they would be willing and able to track migraine symptoms for their health care providers or if they were taking part in a research study. For example, participant 3233 commented, "*If it were for purposes of, you know, a clinical trial where, you know that stuff becomes meaningful, right, because it tracks adverse effects and, you know, all those things, I – you know, I – I would do it. Or, "Do you need to do this for your own – for yourself in order to gauge to see if the medication is working?" No, I don't need to because I have titrated up and down on so many different medications, I can tell if a medication is working. But if you need me to journal or log in my data so that that way you have solid evidence on it, sure, I'll do that.*" (3233)

3.5.3.1. Implications of Recall and Tracking Findings for Measuring Migraine

These findings suggest that most people with migraine can provide a general assessment of their overall experience with migraine over a 1-2 week period. Memory of specific experiences, however, may be affected by whether an attack was unusual or by anchoring events that enhance ability to recall. Accordingly, measurements of migraine experience based on recall over 1-2 weeks may benefit from being limited in their specificity—for example, it may be better to ask about migraine effects on ability to socialize in general, rather than to ask separately about ability to spend time with family, meet with friends, or attend social events. Alternatively, items may benefit from being specific, but capturing extreme or anchoring experiences, such as having to miss an event. However, these questions could then fail to capture a level of severity or difficulty that affected participation, such as when migraine did not prevent going to a social event but impaired a person's ability to enjoy it.

Although participants were very willing to engage in daily diary tracking in the context of research, their comments about perceived burdens could be used to improve measurement design. In particular, participants found tracking most useful when it served their personal needs for understanding; thus, daily diaries used in clinical trials may be improved by including components that best meet the needs of patients, which will differ from those of the trial itself. Similarly, participants' comments that trackers often focus on medical topics (e.g., time to relief from medication) and negative experiences (e.g., severe pain), which participants found annoying or depressing, suggest that daily diaries could benefit from more questions that ask about positive topics. Although these questions may never provide any data that is useful for assessing treatment efficacy, they could offset the perceived burden of completing the instrument and might enhance study participant trust that research is patient-centered and not narrowly focused on clinical aims.

Table 21. Recall of Migraine Attacks

Perspective on Recall of Attacks	Quotations
Not able to remember attacks	• They kind of all bleed together. (2692) • It's hard to remember something that happened two weeks ago. Sometimes I can't remember what happened the day before. (2703) • No. I mean, I could – no. I mean, they blur even more. It's even harder to tell when an attack starts and ends, because I keep track of it on Migraine Buddy app. But I don't know how true my days and lengths are even because I get the prodromes and postdromes, so are those blending together? Am I having back to back migraines, or is it just a really long attack? I can't even tell that at this point. (2813) • Two weeks ago, probably not. (2882) • [Laughter] If it didn't get written down, you've got to be kidding. If I don't write it down, I don't remember it. (3184)
Remember clearly	• So I can remember, like, almost like I can feel it, the nausea that's associated with it. When I think about migraine attacks, I think about the feeling of how it feels in my stomach. And I also really think about the way that – maybe this is weird – felt emotionally. (2691) • I have a pretty good idea. I wouldn't say that it is – in terms of the details, that's going to be challenging, but in terms of the broad strokes, no problem at all. (2797) • That would be easy. But if you asked me what happened with the attack yesterday or two days ago, that could be a little difficult. The further out, the better my memory is. (2940)
Remember attacks that are out of the ordinary	• It depends. Like, clear in my mind is the one that lasted for four days. … (2691) • Yeah, at times, I do. There are some that stand out just because either their uniqueness or their severity. A lot of them kind of are, you know what you're in for, you know what you didn't sign up for but you're going to get it anyway. So, I think the ones that stand out or are weird, for lack of a better way to say it, are the ones that I remember. The ones that are kind of like run of the mill, if it can ever be such, kind of just flow together into one big, typical migraine episode label. (2997) • The more severe ones I remember more clearly. Oh, and then talk about, I don't know, where [unclear 00:21:50]. I also have mood changes. Like, I do get more angry or irritable depending where I'm at in my migraine, and that affects my relationships. So those moments I remember more, for sure – like, an attack where I've had to rely on my partner where there's an issue. Otherwise, yeah, they kind of blend. (3005) • I feel like more recently, they're a little bit harder to remember just because they aren't so devastating and life stopping anymore. (3104)
Remember attacks linked to specific events or activities	• Typically, no. It all tends to blur in. The things that I remember are some traumatic event around it, like the beginning of the pandemic or seeing the audiologist. Those, I can remember a lot more clearly as to what happened. But otherwise, it's too common. (2972)

Perspective on Recall of Attacks	Quotations
	• I can remember if I was working during a migraine. But it is more difficult for me to remember all of the aspects that happened with a migraine unless it was also – like, for instance, at work, if something happened and I felt embarrassed because of communicating, I can remember that more. So things that happened because of those things, I can remember. (2691) • It's funny, some of them I remember so well because I remember where I was when it happened. And some of them, because they just happen so often, I couldn't tell you about. So, two weeks ago – I don't know even know what was happening two weeks ago. So, I think it would depend. … I can remember the ones that stuck out, as in, on my [age redacted] birthday, I had this horrendous one and had to go home and lie down. Or the one that sent me to the hospital. But two weeks ago, was just probably like, "Eh, that was a bad one," or like, "Eh, it wasn't." So yeah, I couldn't tell you anything specifically like that. (2830) • I could remember overall like specifics, like a summary, but I wouldn't be able to tell you at 2 p.m. on Thursday, this specific thing happened, unless for some reason it was noteworthy. Where there was a specific thing that it – like for example, I can vividly remember – I don't really know the date, but it was about three weeks ago that I was working on something. And I remember having a very hard time, and being like, "This is really important that I do this." And I just had a really hard time focusing. … So, things like that I could remember, but if it's like over the day, did your pain go from an 8 to a 6, then probably not. (2915)
Memory prompted by migraine records	• [My recall] it's pretty clear, because I have those notes. Yeah. Occasionally I'll forget to write down a couple of them, and then I won't be so clear. (2689) • If I don't write it down, I don't remember it. … It's pretty much writing down in the moment or it's gone. (3184)

3.5.4. Physical Function Domain

Participants described a variety of ways in which migraine affected their ability to carry out activities and responsibilities that involve physical activity. Participant perspectives on physical function were grouped hierarchically into 13 concepts, shown in Table 22. In this report, both sleep and use of communication or information processing devices are included in the physical function domain. Although sleep itself does not require physical activity in the way that the other concepts do, participants uniformly discussed sleep in terms of ability to or need for sleep. Communications and information processing devices have traditionally been grouped within physical functioning because in the past they required physical activity to use (e.g., getting up to answer a telephone or use a computer that has a fixed location). However, this aspect of these devices has rapidly changed in the last decade and thus the fit between this concept and the physical function domain is changing.

Interview participants described a wide range of physical functions that were affected by migraine and many people reported suspending physical activities, either selectively or entirely, during migraine attacks. Capacity for physical functioning was related to the precise symptoms experienced during an attack as well as their severity and duration. For example, severe pain was usually described as completely disabling while even mild levels of dizziness or muscle weakness could profoundly affect a person's ability to walk or prepare a meal. Symptoms that occurred frequently or persisted for many hours/days could impair a person's ability to engage in physical activities that occur flexibly, such as running errands or exercising. As with other function domains, the relationship between specific symptoms and impairments was variable. For example, difficulty bending over could be related to pain, dizziness, vertigo, or perceived sensitivity to motion and individuals who experienced all these symptoms might attribute impairment during a given attack to one or more symptoms. Impairment itself was also variable. Participants described being unable to move around during an attack, being able to move around slowly, being able to move around only with support, or being able to move around but having to endure considerable discomfort to do so (often called "pushing through"). Finally, many participants made it clear that they avoid many activities during migraine attacks, regardless of whether they are experiencing actual physical impairment. Moreover, all these scenarios could occur during a single attack: a person might have a time period where they were unable to move (or chose not to), a period where they could move about slowly or while holding onto furniture, and a period where they pushed through their symptoms to manage an imperative task, such as feeding a pet.

Some physical functions could be impaired either by symptoms or the way that symptoms impaired other functions. For example, symptoms might directly hinder a person's ability to run an errand by making it hard for them to move their body or symptoms might indirectly affect errand-running by impairing a person's ability to concentrate, leaving them unwilling or unable to drive.

Table 22. Summary of Physical Functioning Concepts

Physical Function	Summary	Quotations
Ambulation	Found in 27 transcripts, with 151 references coded. Ambulation arose primarily in ictal contexts (n=25), but also appeared in discussions of interictal experience (n=11). Interictal references focused on body movement as a migraine trigger. Participants reported impacts on ambulation and body movement including: • Ability to walk (n=17) • Ability to make postural transitions such as bending over (n=10) • Ability to stand or sit up for prolonged periods of time (n=10) • Immobility, or an inability to stand (n=7) • Ability to move the head (n=6) Participants reported impacts on ambulation and basic mobility such as moving their body, bending over, getting up out of a bed or chair, walking around, or climbing stairs. These impacts related to symptoms of pain, dizziness or vertigo, fatigue, nausea, muscle weakness, and visual disturbances. Many participants had experienced attacks when they were unable to move at all. By contrast, some	**Walk** • I mean, it's a pretty full-bodied thing. Even my balance goes at a bad attack. So I have a walker that I keep in the house for bad attacks. I don't want to fall. (2797) • I can't walk because I'm dizzy and I can't walk around because I'll throw up because too much motion on my stomach will make me throw up. (2798) • I can't walk up this flight of stairs because it's just a little too – I'm either too dizzy or the pain is just a little too much and it exerts too much. (3104) • I've had a few migraines where I couldn't hardly walk. I basically just either had to sit or lie down. And I used the walls and furniture to navigate when I had to go to the bathroom. (3184) **Postural transitions** • When it's bad, going from if I'm laying down on the couch, going from that prone position to just sitting up on the couch is incredibly difficult. (2672) • Bending over is really, like, oh my God, please don't make me do that. I can pick up things with my toes very well now. (2689) • If I get up too fast sometimes, I feel like I'm going to get dizzy or I'm going to, you know, something's going to happen, I'll have to hold to steady myself. (2709) **Stand or sit for prolonged periods** • Yeah, if I'm standing for too long, that could certainly trigger one (2693) • It takes me, like, you know, two days, because I can't stand long enough to finish the dishes, so I take breaks, and then I can't really finish them, so they have to stay in the sink until next day. … I had to quit because I couldn't do physically, and I had to quit after two weeks. I was a cashier in a food truck, and after two weeks I physically, like, collapsed. Like, I couldn't stand anymore, so I had to quit. (2913) • I actually ended up investing in a shower chair or shower stool to kind of keep in the closet just in case I really need to take a shower or wash my hair or something. It would just feel nice to be in the water, but I can't stand up for that long, or I'm scared to stand up for that long just in case I fall. (3104) **Immobility** • And then vertigo, because there's no way to push through vertigo, as you're not able to stand. … Yeah, so if I do experience vertigo, then I'm not really able to do anything. And if – sometimes my migraine are to an intensity where I can't get out of bed, and so in those cases I feel like it impacts

Physical Function	Summary	Quotations
	participants noted that walking was helpful during migraine attacks. For many participants, changes in position or movement during an attack worsened migraine symptom experience while for others, staying too long in one position, such as sitting in a car, (3005) could worsen migraine. Other participants described impairment or inability to move similar to physical weakness: “*It's like I'm pushing against the sofa as hard as I can, and my body just doesn't want to move*” (2672). Participants who experienced dizziness or visual disturbances also connected ambulation impairment with concern for physical safety, such as worry about falling. Participants described both the inability to move and impaired movement. This included feeling too sick to move around, moving more slowly, needing to hold onto something, and experiencing difficulties with balance or gait. Participants consistently described stairs as a greater challenge than walking on even surfaces. Several participants reported using assistive devices, such as a walker or shower chair, during attacks.	my ability to do anything at all, including, you know, going to the bathroom or getting the water that I need to drink and things like that. (2691) • Kind of how much it kind of throws me – like, some attacks are so bad that I have to lay in bed and with my head under, like, a weighted mat, and I cannot have any sound and anything, and I just have to be completely still, can't move. (2692) • If I'm having more intense migraine symptoms, it's kind of obvious that I can't really stand or do anything. (2813) **Ability to move the head** • There's no bending down to grab anything or too much turning because I just have to kind of keep my head very still. … Or, if I do something that has ab related exercises, basically anything that involves movement or especially that kind of repetitive movement or lifting weights, it certainly makes it very difficult to do. (2915) • I can't go on bouncy rides or anything like that. Anything that jars the head makes the head pain worse, so. It's almost like having a bobble head. It's the weirdest thing. (3018)

Physical Function	Summary	Quotations
Basic self-care	Found in 15 transcripts, with 37 references coded. The majority described self-care impacts in ictal phases (n=13), as related to ambulation and basic mobility. No participant mentioned direct interictal impacts on self-care, but several participants (n=3) described these activities as migraine triggers or reported simplifying their clothing or hairstyle to make it easier to manage. Participants reported effects of migraine on the following self-care abilities: bathing (n=9); dressing (n=2); eating or drinking (n=4); grooming (n=4); toileting (n=4). When participants felt unable to walk or stand, they typically avoided or limited self-care. Participants also noted that migraine symptoms could be worsened by physical activities like chewing or sensory inputs from activities like brushing hair or showering. In one notable reference, participant 2830 described that having to get dressed and be presentable contributed to a lack of motivation to undertake social activities.	• Sometimes my migraines are to an intensity where I can't get out of bed, and so in those cases I feel like it impacts my ability to do anything at all, including, you know, going to the bathroom or getting the water that I need to drink and things like that. (2691) • The shower is scary. It is not a happy place. The water that comes down on my scalp is painful and my scalp gets really red, really tender. … even the thought of having to get in the shower is just really [sigh]. … And then the noise of the water and the echoing of the bathroom in the shower, just all of that is just not a happy place. So, I have to wait until I'm in a good space in order to do that. … hot water makes my head hurt more too. Which is another reason why a bath is not good. I can't sit in hot water. So yeah, and then brushing my hair. There's no way I can brush my hair. (2798) • In fact, because of the migraines, I went from like – so, I have like an afro hair and I was just doing wash and gos for my natural hair, but I switched to locking my hair. So, I'm actually doing freeform dreadlocks. So, I just have to wash my hair regularly and that's it because I just – I was like, I can't. I either have to cut my hair super short, or I have to dread it because I just don't have any energy for this. So yeah, so it did affect that. I made a conscious choice. And then I also started buying a lot of hats, so I just don't have to put as much effort into styling it. (2813) • If I have to put clothes on and go to the [location redacted], I will fall apart. … And I really had this moment where I thought, "But I have to put a bra on and go on one train, and go to the next train, and I will not make it." (2830) • During a migraine, no, nothing's getting accomplished. I barely can feed myself and go to the bathroom and things like that. (3184) • Showers are really tough for me. I have curly hair, so if I put the shampoo in and rub it in, and then I towel dry my hair, that can trigger a migraine. And I was even having problems with brushing my teeth and the motion of brushing my teeth was causing migraines. … one of the things I end up doing that I'm embarrassed about is I take less showers because I'm totally paranoid about getting in the shower, massaging in the shampoo, and then trying to towel dry my hair. … I just got my hair cut really short so now I can like sponge it, just take a towel and touch it or just let it dry quickly. So, I've taken that away. (3214)
Communications and information processing systems	Found in 10 transcripts, with 24 references coded. This code reflects participants who reported that migraine attacks impaired their ability to use computers, phones,	• So, now I'm trying to do school on the computer, which is another thing that migraines affect because it's hard to look at the screen for that long. (2798) • Like things that don't have screens and noise is really just amazing for me. To just get outside. I'm not really a camping person, but not having the screens and just having the nature noise, it really

Physical Function	Summary	Quotations
	mobile devices, or other communications systems. Time spent on these devices could also trigger or exacerbate symptoms. Most participants, by contrast, referenced frequent use of computer or smartphone devices, including during attacks, and indicated that they relied heavily on these devices for many purposes. For example, participants referenced using smartphone apps or computer programs to track their migraine experiences (see Recall of Attacks), for reminders and alerts to support memory function, and to work or engage in community service through a virtual platform.	heals my brain. We went to a hotel a while back and I left all my screens and computers and stuff, and that really helped. (2813) • Yeah, I mean, looking at a computer, definitely, if it's really bad, I can't just look - I can't look at a screen I have to [unclear 00:19:41], so that affects work. (2850) • A severe one, I can't do any of it. I can't even usually talk on the phone. It's just that bad. I can't function. … I'm not good at picking up the phone and calling people. I'm terrible. I'll text and say, "Hey, hope you're doing okay," and that's about it. (2882) • I usually kind of like do this situation when it's really pounding, and that's definitely where I cannot be doing anything because that's going to make it - especially where it's like, all right, cool, let me not be on screens. (2915) • Too much time on the computer triggers a migraine, so I have to be really careful of that. … And sometimes I can type where I can't talk, I find. Like, I can text a message, even though it hurts my eyes to be reading. (3005)
Exercise	Found in 22 transcripts, with 58 references coded. References to exercise occurred in the context of ictal (n=13) and interictal periods (n=10). Ictal experiences focused on impairments, while interictal experiences included comments about choosing to exercise on migraine-free days. Participants noted that exercise was an important part of preventing migraine and maintaining general health and wellness, though some participants also	• Slowly walking outdoors with the fresh air helps me. Indoors does not. … For some reason, fresh air always makes me feel better. Running or anything like that is obviously out of the question. (2689) • You know, I used to do, like, boot camp, sign up for things like that. I used to sign up for Team In Training to walk half marathons. That's just stuff I haven't done in a long time. But a lot of that is the obligation part, you know? Because my health is just so up-and-down now that I wouldn't want to sign up for something and then, one, pay money, and then not end up going to half of them. And the other thing is, would I actually be able to do it now? I don't know. So it's just much easier for me to have a recumbent bike on the back porch and walk my dogs and, you know, that kind of thing, other than - not that I would, you know, belong to a gym right now, but, you know, than spend that money on that. (2692) • I hate to exercise, but I walk every day with my dog. (2693) • So yeah, if I were to go out and say run a half a mile with a migraine, it's not something that I'm going to do because it does increase the pain. It probably moves it along quicker to become worse as well. (2753)

Physical Function	Summary	Quotations
	indicated that they disliked or avoided exercise in general. Participants uniformly said they avoided strenuous exercise during a migraine attack because it could exacerbate the severity or speed of onset of an attack. Other participants noted that exercise during attacks was not possible because of symptoms such as dizziness, fatigue, or nausea. Some participants said that mild exercise, such as stretching or walking, helped with migraine symptoms. Participants noted having to change their preferred form of exercise and experimenting to find exercise activities that worked for them. This included selecting activities that were lower impact; done at home or on a flexible schedule; free or low-cost due to frequent inability to attend; and did not require bending over (e.g., many yoga positions require lowering the head), going to a gym facility with bright lights and loud noise, or participating in group activities.	• Yeah, definitely I like to be active, work out, play sports, and the migraine definitely - sometimes I have to sit it out. Sometimes I'll go and try, because sometimes the adrenaline from exercise makes you feel better, but you have to be in the right place. I don't know. Sometimes it makes you feel better, and sometimes it makes you feel worse. … Yeah, headaches and dizziness, yeah. Because you - there's definitely certain exercises - like, if it involves a lot of head movement - that triggers the dizziness. Like, there's certain exercises that I just can't do, because they make me feel really dizzy. (2850) • I strongly believe in the medicinal qualities that it [exercise] has. And so, I'm obsessed with it, and when I don't do it - when I do it regularly, I feel powerful, I feel strong, even invincible at times with some. I like that feeling because of course, when I don't do it, especially if it's a week or so that I don't do it, that's when I actually feel very sick because then my body feels stiff. Then I feel a lot more pain. And I'm also - I think it of course helps my cognition in general, I sleep better, all these things. (2915) • [During an attack] I do lots of - or, I try to do gentle stretching and movement and hydration. (3005) • But at the same time, my gym has pretty heavy fluorescents overhead, and I usually - yeah, I end up in a situation where I'm taking in more light than I appreciate. (3022) • And I've noticed that when I go to the gym when I'm experiencing symptoms, it will rapidly increase the - it will rapidly shorten the period that it takes for it to reach peak migraine. So, I don't know that I would say that physical activity causes them, but it's definitely like makes it go from zero to 100 very quickly. (3225) • With prodrome, I will usually at least give it a shot. Depending on exactly what I'm feeling from the prodrome, you know, sometimes it's hard to jog and feel light-headed at the same time. Sometimes I'll just walk instead. I try to struggle through with prodrome stuff, basically because it feels like I'm being cheated if I'm not in pain to have to behave like I am. So, I will try to work through it in that case. Sometimes that works, sometimes it doesn't. (3248)
Fine motor control	Found in 8 transcripts, with 12 references coded. Some participants commented on ictal impairment of fine motor control, such as picking up small objects or opening packages. One participant noted that	• You know, they don't make those [medication] containers easy to open when you have a headache. That's my - I got a pet peeve about that. Whoever designed the packaging so you can't get into it when you can't function has got to get their act [together] (2744) • I absolutely love crafting. Love it. Any kind of crafting, like, you know, coloring. A friend of mine gave me a coloring book a few years ago, an adult coloring book. I can't do it. Those lines are so small, and I can't do that, you know? It's just, oh, it's awful. And I love just doing things with my

Physical Function	Summary	Quotations
	medications they used for migraine could also have this effect (2813).	hands. My husband does some woodworking here and there, and I like to paint on them and do them. I can't do them. (2882) • Not so much the lack of motor skills, but in the fine motor movements, it's hard for me to pick up things, but I can still walk okay. (2997)
General function - Live life	Found in 21 transcripts, with 60 references coded. This code was used when participants made statements that concisely synthesized the totality of their experience and reflected on its overall impact. The concepts woven together in these statements are described individually in detail throughout the report, but the content in this code provides an opportunity to see how people living with migraine condense their experiences, often into stark imagery that powerfully conveys their overall experience of migraine burden. These images include the shrinking world, the world that is out of step, and the ever-present, inescapable, silent threat that hangs over every moment of every day.	• I feel like I miss out on that. And when I stopped being able to work and I got very sick, I had to leave [location redacted], where I was living, and move back up to the [location redacted] to live with family, and so I lost a lot of independence, you know? So it's kind of changed my whole world. It's not all for the negative, but it did definitely change. In some ways my world got a lot smaller than it was before. (2692) • The level of pain, at one point, I remember having a migraine that lasted four days. I was lying on my living room floor because that's the only place I could be. And I honestly felt if somebody said, "Would you like me to shoot you through the head right now and end this?" I would have said yes. So that would be the - because it was so painful, and it was just - life had no quality. I mean, people talk about quality of life all the time, but the impact of migraine episodes on quality of life I think is way, way understated because they can be devastating to a person. I know people whose careers have been blown up by migraines because they simply can't commit to a more demanding job schedule or a higher career challenge. They've had to stay where they are because they know the migraine wouldn't let them do that. And you almost wind up anthropomorphizing the migraine because it's always with you. It's like the silent companion that's always with you. (2997) • So, yeah, the world ceases to function when I've got a migraine. Or I should say I cease to function within the world. It affects me negatively socially, physically, my employment, my emotion. … I'm missing out on life. And it's incredibly frustrating and depressing. It gets depressing when you think about it. At the moment, it's just frustrating. So, I'm going to just live with the at the moment, it's frustrating because if I get thinking about it, I'll get depressed. Thinking about all the things I've missed out on. (3184) • If I didn't have to think about having a migraine, that would be a gift. There's not a day goes by when don't wake up and worry I'm going to have a migraine day. Not a day. (3214) • But yeah, I hadn't had any kind of pain management before I met my wife, mostly because I just assumed that everybody gets headaches every now and then. And then in hindsight, you're like, "Oh yeah, they were crippling. Nobody gets crippling headaches like that. That doesn't make sense." … It would be nice if I didn't have migraines at all. That would be wonderful. So, I didn't have to lose basically an entire day to managing my symptoms. But if I could in some way I'd say lessen the symptoms so that I can get more out of my life. (3225)

Physical Function	Summary	Quotations
		• These things are sneaky. One of the things that I remember from the last hour is how much that migraines have gotten into my life without my knowing - that it's usually for the person who has the migraines - it would probably sound worse than we think it is to other people who don't have to deal with it. I don't know if it actually is worse, but it probably sounds worse than it is because the way that I have described it, thinking back on my own words, is that it's like there's a gun to my head all the time. I don't feel that way, but I understand the words that I have spoken and I understand that they can be interpreted that way. Because it's sneaky and it's everywhere and it's insidious and it never goes - like I'm [age redacted], it will never go away. I have to accept that most likely this is my life for the next 40 odd years or however long I get. Like it's a permanent. (3248)
Health maintenance	Found in 21 transcripts, with 47 references coded. Like other activities that involve leaving home, participants noted challenges with keeping healthcare appointments. These were related to impairments of ambulation and ability to use transportation. Many participants said accessing healthcare was easier during the COVID-19 pandemic due to the increased availability of telehealth services; for others, the pandemic limited access to needed treatments that required in-person appointments (e.g., Botox). Participants prioritized keeping health appointments, but also described having to cancel appointments due to migraine. Participants noted that obtaining needed medical care could be time consuming. Some participants described times when they lacked health insurance or switched insurers, noting that this could interfere with their ability to get migraine care (see also Direct	**Visits to healthcare providers** • Late last year and earlier this year I was treated for breast cancer, and you really don't want to miss one of your radiation treatments, so you have to do it. Yeah. But if I was going - I have canceled dental appointments, you know, six-month checkups, because that just is that bright light, and no, that would be intolerable. (2689) • But it started to become a lot, and then I was, you know, leaving to go to the doctor, like, every other week, getting infusions. I was hospitalized a lot. So it started to impinge quite a bit…The expansion of telehealth, really, in my opinion, is one of the only good benefits of the pandemic. (2692) • No matter, pretty much, how bad I feel, I make medical appointments. I've never been at the point where I have to postpone a medical appointment. (2709) • If I have a doctor's appointment in the big fluorescent offices, which they all are like the [audio cuts out]. That's another thing that really bothers me about it is that the hospital's doctors' office are really counterproductive to migraines. And so every time I leave them, I usually have a really big migraine attack and then have to deal with at least another day to recover because of just how those are set up. And then oftentimes, they're touching you and putting lights in your eyes and stuff. (2813) • Sometimes I actually have to cancel medical appointments because I have terrible migraine. The only thing I don't cancel is the appointments with my neurologist because I need those. (2913) • [Regarding pandemic switch to online services] And doctor visits, even. Like, my specialist - unless it's an in-person procedure, being able to not have to commute to doctors is huge, and it really has helped me - yeah. (3005) **Migraine attack treatments**

Physical Function	Summary	Quotations
	Costs). Several participants also described negative experiences obtaining migraine care in hospital emergency departments (see Feeling Heard). Participants prioritized health maintenance activities and habits that were preventative or that treated attacks and associated these activities with achieving greater control over their migraine. These included adhering to preventive medication treatment appointments, checking in with care providers when migraine symptoms changed, taking medications promptly at the onset of an attack, and deploying a variety of other treatments to manage migraine (e.g., devices, ice hats). Content in this code overlapped with Coping and Self-Sufficiency. Some participants acknowledged that it was sometimes difficult to take their medication appropriately. This could happen because they did not feel well or because they were not certain that an attack was occurring or was bad enough to warrant treatment. Participants also discussed how they made choices among their available treatments or adjusted treatment as symptoms changed or medications stopped working.	• I mean, even taking my medicine - like, sometimes I don't even want to go down and take my medicine, because I have to face the light, so I'll just lay there in pain. (2744) • It's one of the reasons I really try to keep them under control is the longer and the more severe you let a migraine go, it just takes you longer to recover. And so, by keeping on top of them and keeping them in the several hour range, my body can pretty much recover and I'm fine later that day or the next day, and then I'm not carrying it over from migraine to migraine. … That's another thing is, when I see people that just regularly don't treat and then end up in the ER or urgent care, I've never done that for a migraine, and that's one of my goals is to never do that because it's not a friendly place to have migraine treated. (2753) • [Regarding deciding which medication to use] First is how well it works, and that's before [audio cuts out 00:45:54], like, does it work well? Does it [overtalking 00:45:57]? And that's number one. And then number two, yeah, the side effect. And then three is how many times have I taken it in that week or month, because I really try to limit so I don't get rebound. And then, of course, there's cost. So there's some that I can't afford anymore. (3005) • You know, you can get on one medication and it works wonderful for a year, two years, five years, and all of a sudden it don't work no more, and then you're back to square one, like, oh my God, I'm taking this medication, but I'm getting migraines back like never before. Then of course you've got to make an appointment; they want to take away, add, or increase the medication. So yeah. So it varies, because it changes. Right now the medication, it helps a lot, but it don't take the migraines away a hundred percent. And then, you know, they play around with the medication until they find out what's right for you. (3013) • I also use propranolol – I believe it's called? – for prophylaxis – which does help. But I was taking Imitrex before Relpax and I stopped taking that because I would get headaches the next day. Bounce-back headaches from taking Imitrex and I was like I am not going to take something for a headache that I know will give me a headache. That feels dumb, so I'm not going to do that. (3248)
Housekeeping	Found in 19 transcripts, with 41 references coded.	• I pretty much had to sell my house because I couldn't keep up with it, the demands of keeping up my own home. So, as I said, I live with my sister now. (2693)

Physical Function	Summary	Quotations
	Most participants (n=16) reported ictal impacts and the small number (n=4) that reported interictal impacts were those with chronic migraine who described having in-home help to manage these tasks (n=2) or having to move in with relatives because they could not manage a home on their own (n=2). Household maintenance activities were affected by symptoms that caused physical limitations (e.g., pain and fatigue) but not by cognitive symptoms. Participants described delaying or skipping tasks; choosing tasks that are easier to complete during an attack; relying on others to complete housework; taking frequent breaks; and adapting tasks or using special equipment to make household work easier. Most participants reported avoiding housework during attacks, but a few described pushing through symptoms to complete certain chores. For people who were unable to live on their own or who valued a well-kept home, inability to complete housework brought added frustration, but many participants talked about inability to complete chores as a mild annoyance or inconvenience.	• Like household chores and things like that, sometimes I don't do because I'm not feeling well. … Least bothersome? Just the cleaning aspect. I'm like, "You know what? I'll get to it tomorrow. I'll get to it the next day." (2703) • When I have a really bad migraine, everything goes. I don't do anything. If it's just like a 5 on a scale from 1 to 10, I'll do some laundry. I might even vacuum, but I have a super quiet vacuum that barely makes noise. … But just the aerobic workout that it causes can make it worse. So I really don't do a lot of that either. But when I have a migraine, I don't feel like doing anything. I don't want to do any of that. (2711) • At most, maybe I could do five minutes of housework, but I would always get stuck and I would get tired, and then the next day, I'd be really sick and couldn't really do anything. Now, I can maybe do stuff for like 20 or 30 minutes and I'm fine. But I still haven't really worked up to stuff like dishes. That seems like too much of a strain. (2813) • I do chores in the apartment when I'm feeling better, but it's not like I'm going to exercise or, like, going hiking. Nothing that requires a lot of physical abilities. So I would do the dishes; I would do the laundry; I would occasionally clean the apartment. (2913) • Well, like, cleaning right now: So I'm in a three-week migraine, and I can't clean my house. I need to vacuum. I can't really bend over. I get too much pain. So, like, cleaning, yeah, everywhere. (3005) • So, if I end up with a migraine, a lot of the time I'll push off just regular tasks like laundry or the dishes or organizing something. It's a lot harder to get those things done, and I would prefer not to do them while I have a headache, but sometimes, it gets to the point where I'm just like, "Well, I already kind of feel like crap so I may as well get stuff done" so that I can lay down and not have to worry about it. But it just kind of depends on how severe it is. (3022) • And so, I love to clean. Cleaning is one my therapies. … So, being able to make my environments clean helps me physically and mentally. And so if I'm unable to do that or I wake up one day not feeling great and I can't clean like I planned on it, then I feel even worse because my environment isn't how I need it to be, and now I don't feel good, so then it's like doubly bad. (3104)

Physical Function	Summary	Quotations
Lifting and carrying	Found in 7 transcripts, with 8 references coded. Migraine impacts on ability to lift and carry objects was reported only by female participants and impairments were described only during attacks. Participants associated lifting and carrying with bending over, which they generally avoided during an attack. Ability to lift heavy objects was limited by the effect that exertion of any kind had on exacerbating pain, as well as by neck pain and muscle weakness.	• My back gets pain really easily and it's because my neck is stiff all the time too, so the pain just travels down my body. So, that makes it really hard to do anything with that, like lifting anything. (2813) • I can't really bend over right now at all. Like, even hunching over with my neck, it hurts, and I know if I did it for any prolonged period of time. So that includes picking up anything heavy, and normally I wouldn't – like, this is a physically bad time (3005) • Yeah, it does impact a lot. I can't do a lot of heavy lifting anymore (3018) • I'm physically – I feel weak. There's not the strength in my limbs. … I can't lift as much weight during a migraine. I have to be much more careful. (3184)
Meals	Found in 22 transcripts, with 44 references coded. Participants reported that migraine attacks affected their ability to prepare or eat meals, with many noting that they delayed meals or kept easy-to-prepare foods on hand. Participants associated these impacts primarily with pain, nausea, dizziness/vertigo, and sensitivity to smell. A few participants referenced loss of appetite or gastrointestinal symptoms (e.g., feeling bloated) as contributing factors. Some participants reported being hungry or dehydrated as a migraine trigger (e.g., 2753). Impacts on meal preparation and eating affected family and social relations, such as having to cancel plans for holidays	• Normally, I know how I'm going to do during the day pretty early on, and if it's going to impact my ability to cook dinner and whatnot, then it's like, yeah, we're going to make plans to do something else. (2672) • There are a lot of things I won't eat because it'll trigger an attack, so that may affect where we go if we're getting together. (2689) • There's just no way I can be around people or function, or leave my bedroom, or cook dinner. Like, I've invited them for dinner. In fact, they were supposed to come here on Labor Day, and I called my daughter in law the day before, and I said, "I'm sorry I have to do this. There's no way I'm going to be able to cook tomorrow. I know it." (2711) • And by not functioning, I mean not eating. … I like to cook, and I'm good at cooking, and my kids like my cooking, so I generally try to cook, because that's the one thing I like doing. But on the flipside, when I'm having a migraine, there's some things I just don't cook because they stink, or they – like, I don't enjoy tacos because I don't like the way tacos smell. (2744) • My primary trigger is hunger. And so, if I get to the point of – you get that little growl in your stomach, that's probably almost too late, and I know I'll be getting a migraine. (2753) • I have to eat a completely different diet. And I do, and I stick to that diet. I am very careful about what I eat. I don't eat chocolate or cheese or no wine and no – really no alcohol, and no processed meats. I mean, the list just goes on. I'm very – I stick to the migraine diet. (2798)

Physical Function	Summary	Quotations
	meals. Many participants tried elimination diets and found food sensitivities that contributed to their migraines, while others reported being unable to identify any food triggers. For those with food triggers, migraine restricted places where participants could meet with friends for a meal. Participants occasionally mentioned challenges managing proper nutrition and weight. One participant reported experiencing protein deficiency due to lack of proper nutrition (2909). Several people reported weight gain after becoming more sedentary due to migraine. One person lost weight after finding it hard to eat properly due to frequent, prolonged attacks. In contrast, one participant had lost weight to improve their health and had successfully reduced the frequency of their attacks.	• If I can't cook, I have a bunch of microwavable food all the time that I can make if I'm not feeling well. (2850) • It affected me a lot. I have been protein deficient twice…I don't feel like eating on those days, and I just want to lay down, but then my house is messy and I don't have anything to cook in the house. Like, I'm eating frozen pancakes, and it's like, "Oh wow, look at you, you lost weight." (2909) • But with a migraine, it really does knock the feet out from under you, and even the idea of making a cup of tea or a cup of coffee, it becomes an hour process because you have to talk yourself up to it and try to convince yourself to do it. And then try to do it. And then there's that whole point of, "Okay, how do I do this, and will I drop the cup, will I drop the hot water." (2997) • Having the migraine itself definitely prevents me from eating, but I don't know if that's directly related to the nausea or the fact that I'm just in a stupid amount of pain. Once I've been having a migraine for three or four hours and it starts to peak, I just will not have the willpower to actually eat anything. (3225)
Mobility and transportation	Found in 27 transcripts, with 121 references coded. Participants mainly addressed mobility in ictal contexts (n=24), but it also affected interictal experience (n=10). This concept captures people's ability to move around in their community, which had a significant impact on many functions and roles. Participants described migraine's effect on mobility in terms of their ability to	**Drive or be a passenger in a car** • Depending on the severity of the migraine, absolutely, I won't drive. Depending on the medication I took, I won't drive. So, yeah. Oh, absolutely it, yeah, affects that. (2689) • If it's severe, no. Or I've had to have somebody pick me up from work before. I couldn't drive home. Because that's when I see the aura and sometimes the double vision, so I've had to have my sister pick me up a couple times from work. (2703) • All of a sudden, you know, you slow down for a traffic light. A couple of times I felt I was still moving after I stopped, which was not very fun, because all of a sudden you think, well, am I going to hit someone? (2709) • Well, it's hard being a passenger. Easier than driving though, sometimes, definitely. But I would say that the nausea is what makes that the worst. (2798)

Physical Function	Summary	Quotations
	• Drive or be a passenger in a car (n=27) • Use public transportation (n=5) • Travel (i.e., by plane) (n=3) Ictal references focused on impairment of mobility during attacks. Interictal references included talking about transportation as a migraine trigger, choosing to work from home rather than commute, and taking advantage of migraine-free days to go out in the community. Participants linked mobility to symptoms of pain, mental acuity, vision disturbances, sensitivity to light or motion (including dizziness or vertigo), and nausea. Sensitivity to smell was a problem for people using public transportation or car services like Uber or Lyft. Many participants expressed reluctance to drive due to safety concerns (e.g., from vision or cognitive impairment) and past experiences of being stranded. Ability to drive was also affected by medications used. One participant (2940), who described symptoms consistent with hemiplegic migraine, reported losing their driver's license. Impacts on community mobility varied greatly. For example, some participants were unable to drive during an attack but were able to be a car passenger or use public transportation. Some participants	• And usually I take Uber. Like, my husband is at work, and I don't drive, so sometimes I take Uber. Every time I have an appointment, actually, I need to take Uber to drive me there, there and back again, which runs very expensive as well. (2913) • Back in 2014, I had a migraine attack that was very severe that required me to be hospitalized. They couldn't figure it out because it kept looking like a stroke but it wasn't showing up as a stroke. So, when they finally figured out that it was a type of migraine, they said because this type of migraine hits fast and furious and we still don't know enough about it, we think it's best that you don't drive anymore. … And the [state name redacted] driving commission said, your doctor said that you're not physically able or capable to drive, turn in your driver's license. (2940) • When I have a migraine, I can't drive. … It's actually due to the fact that I can't see very well. The left eye, very often it's so painful I have to keep it shut, which reduces me down to just using my right eye, so that's kind of hard for me. (2997) • I didn't want to drive, because of the bad neck. I was in a migraine. And I took Uber, and they always have really bad smells in the - like, perfume, whatever you call that - I can't think of the word right now, but air freshener. And I'll get sick. And there's no way to request - and I've tried - a lift or ride without those. So that's the thing. Like, it affects everything I do. (3005) • I drive for work, so I usually just have to force my way through it. It's not ideal. It does make it a lot worse and I find myself getting a lot more irritable with the drivers around me. But, I'm sure it probably does impede my ability to focus as much and drive as safely as I would if I didn't have the migraine. But for the most part, I can do it while I'm having migraines, it's just not ideal because a lot of the time I'll be driving towards sun and it's a lot of harsh lighting. And then, I find myself getting drowsy if I'm wearing sunglasses, so it's really hard to find a way to manage that just because I can't really wear sunglasses and drive for eight hours without getting drowsy. And then I'm worried about being drowsy and driving (3022) • I also get motion sickness in the car, car sickness, and I get it really, really bad to the point where I will oftentimes, if I'm the passenger, have to ask the driver to pull over so I can recover. (3225) **Public transportation** • I don't really take public transportation, but yeah, it's better than driving though. (2798) • There have been times when I - and this is luckily that I'm in the city - will walk instead of taking the subway. (2830) • Because public transportation is really bad. Like, I've been stuck on public transportation in a bad attack, and that's, like, the worst experience (3005) **Travel**

Physical Function	Summary	Quotations
	could not use public transportation but could ride in a car. Some participants reported preferring to walk instead of using transportation during an attack. Finally, a few participants mentioned living in areas without public transportation or referenced high costs associated with using paid car services.	• I couldn't go anywhere. I couldn't fly in the plane. I couldn't go anywhere. And finally in 2019, I was able to travel, and I was able to go see my mom. And I hadn't seen her since 2012. … And I used to love to travel, but again, the whole being overstimulated, at the airport, running through the airport, going through security, being around all those people. Those are all things that kind of made it difficult for me. And then, let's not talk about trying to fly in an airplane with your head pounding. I did that one time, that was a bad mistake. (2940)
Shopping & running errands	Found in 13 transcripts, with 23 references coded. Participant perspectives on shopping or running errands were closely related to both ambulation and transportation. When these functions are impaired, people's ability to go shopping or run errands is also impaired. Participants also noted that stores and other locations are often brightly lit, busy, noisy, and filled with strong smells, thus creating profound challenges for people experiencing symptoms of pain, nausea, or sensory sensitivity. In addition, participants noted that shopping includes a psychosocial component. For example, for one participant, shopping was their only regular 'going out' activity with their partner, while another said that shopping fell largely to their partner. Finally, two participants noted using delivery services or drive-through options that contributed to an isolated, homebound lifestyle (e.g., 3233).	• If I have a migraine, I'm not doing any of that. If I'm okay, that's when I can do that. I've actually tried to go to the mall once before, and as soon as I walk past Yankee Candle – I didn't even go in the store – but the smell of all those candles, I ran to the bathroom and I'm like, "I can't be here." (2713) • There was a period of time when I was having a lot of trouble going into a store, a big-box store like Costco or Walmart or someplace like that, with five minutes of those overhead lights. (2797) • Like, on the weekend, we – my husband and I, we go out, and by "out," we go to Costco. [laughs] So we go to Costco and we do grocery shopping together. (2913) • In my state, in several towns during the spring and summer, they do what is called girls night out. They get the local vendors and business owners together, and they have discount sales and you have activities, and it's like this big event. And the last one I went to, I was so miserable that all my friends were walking around to the different stores, and I'm sitting on the park bench trying not to have a whole problem because I'm sick. And I didn't want to leave because I hadn't seen my friends for a minute. This is like our three time a year get together at these three events, and this was the first one. (2940) • Grocery shopping. I can't go in a grocery store right now. It's too painful. I'd be too disoriented. I get dizzy also in migraines, so I'm lucky my partner went shopping for me. … So errands, it's the same. It depends on the errand. Like, if it's in a loud, noisy space, then it's hard for me and I can't do it in an attack, or it might trigger an attack. It really depends on the environment and the errand. (3005) • That's another thing. I've had to order groceries and have them delivered, which is very expensive, because I'd have three migraine days in a row and I just know that even if I don't have one that day, it's too much for me to grocery shopping physically. (3214)

Physical Function	Summary	Quotations
Sleep impacts	Found in 12 transcripts, with 23 references coded. Participants reported several ways in which migraine affected their sleep. Some participants described being awakened by migraine pain or being unable to sleep because of an attack. Others reported becoming sleepy (which could also be a side effect of medications) or using sleep to treat their migraine attack. Several participants associated restless, interrupted, or unrefreshing sleep with their migraine. Lack of sleep or interruptions of sleep routines triggered migraine attacks for some participants.	• The past couple of months, I wake up tired. And I'm getting, most nights, you know, six, seven hours, but I wake up a couple of times. (2709) • Interviewer: Do your migraine attacks impact your sleep as well? 2711: They make me want to sleep more. (2711) • If I go to sleep – or if I don't get enough sleep – If I go to sleep super late or have to wake up too early, then a lot of times, that leads to migraines. … I mentioned that sleep impacts my migraines, but the other way around is also true. If I'm trying to go to sleep at night with a migraine, sometimes that can affect my sleep. (2915) • You can wake up with a migraine, or a migraine can wake you up out of your sleep. … They were waking me up every day, every night in the middle of the night. (3013) • I started sleeping terribly. I used to never have problems with sleep and I still do now. I take melatonin every single night just to make sure. Because I would go to sleep and then I would wake up and be in pain or I would wake up and feel nauseous or have a hot flash or my face was tingly or whatever, and I could never stay asleep during the night. (3104) • If it just so happens to peak at three o'clock in the morning, the pain will wake me up at like two or three, and then continue to wake me up throughout the rest of the night. So, that has been probably one of the worst parts. (3225) • Sometimes I will feel a sensation of tiredness, but I can't go to sleep. (3248)

3.5.4.1. Implications of Physical Function Domain Findings for Measuring Migraine

Currently utilized COIs for core physical functions are robustly validated by the findings. The interviews underscored the universality of migraine's impairment of basic physical functions such as walking, preparing meals, caring for oneself, and carrying out all manner of chores, errands, and day-to-day activities. Impairment of these functions also largely varies in alignment with the severity of ictal experiences: the more severe an attack, the greater the impairment of these functions. These functional concepts also are the most clearly connected to disability, or the complete inability to perform tasks and activities during migraine attacks.

The interictal effects of impairment on some core physical functions may be mostly indirect. Participants were, by and large, able to undertake basic physical functions during interictal periods. However, it is important to note that many participants did describe an interictal effect of having to 'catch up' on some functions, such as cooking, cleaning, or other day-to-day activities. A measured understanding of interictal burdens of migraine might potentially benefit from strategies to capture how much migraine-free time people are using to catch up on missed activities.

Some specific physical functions are subject to contextual factors that may make them less useful in a PROM or affect item phrasing or response options. Physical functions that are linked to individual circumstances may be less useful in a measure even when impairments are extremely important to those patients who need or want to function in these ways. Examples include driving and shopping. Driving is not something that everyone does, for example, while challenges with shopping can be perceived as both a physical (e.g., physical inability to go to a store) and social (e.g., limited ability to shop recreationally or with friends). Both these functions may also be interwoven into people's sense of self (e.g., ability to drive is related to people's sense of independence) or connected to emotional burdens (e.g., guilt that a partner has to manage all routine shopping and errands). These findings demonstrate that functions that may initially appear straightforward and easy to measure may in fact create considerable complexity for writing items or interpreting results. Similarly, successfully measuring these concepts in a rigorous, systematic way may require adding additional response options (e.g., a 'not applicable' option for people who do not drive or do not go shopping).

The use of communication and information processing devices may no longer fit best with the physical function domain. This study demonstrated that the traditional conceptual construct of communication and information processing device usage as an aspect of physical function may require some rethinking. Over the past 10-15 years, the concept of a telephone or computer that requires a person to move to a specific location to access a device, to hold a device to their ear or to sit in a specific position to use it, and that permits limited control over the amount of sound or light a device generates, has changed. Instead, highly customizable, compact, portable devices have rapidly become the norm. Participants noted that these devices provide useful supportive services, such as spell checking or text messaging. In addition, these devices can support social interaction through applications like Skype (e.g., 2913) or allow people to work from home. Finally, some participant comments suggest that newer devices have changed the dynamics of communication in beneficial ways. For example, when someone telephones, people have the option of texting a reply. However, the ubiquitous and multi-functional nature of these devices also means that people spend a great deal of time in the presence of lighted screens, which is problematic for people with light sensitivity.

The result of these changes is that perspectives on impairment of ability to use these devices is less clearly connected to physical functions and more clearly connected to light sensitivity and cognitive function. Portability and flexibility may improve participants' physical ability to use devices, for example by permitting use while lying in bed in a dark room and by allowing dimming or silencing. However, most participants indicated that the amount of time spent working with screens could trigger or exacerbate migraine considerably: "*my brain just kind of got tired of screens, screens, screens, screens*" (2813).

3.5.5. Psychosocial Function Domain

Coding and analysis identified 22 overarching concepts related to migraine's effect on psychosocial function. For this report, these concepts have been grouped into three organizing categories: social role functioning, managing migraine, and the emotional and psychological aspects of living with migraine (see box at right).

In the sections below, summaries and detailed tables presenting perspectives shared by interview participants are provided.

Interview participants perceived that migraine engendered a variety of psychological impacts and burdens, including short- and long-term effects on their ability to undertake a variety of roles and activities that require social interaction. Participants also described impacts on their emotional state of mind, sense of individual identity, and general sense of well-being. Participants noted that life with migraine exposed them to a range of stigmatizing experiences, including when seeking health care. Participants also talked about learning to accept and adapt to life with migraine, which permitted them to define a "*new normal*" and to contextualize their experiences in terms of what they could do. However, participants who had accepted a new normal were still quick to identify burdens and to express desire for improved treatment. Thus, accepting and adapting constituted a deliberate shift in attitude towards migraine experiences, but did not appear to directly alter the perception of burdens.

Psychosocial Domain Codes

Codes for social role functioning

1. Care of others or pets
2. Family relations
3. Interpersonal relations
4. Intimate relations
5. Recreation and leisure
6. School
7. Social, community, and civic roles
8. Social support or isolation
9. Spiritual life
10. Work

Codes for emotional and psychological aspects of migraine

11. Accepting or adapting to life with migraine
12. Emotion states, including all descriptions of symptom impact on mood
13. Feeling heard
14. Identity
15. Life satisfaction and meaning
16. Stigma
17. Well-being

Codes for managing migraine

18. Coping
19. Direct costs of migraine
20. Predictability-control
21. Pushing through
22. Self-sufficiency

3.5.5.1. Social Role Functioning

Interview participants described impacts from migraine on their ability to engage in all types of social roles, often describing impacts on their ability to "*be present*," a phrase that conveyed both physical presence and mental/emotional presence. The nature and magnitude of these impacts depended largely on the severity and frequency of migraine symptoms. People with severe, prolonged, frequent, or treatment-resistant migraine described a range of profoundly constraining effects on their home, social, and work lives. These included limited or no ability to work, the loss of personal relationships, and a lifestyle hallmarked by isolation and limited capacity for social recreation or civic life. By contrast, those with less frequent, less severe, or treatment-responsive migraine described challenges, but were often able to maintain substantial social role functioning. However, migraine's impact on social roles was also greatly influenced by the level of support and understanding that people encountered in their social environments. People who described having supportive social environments noted that this mitigated the constraints and challenges of carrying out social roles, even while living with severe migraine. People who described unsupportive family or social environments found that these exacerbated the social role impacts of migraine even when their disease was not severe.

In addition to the direct burdens from migraine on social roles, participants often described indirect negative or unwanted experiences that were associated with these impairments. These included stigma and negative emotional responses such as guilt. Social role impairments were also linked to participants' perspectives on their identity and general well-being, with numerous participants identifying the loss or impairment of important social roles as one of the most difficult aspects of living with migraine.

Social role functioning was, however, also influenced by individual decision making related to "*pushing through*" attacks and lifestyle adjustments or acceptance of migraine as a "*new normal*." For many participants, social disengagement or withdrawal was not an option, while other participants described prioritizing social role functions. These participants described pushing through attacks to fulfill these roles, as well as orchestrating their lives to make social role functioning possible. For example, some participants described finding alternative employment or undertaking meaningful, satisfying work or social engagement by joining migraine support or advocacy groups. These choices offered them more flexibility and understanding than other social role environments. Similarly, some participants described finding new friends or new hobbies and recreational outlets that were more suited to their life with migraine. In the context of the coronavirus pandemic that had unfolded over some 18 months prior to the time interviews were conducted, multiple participants also noted that increased opportunities for social role activities online had been beneficial. This included greater opportunities to work flexibly from home and widespread online access to social and civic events, such as community meetings, religious services, or artistic performances.

A summary of themes related to social role function is provided in Table 23.

Table 23. Summary of Social Role Functioning Concepts

Social Role Function	Summary	Quotations
Care of others or pets	Found in 16 transcripts, with 41 references coded. 13 participants talked about ictal effects and 4 mentioned interictal effects. Participants described impacts of migraine on their ability to take care of pets or people who were important to them, including their partners, roommates, children, or parents. *People*: Participants described both pushing through attacks to take care of others and being unable to do so. Participants benefitted when other supportive people could take over care responsibilities, while also describing a variety of emotions linked to being unable to provide care, such as guilt. Several participants also noted feeling like a burden because care responsibilities fell on partners or other family members. One younger participant mentioned feeling like she could never start a family of her own because of her migraine. *Pets*: Many interview participants had pets and reported prioritizing pet care. Some participants described limiting the amount of care they gave during an	**Care of other people** • I don't feel like I could have a kid. And I don't - I mean, I've dated and I've had boyfriends and stuff but none of them have lasted very long because I just always felt like I am - I would demand too much. I would be too much of an imposition. I would need too much because of my migraine disease. • My partner has to do more stuff. My mother lives with me, so he has to be kind of her caregiver but also help me out and stuff like that, so it definitely puts more weight on him. (2813) • I have to go take care of my [age redacted] father, who is very self-sufficient, but I do feel bad sometimes because I have to call him and say, "I just - I can't come over today." There's a lot of guilt with these. Really is a lot of guilt with migraines. (2882) • I have two kids that I care for, I have a senior father, and two pets. There's just me. So, if I don't do it, it's not going to get done, so I just have to just plow through it. I do what I can do. What I can't do, I just leave it for when I can do it. (2940) **Care of pets** • Like today, I felt a little bit better in the morning, so I took my dog to the dog park for an hour. … I make myself go on walks because it's good for me and it's good for the dog. But, it's not something - like if I didn't have to go, I'd probably just sit on my butt. (2711) • If I'm in pain - like, I'll go down and open the door and I'll leave the door open … so he [a dog] can go out and in whenever he wants. (2744) • The only thing I would say it would interfere is when he's barking. You know, it just - oh, no, I can't do it, you know. (2882) • They [family members] will help take the dog out to go to the bathroom and things, because for the most part everybody knows I have a migraine, I am not doing too much of anything but going to the bathroom and getting back in bed. (3013) • I still try to make sure that I take care of my dog and that I'm still letting her run around and be physically active even if I'm kind of not feeling as well. I may avoid going outside as much with her, but I try not to let it affect my ability to make sure she has water and food and taking her to the bathroom. But it does definitely make it harder. (3022) • When I'm not feeling good and if I'm lying on the couch or on my bed, you know, and the dogs and my cat, who sometimes thinks she's a dog, they - you know, they're comforting.

Social Role Function	Summary	Quotations
	attack (e.g., letting a dog out into the yard rather than going for a walk) or that pet care would fall to another person in the household. Several participants noted that having pets was beneficial, for example by helping them stay active or by providing comfort and companionship, while others described how pets could exacerbate migraine experience (e.g., by barking).	They kind of curl up around me, and they know I'm not feeling good and, you know, so they kind of in a way help me get through it. (3223)
Family relations	Found in 26 transcripts, with 96 references coded. Participants described a wide variety of ways in which migraine affected their ability to engage in or enjoy family relationships, as well as impacts from their migraine on others in the family. Impacts on family relations spanned ictal and interictal phases, with ictal effects (e.g., missed family events, interference with family time) routinely leading to interictal effects (e.g., strained relationships, feelings of guilt). The high level of variability in impact on family relations resulted from multiple factors, such as the frequency and severity of migraine attacks, the participant's specific family roles and responsibilities, the overall level of support and understanding shown by family members, and cultural norms and expectations.	**Migraine limits time with family** • You miss out on family time. And those are the things – but, you know, particularly family time. Those things you don't get – you don't get that time back. (2797) • So especially with bigger gatherings and things like that, usually I'm having to leave and not be present. And I think the frequency of my pain makes it so that when I'm interacting with those closest to me, pretty often I'm thinking about the pain that I'm in, so I feel like not being able to be totally present with them has been a big impact. (2691) • It just changes my functionality level, you know, so. Sometimes I'd like to be present more with my kids but I'm in bed. … They don't understand that I'm doing my best when I'm in the pain to be present, and it's taking all my effort for myself to be present sometimes. And sometimes being present is a lot of work, you know. Being present and accountable is a heck of a lot of work, you know. (2744) **Migraine burdens family** • And I think it didn't help my marriage [participant is divorced]. I don't think it helps raising my kids the way I like sometimes. (2744) • My family has to do more for me, that's for sure. You know, I do less cooking, less cleaning, and so … But like I said, they're supportive." (2693) • I feel it's affected a lot, but my husband say no. Like, my husband is like, "It's okay. It's not your fault you have migraines." But I always feel like I'm a burden. No one wants to be a burden, and I always feel I'm a burden. … So I really don't like that. I grew up being, like, independent and all, and now I'm, like – you know, now I'm dependent on him in everything. He carries everything because I can't carry anything. You know, he needs to take care of the family. (2913)

Social Role Function	Summary	Quotations
	There were several major, interrelated themes describing how migraine affects family relations: • Migraine limits time with family or results in *“not being present”*, which includes both physical absence as well as being physically present but disengaged • Migraine burdens family members • Migraine contributes to family tension	**Migraine contributes to family tension** • When I went home [to a country with a different culture] one time, I was, like, such a – like, I was a mess, because I just wanted to sleep. I had terrible migraine. And, you know, you're traveling to meet people, but I really didn't want to meet anyone. So that, of course, made, like – we fought at home about that with my family, because I couldn't meet anyone, I couldn't spend time with anyone, and I was only there for two weeks. (2913) • In terms of family, they don't live here, but the health situation has also sometimes put maybe like a strain because people, they've said things like – they're very religious and I'm not. And so, they basically blame me for not being religious, for being sick. So, it's kind of hard to be close to someone who thinks that it's your own fault, when I literally did – I'm trying my best to not have it. And so, I think I would say sometimes dealing with how I've been treated is more difficult than the actual physical symptoms and even the limitations themselves. (2915) • I feel my brother and my relationship is very strained. We were really close, and then the more the migraines got worse – yeah, it's been hard. When I've gone to visit over the past year since it's been chronic, he doesn't get it when I want him to turn the music off, and doesn't want to. And he's a very caring, loving person, but it's just, for whatever reason, he can't get it through his head that this is a real thing that I have and that these are the changes I need. To him it's, I don't know what. I can't speak for him. But it's been really hard and therefore makes me pull back, and I'm not in his life.” (3005)
Interpersonal relations	Found in 28 transcripts, with 77 references coded. Participants described effects in interictal periods (n=21) more frequently than ictal phases (n=17). Participants described a wide variety of ways in which migraine affected their ability to form and maintain relationships and engage in interactions with friends or acquaintances. This code overlaps other psychosocial codes because effects on interpersonal	• It's impacted my ability to spend time with and therefore build relationships with people. (2691) • As far as friends, it has limited the amount of time I can physically spend with friends. … But it takes its toll on me just because I feel like, ugh, that sucks, I don't want to be that person. But it still is hard, because I just don't get to do what other people are doing. (2692) • I gotta say, migraines certainly – because, you know, when you get into a new relationship, you have to be, probably, a little more present. And to start dumping on a person, "Well, I have chronic migraine, this and that, and that and this," and – it's been a problem. So I guess it would be fair to say it has had a major impact with existing people, and people yet perhaps to come into my life. (2709) • And yeah, I've lost friendships because they don't want to hear me complain, or they don't want to be canceled on. (2711)

Social Role Function	Summary	Quotations
	relationships were influenced by the social roles a participant had, their perspectives on how understanding or supportive their social circle was, and the specific coping strategies used. Engaging or managing interpersonal relationships required participants to balance these aspects of experience while navigating interactions with other people. When the sum of migraine experience resulted in substantial disability, participants had limited and unpredictable amounts of time and energy to devote to interpersonal relations. This affected their ability to nurture existing relationships as well as to make new ones, which sometimes also resulted in the loss of relationships.	• And I've been very fortunate to have people who have understood that. The people who haven't understood it, well, needless to say, we're not in touch anymore because they couldn't get their minds around it that this isn't a headache and I can't pop a couple aspirin for this. And I really did want to hang out, but I just can't, there's no point in having me be there in pain. I just wouldn't be any fun and it wouldn't be any fun for me either. (2997) • I've also lost friends because of the migraine. Like, my going-out friends, friends I thought would be understanding, or seemed to be understanding, and then something would come up with the migraine and they just, yeah, aren't interested in supporting me. And then I'm like, okay, I'm not interested in having non-supportive friends right now, because I can only see so many people in a given time nowadays. So it's definitely limited – made my friendship circle smaller. And in terms of getting new friends, yeah, I don't know how I would do that at the moment. Not saying it won't happen, but definitely put that to a stop. (3005)
Intimate relations	Found in 17 transcripts, with 31 references coded. 12 participants discussed impacts on intimate relations in ictal phases and 6 referenced impacts in interictal periods. Participants described migraine's wide-ranging impacts on their relationships with their partners or spouses. Migraine made it difficult to start an intimate relationship as well as to sustain an existing one. Migraine interfered with people's ability to spend time with their partners and affected the dynamic of the relationship, in which the participant	• [It affects] sex. Orgasms trigger a migraine. (2689) • The partner that I have, we've been together for a long time, and so they have taken on some caretaker responsibilities when I'm very sick, and that has also been very impactful. … I think it's impacted our communication and relationship in ways that took some time to learn how to navigate, with my consideration being my health and their well-being, too, and trying to help when sometimes there's not much that either of us can do. (2691) • I'm divorced, which I think had an impact in my – I think migraine had an impact in that. … Well, I wasn't the person anymore that he married who could do all the stuff and focus on him. (2693) • Like, you know, if we're trying to have sex or something and I have terrible migraine, so it's not going to happen. So even, like, being intimate with him, sometimes it's a huge thing. Like, sometimes it needs to be interrupted. (2913) • It strains the relationship with my partner, for sure. Yeah, we're constantly trying to navigate it, and he [audio cuts out] to be as helpful as he is, but there's definitely points where we get into arguments around different things around the migraines. Like, he

Social Role Function	Summary	Quotations
	often felt like a burden or worried that they were not able to "*be present*" and fulfill their partner's needs. Three participants also reported that migraine directly affected their sex lives.	understands now why I need it dim all the time, and quiet, etc., but I know that he doesn't love that, and he feels like he's constantly making all these compromises for me. (3005) • You know, I don't have - it has really destroyed relationships, both romantic sexual relationships as well as friendships, because it's - it's hard for people to handle, you know, my being sick so much. … So, so, you know, for example, I've gone from being married to divorced bachelor [laughs]. … it has become clear to me that, you know, that it really is more suitable for me to remain single and celibate. You know, I'm not really - because of my health - I'm not really in a position to where I could date or, you know, anything like that. It's - it's too challenging. (3233)
School	Found in 10 transcripts, with 27 references coded. Participants who had experienced migraine attacks while in school reported a range of ictal and interictal impacts, including missed classes, taking longer to complete education requirements, or inability to complete traditional, classroom-based programs. For some participants, this meant abandoning or changing educational goals, or finding alternative modes of education. Participants linked impacts on school to pain, light sensitivity, and impairments of concentration and reading comprehension. A few participants reported that stress from educational pursuits exacerbated migraine.	• So in college I was struggling in school. It actually took me about six years to complete my undergraduate degree, because I was frequently out of class and oftentimes had to leave the classroom in order to lay down outside or communicate with professors that, yeah, that the classroom setting was difficult. (2691) • I didn't get them often until I went to grad school, and then I think the stress from grad school kind of made them go a little bit deeper. (2692) • Through high school, I had to go on independent study because they were so bad. … Because of the pandemic, they shut my store down, and so I took some time off, and I actually reenrolled back in school. So, now I'm trying to do school on the computer, which is another thing that migraines affect because it's hard to look at the screen for that long. (2798) • I was in community college, and the hope was I'd get good grades and I can transfer four years' degree, which I did have good grades, actually. I got an A in everything, and I graduated with honors. However, I didn't go through - I just couldn't go through the same thing again physically, because I was pretty much, like, half dead in my school year. In the graduation year, I was, like, working my butt off, and after that I just, like, physically and emotionally, I couldn't go through the same thing again, so I didn't apply for a scholarship to go to four years' degree. … And not going to four-year degree. That was heartbreaking, actually, because I worked so hard for it, and I had the grades and I had everything. I just couldn't do it. So that was really hard for me as well. (2913) • And I did try to go back to school when I became chronic. I thought, well, now is my time to change careers to something less stressful. And I knew enough - I knew that I was having migraines and that I would need accommodation. I knew that I couldn't attend classes in person full-time, and I went to the whoever, you know, for new students, proposing - and they said, "Oh, no. There's no way you could have those accommodations." So I gave up. But

Social Role Function	Summary	Quotations
		what I know now is that, absolutely, you can get accommodations. It's not easy. I've talked to a few grad students who have had to advocate for themselves together accommodations, meaning maybe working remotely or having more time to take the tests. (3005) • Schoolwork is a struggle with trying to read stuff. Like, concentration. So if it's real bad, then I'm reading it seven or eight times, and I'm like, I used to not have to do this. I could read it once and it was in my head, and if the headaches are there, then I'm reading it over and over again, and I'm like, really? (3018)
Recreation and leisure	Found in 28 transcripts, with 89 references coded. This code included comments by participants about migraine's impact on a very wide variety of activities, ranging from quiet, one-person, at-home activities (e.g., reading, painting) to group activities outside the home (e.g., attending concerts or festivals, engaging in recreational sports, dancing, vacation travel). Some participants also discussed exercising or social activities, such as having dinner with friends, as recreational activities, but these comments were coded under Exercise and under Social, Community, & Civic Roles. Participants reported limitations on their ability to participate in all these activities. Limitations were primarily linked to light and sound sensitivity, mental acuity, pain, and the unpredictability of migraine attacks. Impairment of recreational activity was thus tied to the environmental context in	• I used to do a lot of that, where I'd go to movies and everything, theaters. Early on, years ago, I used to go to concerts. I've stopped doing that. I don't know when they decided to start using lasers at concerts, but that's one of the big things that turned me off on going to concerts. (2672) • I was part of an improv troupe for years and years and years, and I wouldn't say it's, like, physical activity – I mean, it is. You get physical, because you run around and do stuff like that, but I wouldn't sign up to do that, because I'd have to be there every week and I'd have to run around and exert myself and do that kind of thing. And it's an obligation, and I just wouldn't be able to do that. People would depend on me. So it has absolutely interfered in that hobby. (2692) • I'm no longer able to play my French horn due to the pressure and the head and neck pain. … I used to like going to the movies, I don't do that. Concerts, I don't do that. (2693) • I went on vacation in August, and as soon as we got there, the first day, the migraine was like, "I'm coming along with you. Did you forget me?" And sure enough, I couldn't even go to the beach that day, it was that bad. … But as far as recreational activities, I go out a little bit here and there with my husband and it just depends on where we're going. And I'll try and take something before I go. (2703) • I'd love to go different places. But who wants to go, first of all, to a strange place and be miserable? First of all, you're spending a lot of money, and just to, like – let's say it's a bad week or whatever period we're talking about. Who wants to spend thousands of dollars, go to a place you're unfamiliar, far away from your medical care, if need be, to be miserable? (2709) • I've gone on a trip to [location name redacted] a couple of months ago, and I had some migraine time, but it wasn't enough to ruin the trip. So in the past I would've been much more reluctant to do that, perhaps – to spend that kind of money knowing that there's a

Social Role Function	Summary	Quotations
	which the activity occurred and the physical or cognitive demands of participation. Several participants described weighing the tradeoffs of signing up for an activity that cost money against the likelihood of having to miss it; when recreational activities were more expensive, such as travel, participants seemed more inclined to avoid them. One participant also noted that travel entailed being “*far away from your medical care*.” (2709) Participants frequently described • Reduced or no ability to participate in recreational activities during ictal periods • Reduced or no ability to participate in recreational activities that entailed exposure to triggers (e.g., performances with loud noises and spotlights, the beach with high temperatures and direct sunlight) • Reluctance or inability to participate in recreational activities that required an ongoing or scheduled commitment (e.g., playing on a sports team, going on a trip) Participants noted using migraine-free days to catch up on recreational activities. Similarly, participants mentioned that when they found	good chance that several of those days I'm going to be out of it. Given that I'm at a better place, I can now do that. (2797) • I'm, like, going out to a bar, and even if I were to just like sip on a beer, the clinging of the glasses and the din of a noisy area, and the light and the harsh light - and I used to love to go out to the gay bars and dance and have fun, and I can't do that anymore. I just can't. And there's no reason why I shouldn't be able to other than the fact that my head just, it kills me. (2798) • So we wanted to go to Disney again. We took our son and his girlfriend. Second day, we were supposed to go to Epcot, which we had only been there once before, many years, with my mother, who ran us through. I woke up; I couldn't go. They went without me. And it just killed me, and my husband was so upset that I wasn't able to go. (2882) • I used to be an avid reader, and it's all gone out the window. (2909) • There have been days, weekends, where it's like, "Great. It's going to be a great weekend, I'm going to bake all weekend, I'm going to do all this fun stuff around the house," and then boom, you get a migraine, and all you're doing is lying in bed. I mean, that's just it. (2997) • [On migraine-free days] So you try to catch up on things that you weren't able to do when you had a migraine for three or four days in a row: go to the movies, out to dinner, go to a park and you want to ride your bike. I like to bike ride, I like to roller skate, and I like to read. So of course, you can't read a book if you've got a migraine, so on days you don't have a migraine you try to pick up your book and try to read and see - you know, you can catch up on some of the books you were reading. (3013) • I can't play volleyball anymore. I did that probably about seven years ago, I was playing volleyball, and it seemed to be okay, but can't do that anymore. (3018) • With painting and playing the piano, both of those, I feel like if I start to feel a headache or a migraine coming on, I pause it just because it becomes a lot harder to do the same thing because so much of my focus is being pulled off of what I'm doing at the moment. (3022) • I do like to go hiking and do things like that. So, when I have something planned and I want to go outside and do something outdoors and it's something I've been looking forward to, not being able to do that will bum me out for like a week. So, that is always an unpleasant thing just because I get to go out and do that kind of stuff so rarely, so when it gets impacted by my migraine, it's never good. (3225) • I just assume that I'm half as capable and then maybe more, maybe less after that. But 50% gone. That's one of the reasons why I can't play bridge is because it's such a weird - it's like

Social Role Function	Summary	Quotations
	effective medication and had a greater sense of control over their migraine, they resumed activities they had previously avoided. Although they knew that migraine could still interfere with their participation, their appraisal of the tradeoffs was altered by the reduced likelihood of an attack or the confidence that an attack could be relieved promptly.	playing Cricket with cards and I can't do it. … So, I could probably do gin rummy when I couldn't do bridge, but like I said, 50% gone – right off the top, and then we'll see how it is.” (3248)
Social, community, & civic roles	Found in 28 transcripts, with 160 references coded. Social, community, and civic roles received balanced discussion in relation to ictal (n=20) and interictal (n=20) periods. Three participants focused their discussion on specific social roles such as family or work and did not address community or civic roles. This code encompasses participants' ability to participate in a broad variety of social contexts, ranging from social gatherings to activities in support of community improvement or political action. During ictal phases of migraine, participants described the inability to cope with symptoms in communal, public settings. Interictal impacts included reluctance to engage in social or community events due to the possibility	**Community and civic roles** • Yeah, I do less and less and less and less. I used to be very active before all this started, and then, I just stopped participating. I stopped volunteering because I didn't know when and where the next one [migraine attack] was coming from. (2711) • And I got to the point where I just said, "Hey, I'm no longer going to be president. I'm out of here." The migraines were almost consistent, so I'd have the migraine for several days, and then I'd have the aura afterwards, and the time off in the middle was, I wasn't getting anything done at home. All I was doing was having migraines and going up and taking care of the association. I got out of that situation. (2797) • I'm a volunteer transit commissioner here in the area where I live. I write letters to the elderly who have no one to write to them. So, I'm trying to do the things that I can do that can work with the migraine. I'd love to be more active. I'd love to be more out and engage with the public on causes that matter to me, but I realize that I'm limited by what I can do. So, working around the migraine to be a virtual supporter of the causes that I believe in seems to be the way that I'm going to be going. (2997) • For volunteering stuff, a lot of the times, the volunteering that I take part in is a lot of the outdoor stuff and a lot of helping specific organizations with stuff. So, it's usually something where I figure out what it is that I need to do and I'm kind of able to go off and do that on my own. And so, in those scenarios, I can just kind of listen to music in headphones or something like that, so it's not something that needs my full focus, but it's also something where if I had a migraine, it wouldn't really change what I was doing and it wouldn't make it that much harder just because I don't have the stress of needing to work as fast or anything like that. (3022)

Social Role Function	Summary	Quotations
	of an attack and the subsequent need to cancel or leave. Participants found social, community, and civic roles and activities important and rewarding, but they often required the type of advance commitments and timely fulfillment of obligations that was challenging for people with migraine (see Predictability & Control of Migraine). Participants reported being selective in what social and community engagements they undertook, allowing them to tailor their involvement to suit their migraine experiences. Others reported that they had curtailed or ended social and community activities, including two who described themselves as living like a "*hermit*." (2882, 3233) Finally, several participants noted that social and community participation had become easier during the COVID-19 pandemic due to the huge increase in availability of remote access and participation.	**Social life** • So I would say it has impacted over the years to the point where I don't have a super social life. (2691) • I did go to one party and I kind of popped in and popped out. There was a going away party and I probably would have stayed much longer. And at the wedding, we probably would have stayed longer. We made it through most of it - we left at the reception time. So yeah, I would be able to spend more social time with people. (2813) • The past couple years, probably no, because there hasn't been a lot of things going on. But I do have another friend that I used to love to go over to her house and have coffee or whatever once in a while, and I haven't done that in a couple years, because I just couldn't do it. I just couldn't drag myself out of the house. Sometimes I feel like I've almost become a hermit. (2882) • Between the sound sensitivity and the light sensitivity, and the temperature sensitivity, and the physical just pain, both in my head and possibly in my body, depending on the migraine, social activities - it gets canceled. I've missed fourth of July celebrations, I have missed parties. It's just no. (3184) • So, my days are, you know, I'm very sedentary and, you know, I live kind of a, like a hermit. … It's kind of whittled my close relationships down to a very short list of like three people - Whereas I used to be very - I wouldn't say I was an extrovert - I was like an extroverted introvert. So, you know, I used to live in [city redacted], have a very active social life…it's kind of whittled all that down to a very, you know, reduced footprint. (3233) **Benefit of online access and participation** • You know, it's funny, with the pandemic, I've actually been more active in the community because I don't have to get up and go anywhere. I can just be on the screen or be on the phone. (2997) • Like, I can't necessarily show up at any specific time, because I might be in a migraine attack, because they're unpredictable. In person - so right now, like, during COVID, I was able to access more. Like, there's a local group that helps our homeless neighbors, and so they were doing their meetings online, so I could pop in when I could. I wouldn't have to turn my camera on. I could just listen. But now they want to do in-person meetings, I probably can't do that. (3005)
Social support and isolation	Found in 22 transcripts, with 70 references coded.	**Receiving social support**

Social Role Function	Summary	Quotations
	Social support/isolation was discussed by 15 participants in the interictal context and 11 in an ictal context. Participants reported accessing support from family and friends, migraine community groups, and others in the community. A few participants also described the ability of pets to provide needed support. Conversely, participants also reported the inability to access support or a lack of support which was associated with feelings of being alone or isolated (as expressed in the themes described below). Although a few participants were quite isolated in all respects, most reported different levels of support or isolation depending on the social context (e.g., having family support but feeling isolated at work). Social support/isolation often overlapped with the concepts of Feeling Heard, Stigma, Getting Help from Other People, Family Relations, and Interpersonal Relations.	• It's like a family, another family, the whole migraine community. Everybody's accepting and warm and you can talk about anything. So, I've grown to know all these people over the past 2.5 years, and I've had two people that have really mentored me. And I met one already, now I'm going to meet the other one. I just feel like they're like a family. You can say anything to them and they're always there for you. (2703) • But when I'm depressed, my cats are like – they love me unconditionally. And one of my cats just lays all over me, and they're really good at breaking me out of moods. So, I do think having companions for people is really helpful, but I don't know what I would have done if I didn't have my cats. I even got a second cat right when I was starting to feel worse because I just needed something else to focus on. So, that has gotten me through the emotional parts of it. (2813) • I have a couple of really, really good friends – my best friend, one of them – and we're always taking little vacations here and there for a couple of days, and it stresses me out to think about it, but they're all like, "It's okay, [name]. It's all right. If you don't feel good, you just gotta lay down. Don't worry about it." (2882) • And plus, he [husband] needs to see me through this terrible pain. Sometimes he actually needs to take days off work because – like, [clinic name redacted], for example, he needed to take, like, days off to drive me back and forth and be with me with the doctors because the tests they did was, like, they were really painful tests, so he needed to be with me. (2913) • That's something I would say, that people that have migraines understand that there might be support groups out there that can make you feel accepted, that other people understand you, that there's empathy, that you can ask questions and ask for support. (3214) **Lacking social support, feeling isolated** • And with my sisters, one is supportive. The other one tries to be, but you know, she says, "You can't always have a headache." I say, "Really? I can't?" And even my husband has that. I'll say, "I have a migraine." He says, "Oh, you always have a migraine." I say, "Yes, I always I have a migraine. Now you're starting to understand." Because it's like they just don't believe it for some reason. They think I'm making it up. (2711) • But overall, I would say horrific and pretty traumatic because if you're going to someone [a healthcare provider] who you think is going to help you and help heal you, and you just – they make you feel like you're crazy and that there's actually nothing wrong with you, then who else can I go to if you're the person that is supposed to help me? (2915)

Social Role Function	Summary	Quotations
		• Oh, there's been times where, "Oh, you know you can go. It ain't that bad." Or, "Why you always say you got a migraine when it's time to go somewhere?" And sometimes they think I use it as an excuse. [laughs] At least not as much as now, but back when I was in my 20s and stuff, they, "Oh, she ain't got no headache. She's just saying that because she don't want to go." So yeah, I have had some little chitter-chatter in the background of family members saying, "Oh, she always say that. She always got a migraine. She never can do anything." So yeah, growing up it was an issue. (3013) • But the migraines really isolated me. And I do struggle from depression, and it just magnified that a bunch. It was really brutal. (3214) • But I would say that, you know, one of the most challenging parts of all this has been, you know, the isolation – the social isolation aspects of it. You know, I guess people might label that as loneliness, for example. (3233)
Spiritual life	Found in 5 transcripts, with 6 references coded. A few participants commented that migraine interfered with their spiritual life by impairing their ability to take part in religious services or related activities. For one participant, religious life was their primary and most important social group, making the impairment more difficult to bear. During the COVID-19 pandemic, two participants noted that they were able to engage in religious activities online, which was helpful to them as people with migraine.	• People at church know that I have migraine, so I may not show up for a Bible study or something. Or if I'm scheduled to be an usher, I just, you know, I'll send them a note saying, "Migraine." And people are pretty understanding. (2797) • Well, one of my big things is going to church and helping out at church and stuff, and I haven't been able to really go to church not much or help out in the past several months, because I just – I can't sit through a service for a whole hour. (2882) • The biggest thing is my church. I go to church. There are some days where I start out at church and I end up at home because I've been run out of the church because the noise, the smell. But they understand. So, I'm very selective who's around me for the simple fact that it's just easier that way. … Because some people meditate, some people do yoga, church is where I find my balance and my centering. So, when I can't go and be around my church family – because these are people who've been with me through all the illnesses and the migraine attacks, it bothers me that I can't be there to be with them, and I miss activities that they do because I just can't do it. They go snow tubing, they go to the amusement parks and I can't do anything. So, that's the most bothersome, that I can't participate in activities all the time. (2940)
Work	Found in 31 transcripts, with 386 references coded. Participants referenced work for pay (29 transcripts) and unpaid work (6	**Missed work** • "But it started to become a lot, and then I was, you know, leaving to go to the doctor, like, every other week, getting infusions. I was hospitalized a lot. So it started to impinge quite a bit. … And then I had a really forward-thinking doctor who wanted to try all these different

Social Role Function	Summary	Quotations
	transcripts). Unpaid work included volunteering, which overlapped with content coded for Social, Community, and Civic Roles and thus is not discussed here. Work for pay was discussed in the context of both ictal (25 transcripts) and interictal experiences (21 transcripts). Themes for paid work included • Missed work (n=17) • Accommodations at work (n=16) • Reduced productivity (n=16) • Job or career loss (n=13) • Working through attacks (n=14; this topic overlaps with Pushing Through) • Working conditions as an exacerbator of migraine (n=10) All participants had worked for pay at some point in their lives and 20 (65% of the sample) were working at the time of the interview. Participants reported profound impacts from migraine on their ability to work for pay. Migraine attacks necessitated absences from work and some participants also reported requiring time off work to attend medical appointments. Many participants reported working through migraine attacks either because they had to or because the migraine was manageable enough to do so. As a result, the frequency and duration of attacks and	procedures, but every time there was a procedure it was, like, a day off of work and then a day to recover, so this is two days I was taking off.” (2692) • “I miss work. I miss work all the time. And this feeling of like – I can't miss work for anything else because I have to save any sick day that I have for a migraine. … I can't call in sick for any other reason. If I want to do something fun, I'm scared to use a PTO day or use that because I need to have that just in case I get a migraine, because I know I will. It's not a matter of if, it's a matter of when.” (2798) • “It was, like, every day I had a headache of some sort. Sometimes it was not anything too alarming, and sometimes it caused me to have to go home from work and stuff.” (2850) • “It probably was a month or two ago I woke up with this migraine, I couldn't even go to work, because I couldn't lift my head up off the pillow.” (3013) **Accommodations at work** • Well, I did have accommodations in that they came in and they took out all the florescent lights and did, like, an ergonomic thing. And for a while there, I was just getting so sick in the middle of the day that I would just crawl under my desk and just try to take, like, a half hour – during my lunch, just try to go to sleep for half an hour and hope that the migraine would go away. … And I was also asking to work from home so that I could kind of just lay on the couch in my pajamas and not have to drive in to the office. (2692) • They changed the lighting. They changed the brightness on my monitor. I have a double monitor at work, and they way that I sit, I have a better chair, and they moved my keyboard from on top of the desk so it slides out. And I can take a break whenever I need to. My supervisor's good with that. But they just – that whatever I needed to accommodate me, they would. They did an ergonomic assessment. … So, I feel a lot better that they are very supportive. (2703) • When I have a migraine episode at work, we have dedicated quiet rooms, and if it gets to the point where I need to be in a quiet room, I'll just go there. (2997) • I work in the medical field, but I can still do my job, but if it's real bad, then I just kind of adjust how I'm working. Like, if I'm doing blood pressures and that, sometimes it's hard to bend over because the pressure of the head makes it worse, so then I just have to adjust how I'm doing things. (3018) **Reduced productivity** • It affects my ability to do work in terms of actually doing work, but also how long it takes. So, lost productivity. (2915)

Social Role Function	Summary	Quotations
	the nature of medical care required were substantial factors in migraine's impact on ability to work. Numerous participants described quitting or being fired due to frequent, unavoidable absences from work. Several participants described starting their own business or finding a different type of work because of their migraine. Ability to work through attacks was also affected by the symptoms participants experienced and the level of flexibility offered by their work environment. For example, participants discussed varying ability to control light and sound stimuli at work, or to obtain accommodations ranging from workspace adaptations to flexible hours or freedom to work from home. Productivity at work was affected by migraine, including slowed performance and increased error caused by both migraine symptoms and physical or cognitive impairments, such as fatigue or difficulty concentrating. Working conditions, including work environment, task responsibilities, and overall stress, exacerbated migraine for many participants. Participants perceived that working conditions could trigger attacks, increase the overall	• Especially the work: in between making phone calls, yeah, I would lay my head on the desk for 20 or 30 minutes. Oh yeah. And normally I wouldn't do that; I would try to get off one call and make the next call so my day can get wrapped up early, but if you've got a headache, you can't do that. You've got to put your head down for every 20 minutes in between that you can. (3013) • I can usually get through that because a lot of my job is doing kind of the same couple of things once I get to my appointments. So, I can function with my migraines, it's just sometimes I'll be a little bit more clumsy or I'll sit there and I'll be staring at it, trying to remember what the next step is. … So, it's a little bit harder to converse with it, which is the part that impedes my job, more so, if I'm having migraines on my shift. (3022) • I was so tired that I couldn't finish my work properly during the day. (3104) • When I used to work in an office, I have gone to work with migraines before and nothing happens that day. I spend my entire day trying not to get caught not working because it's not happening. (3248) **Job or career loss** • I stopped being able to work in [year redacted], so I lost my career to migraine and chronic illness. • I no longer have a career in the chosen field I wanted to be in. I'm on disability. (2693) • I went to undergrad, and then worked straight out of - or, all through, and had a career of 15 years that I had to end completely because of the chronic migraine. And yeah, I haven't been able to get back to work, and I'd love to - not necessarily to that career. Definitely something less stressful. (3005) **Working through attacks** • When I was working, I didn't even realize that I was pushing through it. Like, I didn't even realize what I was doing … it wasn't till later that retrospectively I looked at all the jobs I had or the problems I've had with my jobs, and they were probably all caused by the fact that I was in pain or in some sort of pain most of the time. (2744) • So I think, actually, 10 years ago is when they started getting debilitating. But I was still working and basically stuffed things down on override and keep going. (2797) • When I had started working and I was basically throwing up in the bathroom … They must've thought I probably don't want the job, because I hang out in the bathroom, but I was really just sick and throwing up. (2909)

Social Role Function	Summary	Quotations
	frequency of attacks, or intensify symptoms when working through an attack. These work-related experiences resulted in impacts on lifestyle (e.g., several participants had to move in with family), identity and well-being (e.g., related to autonomy or financial stability), as well as feelings of anxiety, guilt, grief, depression, or frustration. Participants who were unable to work typically wished that they could do so, and many of those who did work wished that their employers could be more flexible and accommodating.	• I drive for work, so I usually just have to force my way through it. It's not ideal. It does make it a lot worse and I find myself getting a lot more irritable with the drivers around me. (3022) • But there would be days on end where I would come in and I would work with sunglasses on and I would work with an ice pack on my neck, and work for eight hours, just because I had to get my stuff done. (3104) **Working conditions as an exacerbator of migraine** • I would say at this current stage in my life, working full-time has definitely contributed to, I think, the frequency of my attacks. (2691) • So my last job was becoming kind of very stressful and felt kind of toxic and I just felt trapped and used. And my migraines increased significantly. … now I'm in a better – a job that I really like, and things are – I don't feel trapped and all of that, then, migraine-free days, maybe 20. (2915) • The work that I do is very desk-based. I'm in banking and banking supervision. And you need to be able to focus on spreadsheets, so you're looking at the screen a lot. And one thing I know that I have to do is I have to take at least five minutes every hour and not look at the screen, otherwise there's a possibility a migraine could occur. (2997) • My job has been pretty stressful, and so my sleep and everything's kind of been impacted by that, so there's sometimes where I'll get a migraine almost once a day. (3022) • When I was able to work from home, I was fine. It was just – it was the environment and – you know, I was in a great deal of pain, but if I was at home, I could do what I needed to do while I was laying in my bed in the dark, you know, and just get on my computer, that kind of thing. (2692) • It just depends on what I'm doing at work. If I'm around somebody that's talking very loud or I'm smelling somebody's food or cologne or perfume, it can intensify from there. (2703) • It's been a lot harder. It got a lot worse for light sensitivity when I worked third shift because I was under fluorescents pretty much all night. And it took me a while to realize because I had a job where I was working as a cashier and they had really strong fluorescents that were directly overhead, and I started getting headaches and extreme nausea every single time I was working. (3022)

3.5.5.1.1. Implications of Social Role Findings for Measuring Migraine

Migraine impacts all types of social roles, but the impact is heterogeneous and deeply influenced by individual circumstances as well as disease severity. The heterogeneity of migraine's impact on social roles stems from several key factors. First, because migraine can develop at any age, some patients may already have undertaken specific roles (e.g., spouse, parent) when they become ill, while others have not. Second, the supportiveness and flexibility of each person's social environment plays a large role in the way migraine burdens functioning; this environment can change substantially and abruptly due to external factors (e.g., a new supervisor in the workplace may be unsympathetic, friends and family may tire of being understanding). Third, both migraine overall severity and a person's ability to treat their attacks can influence both the patient's perceptions of their impairments as well as the responses of other people in their social context. However, this is not a linear relationship. For example, a person with chronic migraine may be fully disabled in the social realm and adopt a lifestyle described by several participants as being "*like a hermit*." Alternatively, they may encounter more understanding and willingness to be flexible among people in their social circles than someone whose disease is less severe, and thus experience less impact. As a result of this complexity, PROM items that ask about specific impacts on specific social roles may have limited utility in building an accurate picture of patient experience.

Perception of burdens on social role functioning are layered and entwined with emotional-psychological consequences, as well as individual identity and life goals. Participants' description of social role functioning demonstrated a complex, layered relationship between direct *impairments* (i.e., an attack or symptom disrupts a specific function at a specific time), *avoidance* (i.e., patients may avoid specific functions in general or during attacks because they believe they cannot fulfill them), and *disability* (i.e., a person is unable to fulfill a specific role at all due to migraine). The aggregation of these impacts is then also linked to emotional and psychological responses, such as guilt, a lost sense of identity, or the perception that one cannot undertake specific life goals such as becoming a parent. Because of these entanglements, PROM items that ask about general impacts on social role functioning in general could elicit a wide variety of individualized constructs for both the social role itself and the perception of impact, and these could also vary for the same individual over time. It may be difficult to achieve concise, accurate phrasing that adequately describes the desired outcome in a way that is interpreted consistently by patients. Finally, from the information obtained from these concept elicitation interviews, it is difficult to speculate how patients' perspectives will be affected by applying a response time frame. The inclusion of a 24-hour or 2-week recall period may influence people to focus on specific elements of their experience and to construct perceptions of impairments in a less varied manner, a question that can be explored through cognitive debriefing study.

Despite their heterogeneity, migraine's impacts on social role functioning are closely linked to symptom and treatment experiences; thus, there is reason to believe that many of these outcomes would respond to effective treatment within a short period of time. Examples of these rapid improvements in social functioning were found in multiple interviews where participants described finding an effective preventive or acute treatment and being able to resume social activities or experiencing less disruption and impairment of their social roles. Consequently, if accurate and reliable PROM items that capture social role functioning can be developed, there is good reason to expect that they could yield useful insight into the effectiveness of treatments for migraine.

3.5.5.2. Emotional and Psychological Aspects of Living with Migraine

Interview participants perceived that living with migraine resulted in a variety of psychological impacts and burdens, including short- and long-term effects on their emotional state of mind, sense of individual identity, and general sense of well-being (see Table 24). Interviews elicited information about feelings of anxiety, irritability, depression, relief, and more, as well as insights into how migraine affected people's sense of who they are in the world. Participants also provided extensive information about how migraine affected their sense of being understood and respected by other people and noted that life with migraine exposed them to a range of stigmatizing experiences. Because migraine profoundly affected every aspect of what people could and could not do, these emotional and psychological impacts were pervasive and often negative. However, many participants were also quick to note that they still had joy and lived fulfilling lives, with plans for the future and hope for improvement in their condition. Several people expressed general concern about the narrow focus on symptoms and negative outcomes they encountered in healthcare, while acknowledging that these burdens are quite substantial and of profound concern to them. This focus may, however, serve to exaggerate the negative consequences of migraine at the expense of understanding broader nuances about life with migraine. Participant 3248 perhaps said it best when reflecting back on their interview: "*One of the things that I remember from the last hour is how much that migraines have gotten into my life without my knowing – that it's usually for the person who has the migraines – it would probably sound worse than we think it is to other people who don't have to deal with it. I don't know if it actually is worse, but it probably sounds worse than it is because the way that I have described it, thinking back on my own words, is that it's like there's a gun to my head all the time. I don't feel that way, but I understand the words that I have spoken and I understand that they can be interpreted that way.*"

Many participants talked about learning to accept and adapt to life with migraine, a process that often took years. Although accepting migraine appeared to bring some participants a sense of peace or greater control over their lives—sometimes described as "*making friends with*" migraine—this psychological transition also appeared to do little to lessen the concrete burdens of the disease. Instead, comments about acceptance seemed to suggest that the fight to control migraine, or to minimize its impact on life, may add to the burden of illness. Accepting and adapting to migraine allowed participants to minimize or eliminate this added burden.

The concept of accepting and adapting to migraine is also an example of how the burdens of migraine are linked not only to its symptoms and impacts on functioning, but also to the individualized choices that people make about how to manage and respond to life with chronic illness. For example, participants made varying decisions about whether to use treatments that were effective for them (at all or for a specific attack), when and how to push though or "cocoon" during an attack, and how to adjust their lifestyle in general or their specific plans for a day in response to migraine. These decisions have emotional and psychological components and consequences. For example, a person may push through an attack because they consider it part of their identity to honor their commitments, but the consequences may include increased irritability or depression.

Table 24. Summary of Emotional and Psychological Concepts

Emotional / Psychological Concept	Summary	Quotations
Accepting or adapting	Found in 23 transcripts, with 63 references coded. 14 participants discussed this concept in the context of ictal experiences and 9 in the context of interictal periods. Accepting and adapting encompassed notions related to, but different from, Coping or Pushing Through. These latter concepts included active practices and behaviors, while accepting/adapting reflected a deliberate shift in attitude to accept life with migraine as a "*new normal*" or to adopt "*a positive attitude*" or to "*make friends*" with migraine, which entailed focusing on what one can do rather than on what one cannot.	**"Learning to live with it"** • So after a year and a half, two years of dealing with this, it's like, okay, doctors don't know. I just have to learn to live with it. … And I learned to live my life dealing with it. (2672) • Well, I accept things. It is what it is. (2797) • So right now, I consider myself as controlled as I'm going to get on few medications as possible. … So, is there a pattern to it? Probably – I don't know. There is no pattern to it, I feel like. It's just, this is my new normal. (2909) **"A positive attitude"** • I've tried to adopt, let me call it, more of a can-do attitude, because I found attitude is important. … I try to keep what I'll call my head on straight, and I try to remain – you know. I like being a realist, but I try to keep a positive kind of spin. Like, I ask myself, instead of "what can't I do," what can I do?" (2709) • And so, I think that is the biggest thing is just respecting it and kind of maybe treating it – basically to stop resisting. To treat it more like a friend and try to understand it rather than this uninvited intruder because that just makes it worse. I need to work with it and not against it. (2915) • At one point it was like, make friends with [my migraines] – you know, like, I would try to accept my pain situation. (3005)
Emotional States	Found in 31 transcripts, with 432 references coded overall. Participants described migraine's impact on their emotional state in three primary ways: mood swings experienced as a symptom of migraine (see Changes in Mood), cumulative or longer-term effects on mood caused by migraine, and the	**Anxiety** • When I feel it [an attack] coming on, I start feeling like almost like an anxiety because I know what's about to happen, because I can feel it. And it's starting to build. (2711) • I've always been sort of anxious to get nauseous with migraines because you can't take anything, or there's nothing really that works for it. (2830) • Definitely anxiety and worry, yes, because I know there's things I have to do, and I can't do it, and, well, how am I going to get this done, or, you know, who's going to take care of that if I don't do it? (2882) • You know, so I think I kind of live in fear. So, even when I don't have a migraine, I'm afraid that I'm going to have one or that I'm going to somehow trigger one. (3233)

Emotional / Psychological Concept	Summary	Quotations
	emotions associated with experiences of function impairment. Participants associated the following emotions with their migraine experiences: • **Anxiety** (n=25): Ictal experience as a symptom and a result of an attack, such as anxiety about how severe or long-lasting an attack might be; interictal about having an attack in the future or overall impacts of migraine. • **Anger or frustration** (n=24): Ictal experience as a symptom and a result of migraine, such as anger at having an attack; interictal frustration with overall limitations and impacts of migraine. • **Depression** (n=19): Ictal experience as a symptom; interictal depression linked to how one's life is constrained. • **Irritability** (n=18): Ictal experience only as a symptom or result of symptoms (i.e., people are irritable because they feel sick). • **Relief, feeling invigorated** (n=18): Postdrome and interictal experience as relief from symptoms, sometimes accompanied by a strong desire to catch up on missed activity.	**Anger or frustration** • The frustrations that have come with not having health insurance, not having great answers, and really just, at this point, feeling like I have to live with this. (2691) • The worst thing is when you're trying to concentrate or get stuff done and you just feel like you're going in slow motion. That's very aggravating for me, because there's stuff I need to get done (3018) • I'm missing out on life. And it's incredibly frustrating and depressing. It gets depressing when you think about it. At the moment, it's just frustrating. (3184) **Depression or sadness** • I feel sad, because being in pain is no way to live. (2909) • It is kind of depressing to think about it, when it's piled up, and all the things that kind of immediately get shut down when I end up getting migraines (3022) • If we're being honest, I go really dark sometimes. I get super, super depressed and really quickly, almost like whiplash almost, where an hour ago, I was totally fine (3104) **Irritability** • I feel like when my pain is really high, I'm also very impatient. (2672) • There's the end migraine symptoms, which are like I get the irritation and the depression. (2813) • It definitely makes me more irritable and less patient with everything around me, like people or objects or noise. (3022) **Relief, feeling invigorated** • And when I have a good day, I'm excited. There's a relief when I have a good day, a tremendous relief. … a migraine free day is a gift, and I take them that way. I don't take them for granted. (3214) • You know, sometimes I feel like, oh my god, I don't have a migraine today, I want to go turn cartwheels in the street. (3233) **Energy and drive** • I feel like I get more energy back [after an attack]. (2703) • Between headaches, I get this period that I really want to sleep. Like, I don't want to do anything other than just sleeping. It felt like my body is so, like, heavy, if that makes sense. … And it's really hard to motivate myself as well - like, to tell myself, "No, today is a shiny day. Let's get out the bed and do stuff." It's really difficult for me to do that. (2913)

Emotional / Psychological Concept	Summary	Quotations
	- **Energy and drive** (n=16): Ictal experience of reduced energy; interictal experience of increased or decreased energy, often linked to attack frequency or duration and the subsequent level of fatigue. - **Skepticism** (n=15): Ictal experience as mistrust of ability to accurately judge symptoms; interictal experience as skepticism of treatment efficacy, healthcare provider knowledge, or their own ability to understand and cope with migraine. - **Guilt** (n=12): Ictal and interictal experience as guilt over behavior during an attack, inability to keep commitments, or burden placed on others. - **Happiness or euphoria** (n=12): Ictal experience as joy when abortive medication works or an attack ends; interictal experience on migraine-free days. - **Embarrassment** (n=10): Ictal and interictal experience as embarrassment over impairments like misspeaking words or having to cancel plans. - **Grief** (n=3): Interictal grief over lost opportunities and time. - **Other**	- But it's the energy level. It just really feels like somebody's sucked the life out of you and you're trying to get a little bit back. (3018) **Skepticism** - But I have doubts how well I can cope…I'm sure people do this, but sometimes I question my own sanity. Am I really feeling as bad as I think I'm feeling? Answer is probably yes. But I do question myself. (2672) - I said to a doctor, which I think offended him maybe a little, because he told me how bad he feels, and I said, "I feel worse for you guys." And he says, "Why do you say that?" I said, "Think about it. You went to medical school. You do fellowships. You're double-, triple-board certified. And you still don't seem to know anything about this." (2709) **Guilt** - Things where I feel like I'm acting in a way that I wouldn't if I weren't in pain, and feeling guilty about that. (2691) - I feel bad because I feel like everyone's always having to adjust how they are for me. (2798) **Happiness or euphoria** - One doctor tried me on Maxalt. Within 30 minutes, ugh, the migraine was completely gone. … I was so happy, I wanted to dance around. (2882) - Yeah, because you don't have the pain, you're happy, you're smiling, you're joyful. Happy not to be in pain. (3013) **Embarrassment** - It's very embarrassing, especially in business. You're talking to a new client and your words come out all jumbled up (2689) - I don't know if embarrassed is the right word, but I definitely knew that my reputation was that like oh, she'll flake on you because she won't be there because she's sick, and I hated that. But I also knew it was true. (2890) **Grief** - I grieved a lot for my career (2692) - And not going to four-year degree. That was heartbreaking, actually, because I worked so hard for it, and I had the grades and I had everything. I just couldn't do it. So that was really hard for me as well. (2913) - **Other**

Emotional / Psychological Concept	Summary	Quotations
	○ Other positive thoughts (n=5): Included hope for the future and a deliberate, positive attitude. ○ Other negative thoughts (n=10): Included a negative outlook on the future and thoughts of feeling like a failure.	• That migraines are debilitating. I'm sure you know that by now. But they're coming out with new medications, so it's hope for us migraine sufferers, and we just hope they get them on the market. … Yeah, that's how you've got to look at it. You've just got to look at it, like, you know, with some positivity that they're working on it behind the scenes. We might not see it every day, but they're working on it. (3013) • It's the results of not being able to do something, feeling like a failure, feeling lazy (3104)
Feeling heard	Found in 29 transcripts, with 271 references coded. Most participants described times when they did or did not feel like other people heard them and understood what they were going through. This concept encompassed interactions with family and friends, health care providers, and others within work, school, or general society. Participants described these experiences when discussing both ictal (n=22) and interictal (n=17) periods. Although many participants described having supportive family and friends, clinicians, or other communities, most also had negative experiences with people who did not take migraine seriously or were dismissive of the burden created by migraine. These negative experiences created strain in interpersonal relationships or led to frustration, anxiety, or shame.	**Friends-family** • Most my friends are very understanding, and they're like, "Oh, yeah, whenever you can, and if you cancel, we totally understand. You can cancel last minute." So actually, I would say all of my friends are like that. They know what's going on. (2692) • My mom is hard to deal with. … so sometimes that becomes a problem where it's like, "Can you stop stressing me out because I have a neurological disorder that you're kind of giving me a head pain here?" You know, she kind of rolls her eyes or sometimes - and it was hard at first because I don't think she took it very seriously. (2813) **Healthcare providers** • I also have a really good headache specialist who's willing to, you know, "Okay, come in for an infusion. Okay, we'll try this medication. Okay, we'll do a steroid taper." Kind of like, you know, we're not going to give up. There's always something else that we can try. So I feel like, since I have a good team of doctors, that I'm less likely to totally freak out than someone who maybe doesn't have that support. (2692) • I went to 20 doctors in eight years, and they're basically like, "You're fine. It's all in your head. You're too young to be sick." So, I feel like… they dismissed everything. … So, that was really frustrating. … overall, I would say horrific and pretty traumatic because if you're going to someone who you think is going to help you and help heal you, and you just - they make you feel like you're crazy and that there's actually nothing wrong with you, then who else can I go to if you're the person that is supposed to help me? (2915) **Work, school, or society in general** • I think people understand chronic conditions from afar, if that makes sense. They want to understand, but they don't want it to actually be chronic and actually affect- They don't want to hear that you have a migraine again. They don't want to hear that you can't have their cupcakes that they made because you're going to get a migraine. … So, there was a

Emotional / Psychological Concept	Summary	Quotations
	Feeling heard was related to both Stigma and Social Support or Isolation. When participants had access to a strong support system among friends, family, or other community group, they typically felt heard and understood. Similarly, participants often related their negative experiences with not being listened to or understood to stigma.	time where there was a lot of friction and it was causing me a lot of anxiety because I felt like people weren't being – they weren't understanding, they weren't being empathetic or caring about it. (2915) • My workplace doesn't care at all. … They aren't understanding about the migraines. It's pretty much a scenario of "we don't care if you're physically injured, mentally injured, or something's impeding your day." (3022) • [About a former employer] And he was very, very understanding, and I could take my sick time and leave and go home for taking meds that would knock down the migraine. And he'd send me home before it turned into a blinding migraine. But he understood migraine. (3184)
Identity	Found in 26 transcripts, with 88 references coded. Participants discussed identity in the context of both ictal (n=18) and interictal (n=18) phases. The concept of identity was dynamic and highly individualized, involving a heterogeneous array of internal and external factors such as views on one's personality and values; family relations and social support; life roles and responsibilities; and personal experiences with migraine. These varying aspects of migraine experience jointly and severally affected people's self-image and perceptions of their identity within the world. Many participants discussed loss or reconstruction of identity in relation to their inability to predict or control	**Impact of predictability or level of control of migraine on identity** • You know, I like people to feel that they can rely on something that I do, and I don't like it when I can't fulfill that. That's my self-image. (2797) • I decided to cut out a lot of people because I have often been punished for being sick. And I understand from their perspective, that they think that if I have to cancel last minute that I'm making it up or that it's rude, or they think that I may be flaky, which I hate that. I have never liked flaky people so I would never in a million years want to be labeled or seen as flaky but sometimes I just can't control. (2915) • But who I was in 2019 and what I was doing, where my life was going, before the diagnosis, I hardly recognize that person because over the past however long that's been, almost three years, I've made so many changes in my life because I've had to because it got so bad that I was willing to try really anything to stop the pain. (3104) **Impact of mood changes on identity** • I'm not my normal easygoing self, you know? I'm more likely to be snappish. (2797) • I definitely have felt anxiety spikes and, like I said, anger or irritability that's not my nature normally, my personality. (3005) • I've always, always been very happy-go-lucky, you know, but not with migraines. It's just kind of changed me in that aspect. (2882) **Impact of mental acuity changes and cognitive impairment on identity** • I want to be smart again. That's so key. I just want to be me. I want to be me again (2689) • I think also I don't feel – and I've been very self-conscious about this – I don't feel like my cognitive ability has gone back to normal … And then people also made comments like, "You're witty. You're quick to learn and to catch onto things." And I don't feel like I have

Emotional / Psychological Concept	Summary	Quotations
	migraine attacks, the ictal impacts on their emotional state and cognitive function, and the ictal and interictal impairments of role functioning they experienced over time. However, many other participants had had migraine since early childhood or for many decades, thus change in identity was not anchored to the memory of a migraine-free past but constructed in terms of changes in migraine experiences themselves (e.g., changes in frequency or severity). Finally, not all identity change was viewed negatively and some participants valued new identities that had emerged because of migraine. Some of these participants associated identity changes with a broader life re-evaluation captured in the concept of [Accepting or Adapting]to migraine. Participants identified several aspects of living with migraine as major factors affecting identity: • Predictability or level of control over migraine • Mood changes resulting from migraine • Mental acuity changes resulting from migraine	gotten back to that and I do fear that I'm not going to. And so, that's been something really hard to navigate through because I felt like those were things that were part of my identity and losing those things was a whole thing that I need to navigate through. (2915) **Migraine becomes one's "whole life"** • I'd say I have a PhD in migraine. Like, I have studied it, read about it, lived with it, tried so many different treatments, and it takes so much time to get my treatments covered by insurance, that it's basically my whole life at this point. (3005) • I'm on disability and I haven't been working, you know, this interrupted my career, or ended - ended it perhaps, so it's just kind of turned into, I guess, a way of life, you know, sadly. … Whereas I used to be very - I wouldn't say I was an extrovert - I was like an extroverted introvert. So, you know, I used to live in [city redacted], have a very active social life, you know, a very active career working in [regional location redacted], travelled a lot both for work and pleasure, so it's - it's kind of whittled all that down to a very, you know, reduced footprint. (3233) **Finding a new identity** • It's hard being [age redacted] and not working, you know? Because you go meet a new person, and the question is, "Oh, what do you do?" And, I mean, now I figured that I'd just say, "I'm a patient advocate," or, you know, "I work in advocacy." So I figured out that kind of thing, because I still do work, I just don't earn a living, you know? … [Migraine] has given me a fabulous community, and - I mean, the migraine community is really, really fantastic. And while I do miss my job, the work I do now - you know, I used to work in government relations and public policy, and this is the first time, with the migraine advocacy, that I've ever been able to kind of lobby on my own cause, and it's just been fantastic, so that's really been great. (2692) • I never had a situation where I did have - like that thing that I was afraid of? It never happened. The monster at the end of this book never happened. … It has affected the way that I work more than other things that have affected the way that I work. … I have gotten really, really fast at doing things, and I do things a little differently than most of the people that I know because I'm always thinking about "What if I have a bad migraine one day and I need to get this out the door quickly?" I need lots of little mechanized procedures in place. The software that I have to use, I use slightly differently than a lot of the people that I know just because I am always thinking about speed, speed, speed. How do you do it

Emotional / Psychological Concept	Summary	Quotations
	- Migraine becomes one's "*whole life*" because it occupies so much time and effort	faster, because maybe I only have two hours to work today. How do I do four hours in two hours? I've learned ways to do it. But yeah, it has affected me, but not always negatively. (3248)
Life satisfaction and meaning	Found in 16 transcripts, with 33 references coded. All 16 participants referenced aspects of life satisfaction and meaning in discussing interictal experiences and 4 mentioned it in the context of ictal phases. Participants routinely connected migraine symptoms and impacts to the distal outcomes of life satisfaction and meaning. Impacts on life satisfaction and meaning arose from impairment of functions that in turn affected people's ability to take part in satisfying and meaningful activities or roles. But, there was also heterogeneity in what people said. Participants with profound impairments, for example, often had a more negative view of the meaningfulness of their lives. Others had found alternative ways of constructing a meaningful life. Migraine made some participants apprehensive about taking on meaningful activities and roles. Finally, those who did take on meaningful activities and roles sometimes described their experiences as ones they endured rather than enjoyed.	• I think it was the bucket theory or something like that. Whereas, whatever sensory input, whatever will potentially trigger an attack, you can take so much of it before the attack finally happens. And I remember reading that. It's like, "Oh, I don't have a bucket. I have a thimble." I would love to have a bucket so I could handle more of this and still be able to do what I want to do. Having more confidence that I will be able to do everything without the negative consequences of an attack. Because just knowing that an attack is likely is a big damper on wanting to do things. And it's hard to be excited. … If you're fearful of an attack, that puts a damper on your excitement for anything else. (2672) • I grieved a lot for my career, because I'm a single woman, and I kind of had – my image of myself was a lot tied to my career, and so when that was gone, it was like, ugh, what am I going to do? And so I belong to a whole lot of organizations that I find a way to fill my days with that, to a lot of degree. (2692) • What bothers me the most. It would be easy to say pain, but it's not the pain. It's what I'm missing out of because I have migraine. It's what I can't do or what I would like to do that doesn't happen because of my lack of functioning, whether that's taking care of my kids, holding a job, feeling fulfilled with some sort of hobby or career – even making plans with friends and it not have to get canceled at the last minute because I have migraine. (2744) • I try to volunteer. You know, it's like, I'm [age redacted]. I want to do something just so I don't wither away just sitting at home. (2909) • So mostly I'm just staying home all the time. It gets pretty boring. And with, like, psychological, it's really hard on me, because, you know, like, I'm an adult, and I want to do stuff. I want to do stuff for my own as well, but I really can't do stuff, because – you know, it's being crippled in a lot of ways. (2913) • I think my quality of life is pretty low on – on like a, you know, some of the different scales that health providers use to measure that. So, my days are, you know—I'm very sedentary and, you know, I live kind of like a hermit. (3233)

Emotional / Psychological Concept	Summary	Quotations
Stigma	Found in 23 transcripts, with 68 references coded. Participants reported experiencing stigma in the context of relationships with friends and family and within the health care system, workplace environment, or society in general (external, medical and societal stigma). Participants also described internalized stigma associated with negative emotion states (e.g., embarrassment, guilt), identity, and well-being.	• Probably the most significant thing, the greatest hurdles, I had to go through to get to where I am now – with adequate treatment and everything – was the medical system itself. So whether it's preconceived notion of what a migraine is, or whether it's doctors just not being familiar with the wide variety or the subtypes of migraine, that all caused a significant delay in receiving treatment. And that delay in treatment probably made my condition worse. (2672) • So the speech is definitely bothersome. I feel like communication is super important just as being a person, and that really bothers me because it makes me feel like people don't understand me, and I feel, yeah, like people judge others based on their ability to communicate effectively. (2691) • I had an emergency room visit, and I felt like the doctor was treating me as if I was a drug seeker and didn't really want to listen to what I was having to say. (2703) • Maybe there should be more of a public understanding about what's going on. And just about migraines in particular. There's an awful stigma about migraines. The whole "just a headache" thing. (3214)
Well-being	Found in 27 transcripts, with 206 references coded. This code was used for comments about the general ability to achieve a state of being comfortable, healthy, and happy. This includes references to the ability to have the life one desires and to do the things one needs and wants to do, as well as the ability to enjoy life. There were five themes related to well-being • Impact of migraine on the ability to enjoy life • Impact of migraine on the ability to do what one needs or wishes to do	**Ability to enjoy life** • I just want to be normal. I'm not enjoying this, I'm not enjoying life like this. I just want to be normal, whatever normal is. Pain free. That's it. Migraine free. (2940) • And it's pretty much living a very boring, routine life, because our migraine brains like routine. So, it's frustrating, to say the least. (2693) • I mean, because it interferes with life. … I think even [clinician name redacted] said, because I heard someone else say it – someone asked the question, "Well, can migraine kill you?" And he said, "No, but you might wish you were dead." It ruins your life. (2709) • Not allow me to have a life or live or be present, but just bogged down with the pain and symptoms so much that I can't literally do anything else. (2744) • So mostly I'm just staying home all the time. It gets pretty boring. And with, like, psychological, it's really hard on me, because, you know, like, I'm an adult, and I want to do stuff. I want to do stuff for my own as well, but I really can't do stuff, because – you know, it's being crippled in a lot of ways. (2913) • So really it's the pain and not being able to enjoy plans you already had, or just have an enjoyable life, because you're having 15 or more migraines a month. (3013) **Ability to do what one needs or wishes to do**

Emotional / Psychological Concept	Summary	Quotations
	- The feeling of "missing out" on life - Finding fulfillment - Prioritizing health and wellness These themes overlap with each other—for example, the ability to enjoy life may hinge on the ability to do what one needs to do—and the content in this code also overlaps with many other codes. Thus, the concept of well-being encompasses a variety of experiences that participants condense or blend together into overarching thoughts about their level of comfort and contentment with life. Participants recognized tradeoffs between successful management of migraine and achievement of their vision of well-being. Ideal management of migraine, if it involved limiting activity and exposure to triggers, could result in a constrained or "*boring*" life that was unsatisfying. However, poor management of migraine could result in increased impacts on functioning that resulted in more "missing out." Participants noted weighing these tradeoffs when deciding what activities to prioritize or where to seek alternative sources of joy or fulfillment. Similarly, the conundrum of balancing migraine impacts with aspects of well-being was evident in responses	- I've gotten better at learning to take care of myself and putting my health first before social obligations. But there is something about not letting the migraine interfere with any kind of social responsibilities that I have, whether it's going out on a date or going to a concert that keeps my mood elevated, even though I'm in an incredible amount of pain when I'm doing those things, and for the most part pretending to be engaged with what I'm doing. I am, I would say, happier, have more positive feelings then, than I do when I'm taking care of myself. (3225) - Grocery shopping. I can't go in a grocery store right now. It's too painful. I'd be too disoriented. I get dizzy also in migraines, so I'm lucky my partner went shopping for me. It's even a challenge to cook sometimes. So those are the things I need to do. And then want is, like, a lot of things. Like, my friends went out to the movies; I couldn't join them. Some friends, yeah, were outside having a picnic, and I couldn't join them. And I can't work. I've been trying to - like, I'll try to volunteer, hoping I can get back to work. (3005) - I'm mad because I didn't get to go do something, or I didn't do something, or I didn't take part in something, or I wasn't productive enough, or I wasn't - I think that's where that kicks in, is that I'm irritable and depressed about - and anxious - about things that I couldn't do or didn't do or should have done or would've done if I didn't have migraine pain. (2744) - So, it's the results of not being able to do something, feeling like a failure, feeling lazy when it's not - I hate the word lazy because I don't think anybody's ever really lazy, it's just not being able to do what I want to do. Taking away that independence, taking away that autonomy. (3104) **"Missing out" on life** - It's what I'm missing out of because I have migraine. It's what I can't do or what I would like to do that doesn't happen because of my lack of functioning, whether that's taking care of my kids, holding a job, feeling fulfilled with some sort of hobby or career - even making plans with friends and it not have to get canceled at the last minute because I have migraine. (2744) - I'm tired of losing more time out of my life…But I still want to be here. That's the thing is that I don't want to be canceled, I don't want to cancel out the world. I need to be here. (2798) - So, on one hand, it's kind of like, oh there's all this stuff that I miss out on or that I have to end up omitting from just because of my migraine. But then on the other hand, I don't know

Emotional / Psychological Concept	Summary	Quotations
	participants gave to the final interview question, which asked “what are the key things about your migraine that would have to change in order for you to live the life you'd like to live?” Many participants responded to this question by saying that they wished for reductions in the number of attacks or in the severity of specific symptoms or impacts that would permit greater well-being. Participant 3104, who had had frequent severe attacks but recently found effective medication, may have said it best: *“Really great question. I think that it's almost like I can't even imagine something to be better than what I have now just because I saw and experienced just how bad it could get. So, for me now, even experiencing a couple a month is like nothing that it ever was before, and I'm so grateful to even have those, just to know that it's not - and they're hardly ever as bad as they were…for now, I'm just grateful for where I'm at and for what I've done and been through to be able to appreciate what I have now because I know that it could be a lot worse.”*	the full cause of it, so there's not really anywhere to place blame for it, so it's just kind of like accepting it. (3022) **Fulfillment in life** • It's what I can't do or what I would like to do that doesn't happen because of my lack of functioning, whether that's taking care of my kids, holding a job, feeling fulfilled with some sort of hobby or career - even making plans with friends and it not have to get canceled at the last minute because I have migraine. (2744) • Most of the emotions that bother me the most is, like, feeling crippled, because yeah, I feel crippled a lot, and it's really not a good feeling to feel like that. So that's the most thing that bothers me. And not going to four-year degree. That was heartbreaking, actually, because I worked so hard for it, and I had the grades and I had everything. I just couldn't do it. So that was really hard for me as well. (2913) • I was talking to my friend yesterday, and he's a few years younger than I am, and we were talking how in our brains we have all this energy and all, but then the body doesn't seem to be on the same page. It's like, I have all these ideas - like I said, the artisan baking class - I got all these things I want to do - study with this chef who's world renowned. … But it's - the body just doesn't - and the body is like, you're crazy. (2709) • The irony, right? The irony of it, that I actually went to film school. I studied cinema. I have cinema production certificate, and I majored in screenwriting. So, like, you know, that's what I'm supposed to be doing: watching movies and making movies and stuff like that, but I can't. So when it comes to movies, it really makes me sad that I can't watch them. (2913) **Prioritizing health and well-being** • I've also gotten better at recognizing when I should or shouldn't keep a dinner reservation. Whereas, previously in my mid-20s, I'd be like, "I can totally do this." Then, I'd just sit at dinner with an incredible migraine, not even being able to basically see the other person across the table. And so, I've gotten better at declining those and taking care of myself, and I've gotten better at prioritizing my own health. And in that way, it has interfered with a lot of social activities that previously I would just muddle through unless the migraine was like the top 10% of migraines. (3225)

3.5.5.2.1. Implications of Emotional-Psychological Findings for Measuring Migraine

Some emotional responses to migraine are commonly experienced and are closely linked to attacks, but may persist in interictal periods; thus, these emotions may be suitable as COIs that help better describe holistic patient experiences and responses to treatment. In particular, anxiety, frustration, and irritability are closely connected with migraine attack experiences, but also linger or occur in interictal periods. Changes in the frequency or severity of these feelings may provide added understanding about what people living with migraine experience in response to treatments. For example, an acute treatment that works well and quickly to relieve symptoms, but does so inconsistently, may not provide the same relief from interictal anxiety and frustration compared with one that works reliably. However, it is unclear from these data whether these interictal emotions would respond within a short period of time to an improved treatment, particularly for patients who may have a long history of treatments that worked for a while and then became ineffective.

Most emotional-psychological concepts appear less well suited as COIs for clinical outcomes assessment. Although the evidence showed that many other emotional and psychological components of migraine experience are crucially important to people with migraine and involve profound impacts on functioning, the interviews also demonstrated that many of these are heterogeneous, and some may not be directly connected to symptoms. For many people, these components are also linked to external factors that would not be affected by treatment. A key example of this are those patients who were retired and had adequate financial resources and those who were able to work from home or start their own business. These socioeconomic conditions were unrelated to migraine but, by participants' own accounting, resulted in fewer emotional or psychological burdens.

3.5.5.3. Managing Migraine

Interviews showed that participants engaged in a wide variety of practices aimed at managing or mitigating the symptoms and impacts of migraine, including the use of non-pharmaceutical treatments and withdrawing or cocooning (see Table 25). When successful, these practices affected the level and type of migraine symptoms and impacts people experienced. However, this included increasing the perceived levels of impairment from migraine, as well as perceived reductions. For example, cocooning could reduce perceived severity because the practice could prevent an attack from worsening, but also increase perceived impairment of functioning because participants could do nothing at all during these periods of time.

Participants also described features of migraine, such as its unpredictability and the direct costs it imposes, that presented challenges for managing attacks and contributed to the psychosocial burdens associated with migraine. For example, unpredictability resulted in diverse burdens such as having to always be prepared with a "*migraine toolbox*" of therapies, but also experiencing uncertainty about whether, when, and how to treat an attack, particularly when people had limited quantities of effective abortive medication. Unpredictability made people feel reluctant or unable to make plans, which contributed to feelings of frustration and isolation.

Table 25. Summary of Concepts Related to Management of Migraine

Migraine Management Concept	Summary	Quotations
Coping	Found in 31 transcripts, with 475 references coded. There were six themes within the Coping code. These themes reflect different aspects of coping: • Cocooning (n=29) encompasses practices of withdrawal and self-isolation during an attack; though most participants retreated to a dark, quiet room, this was not the only environment in which cocooning took place. Cocooning occurred during ictal phases. • Voluntary avoidance (n=17) encompasses choosing to avoid selected activities or interactions during an attack, as opposed to fully withdrawing. • Non-pharmaceutical therapies (n=12) encompass the use of multiple treatments other than medication to address symptoms during an attack or employed interictally to prevent attacks. • Lifestyle changes and adjustments (n=11) encompasses interictal actions taken to prevent or reduce symptoms such as adopting healthy lifestyle routines (sleep, diet,	**Cocooning** • If it's really bad, a really bad attack, yes. But at that point I usually retreat into my, as I call it, my cave. My darkroom. (2692) • I just stay in bed in a dark room trying to be as quiet as possible. Just, like, still, you know? Like, just trying to stay still. (2913) • I have a thing that I used to do when I got a hangover in college, at the end of the night, I would lay down in the bathroom on the cool tile with the lights turned off running the shower. So, that is what I will tend to do once it's at its peak. … I just have to sit with something cold on my head and on my neck, and just wait for it to go away (3225) • I just have to retreat. I have to come back and close the curtains in my room, turn off all the lights. … So yeah, migraine makes the world stop and I miss out. (3184) **Voluntary avoidance** • Some of my hobbies are not physically straining, but nonetheless, I like to do lampwork, make glass beads. … But because the flame is so bright and you have to focus so hard, I won't - if I'm in an attack, I don't do any of my hobbies, end of discussion. (2689) • Sometimes you mentally remove yourself because it almost hurts to try and keep up with everything. … And I don't talk. There are times when I just won't participate in the conversation, because I know I'm going to have problems. (2689) • So, it's almost like being on autopilot in terms of a conversation. You can respond superficially to what they're saying, at least enough to keep the conversation going. But as far as being engaged or interested or applying any kind of thought to exactly what is happening, that is kind of off limits. (3225) **Non-pharmaceutical therapies** • Slowly walking outdoors with the fresh air helps me. Indoors does not. … For some reason, fresh air always makes me feel better. (2689) • And I use peppermint aromatherapy cooling sticks - like, it just goes on my wrists - for the nausea, so. … And I have a whole bunch of different weighted masks and that kind of thing just to be more comfortable, you know. (2692) • I use these, they're self-warming masks. I like heat better because I'm always cold. So, at night, I'll put this self-warming mask on my face and it kind of helps me relax. And I bought

Migraine Management Concept	Summary	Quotations
	exercise, etc.) or prioritizing one's own health needs to improve quality of life and reduce migraine burden. Some participants referred to trying these strategies without receiving much benefit (e.g., participant 2744 had tried yoga and other strategies, but found that only medication was helpful). • Sensory control (n=10) encompasses strategies to control, decrease, or eliminate ictal or interictal exposure to sensory stimuli that may cause or exacerbate attacks. • Maintaining (n=5) referred to strategies and behaviors aimed at preventing migraine symptoms or impacts from progressing or worsening during an attack, but not necessarily at obtaining relief.	a different pillow that kind of has that groove in it where your head and neck, it's like cervical pillow, so I have that as well. … And then I just try and do some relaxing. And I make sure I stay hydrated. (2703) • Sometimes, I'll use some essential oils, specifically peppermint. Inhaling that pretty deep tends to constrict vessels up into the sinuses and up into the head, and sometimes that will help. (2753) • I have the ice hat. I do that. I meditate. I do stretches. And then, I stretch out my neck too. (2798) • I think massage and chiropractic has been the most helpful because at the point when I started massage, my whole body just felt like a big spasm. It was just like a stiff brick. And I still have to get a massage at least every two weeks, otherwise my body starts really stiffening up and hurting and things like that. (2813) **Lifestyle changes** • I've done, over the past couple of years, elimination diets in order to try to figure out specific triggers, but one of the big ones was very salty food and pork, and so I am now vegan as a result of doing those food tracking. (2691) • Making sure I don't do anything to disrupt my sleep, which is really easy to do. And I really hate – the doctors were right on this one – but exercise. So, regular exercise, which is really hard to do when you have an attack going. (2672) • I have to eat a completely different diet. And I do, and I stick to that diet. I am very careful about what I eat. I don't eat chocolate or cheese or no wine and no – really no alcohol, and no processed meats. I mean, the list just goes on. I'm very – I stick to the migraine diet. I really do. (2798) • In fact, because of the migraines, I went from like – so, I have like an afro hair and I was just doing wash and go's for my natural hair, but I switched to locking my hair. So, I'm actually doing freeform dreadlocks. So, I just have to wash my hair regularly and that's it because I just – I was like, I can't. I either have to cut my hair super short, or I have to dread it because I just don't have any energy for this. So yeah, so it did affect that. I made a conscious choice. (2813) • I feel like I'm actively working on changing that to live my best life. And that is, paying attention, listening to what my body's saying, and then responding accordingly because that's something, like I mentioned, that I have not been good at because I was focusing on

Migraine Management Concept	Summary	Quotations
		being perfect at work basically that whole overachiever sickness that I'm going to call it because that is not a healthy situation to be obsessively wanting to be the best all the time and prioritizing work, etc. (2915) **Sensory control** • I use, like, this distraction therapy where I'll turn the TV on to something like HGTV where the talking is very kind of even and the lights don't flash or anything like that, but I do have my eye mask on. And it's at just a level where my brain will try and listen to that to kind of take away from focusing on the pain. (2689) • I have these red-tinted glasses - you know, the S1 - I forget the number. And I'll wear them in the house even when I don't have an attack. (2692) • I have a back room that I usually use like a little office area, and it's a dimmer light in there as well. And everybody's knows that's mom's room. And I go in there, and I get on my laptop. I changed the brightness of my laptop. I've gotten these TheraSpec glasses. They're kind of light blocking. (2703) • I never have lights on in my house. (2744) • I've tried the little half ear plugs. They help a little bit, a little bit. … For the high pitched frequencies, like the ones that my air conditioner makes or those kinds of things, the ambulant squeals, it doesn't help. But it drowns out the lower ones. (2798) **"Maintaining"** • I also know when one's going to be coming on. So it's just more of a slow pace when I start feeling one coming on versus when I can just - I used to always just push through and people would say, "Oh, how are you feeling?" And I used to always say, "I'm maintaining." … And sometimes, I just fake it and be like, "Oh yeah, I'm good. I'm good." Until okay, it's two hours now, we can go home. That's where I get the maintaining from. (2703) • I try to maintain so that it doesn't crawl too far into other areas of my life. (2753) • I'm pretty good at doing things like lowering my breathing rate and my pulse rate and my blood pressure, which doesn't abort the migraine, but it makes it less intense for me to ride it out. (3233)
Direct costs	Found in 21 transcripts, with 54 references coded.	• I had to go on Medicare last year and getting things paid for is so much stress, it's unbelievable. I mean, it has me in tears sometimes. I finally find something that works, and it's not covered, it won't be covered, and it's going to cost me several hundred up to maybe a thousand dollars a month. And before that I had private insurance through my employer,

Migraine Management Concept	Summary	Quotations
	The most common direct costs reported were medication costs, time spent seeking medical care, and time spent dealing with insurance companies. Cost considerations were mentioned as a reason that participants rationed their medication or were unable to get treatment. Time spent seeking care interfered with some aspects of life, such as work, and several participants commented on how not working (e.g., due to being retired) made it easier to seek medical care. Participants referenced struggling with insurance companies to get coverage for treatments, which could result in both monetary and time costs.	and everything was covered and I could get an exception - you know, prior approval and things like that. And now it's just like beating my head against the wall. (2689) • And it's like, when I do have acute medication, you kind of, because they're so few pills - you know, it's like Nurtec. … At the beginning of the year, it cost, like, $400 for eight pills, and you're like, "Oh. Great. Is this attack bad enough to take a pill?" You know? So it's, like, rationing and figuring out, how bad is this attack? (2692) • at least now I'm in, let's call it, a better position to deal with it. If I have to go to a bunch of medical appointments, it's not like I have to beg my boss for time off or worry about losing my job, kind of thing. … And VYEPTI is $1,400 for the prescription, without, you know, the installation, let's call it, the infusion. Just for the drug is fourteen or fifteen hundred dollars. So that means I pay $350 for each time I have to get it. (2709) • Like, I have studied it, read about it, lived with it, tried so many different treatments, and it takes so much time to get my treatments covered by insurance, that it's basically my whole life at this point. (3005) • Over the last 10 years I've seen so many different neurologists, doctors, headache specialists, you know, chronic pain specialists, pain psychologists, you know, all sorts of different doctors, and I think I've probably been on, I don't know, I think over 200 different medications, you know, in an effort to try and manage, control, or prevent the chronic intractable migraines. … because of insurance regulations mainly, I'm rate limited to the number of triptan doses that I'm allowed per month. So, currently I'm only allowed nine generic Maxalt rizatriptan doses per month so - … I end up being very selective about when I opt to use the triptan, because I don't have very many of them. (3233)
Predictability or control of migraine	Found in 30 transcripts with 260 references coded. 27 participants discussed predictability/control during ictal phases and 22 referenced it in interictal periods. Participants described predictability/control as	• When the Botox starts wearing off, my - I guess the number of hours I can remain functional decreases during the day. And at a certain point, it's like I can't do anymore. … And normally, I know how I'm going to do during the day pretty early on, and if it's going to impact my ability to cook dinner and whatnot, then it's like, yeah, we're going to make plans to do something else. (2672) • The trends, you know - I noticed once I had more migraines on Fridays. And could it be that the stress from the week has built up? So I can see those kind of things and maybe make some adjustments in my lifestyle if I know what's triggering the attack. (2689)

Migraine Management Concept	Summary	Quotations
	• Consistency or limited variability in the frequency, severity, and duration of attacks • Consistent ability to control attacks or symptoms when they occur (e.g., medication efficacy) • Knowing exactly when and why attacks will occur so that you can plan around them The desire for predictability and control over migraine was directly connected to functioning and one's ability to make and keep plans or commitments, including commitments in work, school, and social contexts. Because participants uniformly perceived that fewer attacks or shorter attacks would result in less overall impairment, achieving reductions in frequency or duration of attacks was associated with more predictability in ability to function and comfort with making plans or commitments. When participants experienced consistent sets of symptoms or levels of severity, this translated to a more predictable experience: participants knew what to expect and could plan accordingly. They also had a better sense of how to deploy treatments for the symptoms of individual attacks.	• I would say the unpredictability is definitely the most bothersome part. … So the unpredictability of migraine as well as the big one: not always being able to control or remedy, or, you know - sometimes you're just out for a couple of days. (2691) • A couple times a week I'll go with my mom to the store, something like that. So I've been getting out. But usually it has to be on the early side, because my migraine tends to hit around, like, one – you know, right after lunch – and then I'm just, like, done for the day. (2692) • Spontaneity is out of the picture. A lot of planning, I have to do to make sure, is it going to be too noisy, too much light, do I have my medicines with me, am I going to be too fatigued and trigger attacks? (2693) • I wake up every day with a headache around 3 to 5, and then it just depends on how my day goes. They can go from 3 to 5, they can jump up to 8. It just depends on what I'm doing at work. If I'm around somebody that's talking very loud or I'm smelling somebody's food or cologne or perfume, it can intensify from there. So every day, I do wake up with a headache, it just depends on what's going on throughout the day. … I think it's just the unknown, when it's going to hit, where am I going to be at, did I make sure I packed my medication today. That's the first thing I grab before I leave the house, so did I grab that. Weather affects a lot, the barometric pressure. So, if it's raining, that's when I feel even worse and I can't wait to get out of work and get home. Or, in my office area, if somebody opens up their lunch and I can just smell it right away. (2703) • The way I've chosen to deal with it is I really can't make many plans, because I don't know one minute to the next or one day to the next, you know, what's going to be, how miserable I'm going to be, so to speak. … I really haven't been able – and that's one of my frustrations – I really haven't been able to identify any kind of systematic where I could say, okay, if I eat this – because I know a lot of people have food triggers, which maybe I have to pay a little more attention to, I've been thinking lately. But to be honest with you, other than the weather, which I'm fairly comfortable believing is having an effect on me, I really haven't been able to figure out (2709) • Yeah, the anxiety is just always because you can't have a static environment. And I think – and I never have a static environment. I literally can go from feeling great to feeling like utter [expletive redacted] in 30 minutes or less, you know what I mean? So it's very anxiety provoking. (2744)

Migraine Management Concept	Summary	Quotations
	Some participants had the ability to predict at least some of their attacks, such as those associated with a weather event or menstrual cycle, or those that resulted from known triggers (e.g., stress or adverse environmental factors). Many participants had experience with effective abortive or preventive treatments that gave them a greater sense of control over their illness. Knowing when an attack could occur permitted planning or coping behaviors that further supported a sense of predictability or control over migraine. By contrast, participants who experienced highly variable attacks or who had not identified triggers or effective treatment, found it difficult to plan anything (or, alternatively, found they had to plan for every conceivable scenario), experienced considerable frustration or anxiety, and reported many disruptions and limitations in their lives. Although participants acknowledged that being able to predict attacks could be useful, they also did not expect this to be an outcome of treatment. The ability to control attacks or symptoms when they occur, however, was a high priority	• I haven't found the magical solution or the cure – that doesn't really exist for migraine – but have learned by being very proactive and advocating for myself and my own management of migraine to find things that have allowed me to live a pretty controlled and pretty normal life around migraine. … I guess just increased control over frequency and severity would definitely help in life. The less you're having wrong, the better quality life can be. (2753) • So, like, I already know that before my period, I should just plan to be sick, basically. And I've accepted that, and I'm okay with that because that's just – it's almost like I feel in control, that I know when I'm going to be sick. So, when I'm surprised and I'm sick when I'm not supposed to be, then that feels like it impacts my life a lot more. (2915) • The unpredictability of the migraine. Again, I could be scheduled for something or have something scheduled and boom, a migraine attack could happen and I couldn't be present, and that would cause – it wouldn't just be necessarily disappointing me or another person in a community role, it would be disappointing a lot of people, and I just don't want to do that. I would rather be somebody who is doing what they can versus doing what they'd like. So, it's really the unpredictability of the migraine and the inability to be present when the migraine is fully operational. (2997) • And a lot of times it's just, they'll come out of the blue, and just weather, anything, can cause them to start. So I really try to take note, if I can catch them in time, to kind of stop them. (3018) • Some of it has been kind of linkable, like the light sensitivity, but the sleep one, sometimes not as much because sometimes I will sleep enough and still wake up with a migraine. So, it's been kind of hard finding the links and trying to cut them out. There's not a whole lot of resources that I've found that make that very easy. … And then, it can impact kind of plans, like if I'll start to feel a migraine coming on, it's like you really can't gauge how bad it's going to be because the mild symptoms can progress into the less mild symptoms and it gets to a point where you can't focus. So, it's been kind of hard because there will be points in time where I don't really know whether or not it's going to get worse, and so I don't feel completely comfortable going through with plans that I had originally intended to, because if it gets worse, I know I won't be able to function during those plans. (3022) • It's anxiety inducing. There's that feeling of waking up with the migraine and it's like "Oh crap, I didn't get to this before it started. How long is it going to go; how much worse is it going to get?" And you immediately start cutting dead weight from your day. I know how to

Migraine Management Concept	Summary	Quotations
	for treatment and the goal of people's attempts to successfully identify triggers or migraine-reducing health behaviors (e.g., exercise, consistent sleep, proper nutrition).	just say, "Okay, that's not happening, that's not happening, that's not happening. This is going to be in the afternoon and now what?" I hate doing that. There's the other side to that, is that when you feel it developing, you know, you see that you're light sensitive and you're like, "Oh god, okay how much do I have to do today to get through?" I don't like the feeling of squeaking by, but that is the feeling that you get and so you feel – I think probably it's anxiety and inadequacy, because you feel like, "I should be able to do more today." (3248)
Pushing through	Found in 26 transcripts, with 154 references coded. The concept of "*pushing through*" denotes the practice of continuing with functioning during a migraine attack despite symptoms or impairments. Although the phrase pushing through was commonly used, other terminology included "*working through it*," "*plowing through,*" and "*grin and bear it*." Participants usually described pushing through to prevent disruptions of daily life or to continue participation in important or necessary activities. Some participants described pushing through in relation to their perceived level of pain tolerance. Participants noted that pushing through could result in negative consequences, such as worsened or prolonged symptoms, that were referred to as "*price*" paid to preserve function.	**Having no choice** • Most of us, I have to say, push through and do everything with a milder attack, because you don't have a choice. You know, every time you have an attack, you can't just shut down. If it's a milder one, you have to do things. And you don't feel good doing them, but that's life. Sorry, bad luck. (2689) • Like, say I take a girl on a date, and, okay, now I get a migraine, I still gotta take her home. I have to be able to drive my car. You know, I have to do this. I've got to be able to function. (2744) • Then there was a time where I lost my health insurance, so I couldn't really be on any medication and I had to just tough it out. … Because I was working two jobs and going to school and supporting my dad and my sister, and if I was just a trooper and I just didn't have time to take care of myself. (2798) • If you have migraines, it's like, unless you are vomiting or like you really need to lie down, you get migraines at the most inconvenient times, so you literally just learn to push.(2830) • There's just me. So, if I don't do it, it's not going to get done, so I just have to just plow through it. (2940) **To care for or avoid burdening others** • I try not to let my migraine negatively impact other people. So, like my mom and I live together, so if it's something that I need to do for her, or if it's something that I told her that I would do, then that's what I try to do. I try to fulfill my obligations to other people. (2798) • I feel like I'm at a slower pace, and I'm like, "All right, how am I going to get through the rest of the day with this migraine? How am I going to be able to function and get things done?" Because people are counting on me to do – so I can do my part, they can do their part. (2703)

Migraine Management Concept	Summary	Quotations
	"Pushing through" was discussed primarily in the context of ictal experience (n=23) but also arose in discussions of interictal experience (n=10) because pushing through could contribute to interictal effects such as fatigue or anxiety. The concept of pushing through overlapped with the related concepts of Coping and Accepting or Adapting. The ability to push through was affected by attack symptoms: participants described milder attacks as ones they would push through to limit disruption of life, but also described times when it was impossible to push through due to the severity or duration of an attack. Pushing through was also affected by the level of importance individuals ascribed to an activity or interaction, as well as access to support from others or a tolerable environment. Participants described having to push through attacks because they had "*no choice*" or "*no other alternative*;" this primarily occurred because participants had unavoidable responsibilities (e.g., work, childcare) or because they were in a situation that precluded ending functioning (e.g., in a public place, driving). However, one	• I respect my family and friends not to bail on them, so even if I'm not one hundred percent, I don't bail. That's disrespectful, and it just goes against my grain of personality, so if I have to grin and bear it for my friends because we decide on a day to do something, then I'm going to do it regardless, but – unless I'm in the urgent care. But other than that, I'm still doing it. (2744) • I had a pretty bad migraine in the classroom. I took an Imitrex. I asked my co-teacher if we could turn the lights off, we did, and all of a sudden, I thought, "Oh [expletive deleted]. This is, in fact, getting worse." Went to the bathroom, thought I was going to throw up. Thought, "Oh, I'm feeling like I just have to lie down on the middle of the floor." Probably, I should go home, but also, there are only two of us. … so I kept setting up the room, but I was also like, really slow, and not at my best, and felt absolutely miserable, and definitely worked at three-quarters speed doing it. (2830) • I will push through because that's my responsibility as a mom. (3018) **To live life / take control of life** • But see, the thing is that sometimes that stage lasts so long, when I'm in bed for that long, I start to get antsy, even though I'm in pain and I know that I can't really do anything. And that's my problem is that like, "Oh, God. Okay. I need to get out of bed now." And so sometimes, I'll try to get up and I'll try to do things (2798) • I do sometimes, and then I pay the price for it. But it's like, I'm not going to live in a hole my whole life. I've tried that; doesn't get better. I'm like, okay, well, I need to see people. But then I might be recovering for a week from that. (3005) • I've gotten better at learning to take care of myself and putting my health first before social obligations. But there is something about not letting the migraine interfere with any kind of social responsibilities that I have, whether it's going out on a date or going to a concert that keeps my mood elevated, even though I'm in an incredible amount of pain when I'm doing those things, and for the most part pretending to be engaged with what I'm doing. (3225) **To maintain one's self-image** • I had to do everything. I do it, you put it aside, and you go back and look at it again. I had to do that at least once, sometimes twice, to be able to get a document off my desk where I felt that it was safe in doing so, I wasn't going to be embarrassed. You know, I like people to feel that they can rely on something that I do, and I don't like it when I can't fulfill that. That's my self-image. (2797)

Migraine Management Concept	Summary	Quotations
	participant also described pushing through attacks because they had no access to treatment. Finally, a few participants talked about pushing through because they wanted to get on with life and not be controlled by their migraine. Participants described four primary reasons for pushing through: • Having no choice (n=10) • To care for or avoid burdening others (n=7) • To live life or take control of life (n=6) • To maintain one's self-image (n=5) • To fulfill scheduled plans or obligations (n=4)	• I think for me, I'm the type of person if I sit and wallow in it too long, I don't get things accomplished, and in my mind, I always have to get things accomplished. (2940) **To fulfill scheduled plans or obligations** • Now, of course, no matter, pretty much, how bad I feel, I make medical appointments. I've never been at the point where I have to postpone a medical appointment, but let's call it elective activities, it's been very difficult for. (2709) • If I make plans, I generally do them regardless of the pain. I grin and bear it, and I take drugs so I can get through it. (2744) **Pushing through related to pain tolerance** • I think this is also especially tied to experiencing the pain for a long time, but other times I'm still able to do what I need to do in my life, and partly due to, I think, pain tolerance. … Often I do push through the pain, I think just because it's been so long. So it's difficult, but not impossible. And when it gets to a point where I can't do things, then I usually lay down. … I would say it's present, but I'm used to – for instance, like, in – well, around the house too, I clean a lot, and then in my work I walk a lot, and I usually, yeah, push through to what I need to do until I can't. (2691) • I can deal with – I've had the pain all my life, so just pain I can usually roll through. (2797) **Consequences of pushing through** • Some days I just push myself too far, and then when I get home, I'm done. I just crash, where I don't want to do anything, be bothered with anybody. (2703) • Because I've learned that if I push too long, too hard, it just gets worse. (2797) • I do want to go on vacation and enjoy a trip. I don't want to stay in a room. So it's like, what are you going to do? You're going to pay the price if you go out. … It's sad, because there's places I can go and I already say, I know I'm going to get a migraine when I leave there, or I know I'm – I already know it. But again, you just don't not want to do any and everything. You gotta do something. So you gotta pay the price for some things you want to do. (3013)
Self-sufficiency	Found in 21 transcripts, with 74 references coded. Participants described a variety of ways in which they endeavored to be self-sufficient in managing life with migraine,	• I travel with my migraine kit, so I have a whole bunch of stuff that I do during an attack and that I carry with me just so that I'm prepared. (2692) • It could just be anything that just comes up but I just try and make sure that I have a bottle of water with me, I have my medicine with me, and then I just make sure that my chair's all right, and I have a little heater that I put on my back to try and relax as well. (2703)

Migraine Management Concept	Summary	Quotations
	which included systematically learning what worked and did not work for them and always being prepared with medications, alternative therapies, and other coping strategies (thus, self-sufficiency is related to Coping and to Predictability-Control). Participants often referenced always being prepared with a toolkit or 'go bag' of items needed for responding to a migraine attack. Some participants referred to deliberately continuing with important activities that would be easier to abandon or delegate as a way of maintaining a sense of self-sufficiency (thus this concept is also related to Pushing Through). Others stressed putting their health first and thus feeling empowered to advocate for themselves and to feel positive about canceling plans.	• I prioritize things. Like, if someone isn't that important to me - let's say it's just a kind of acquaintance and this - and if I'm not really feeling it, I'll just postpone or cancel. I've learned I have to come first. My health has to come first (2709) • I actually built like a migraine emergency kit to deal with especially the depression because it's kind of sudden and I wouldn't know what to do, so I have a kit to help me with that. (2813) • That's part of my pack. I have so many - I have bought, like, professional equipment. [laughs] I have pretty much - if you saw my apartment, you would see I have the hydrocollator, and then I have the really icy packs that they have the - I call them the good packs that physical therapy have. I have my freezer full of that. So, you know, whatever equipment I can keep to help me, I have it. (2909) • And I should say that I think the type of work that I do helps me think about it that way, because otherwise, I don't know if I would notice. If that makes sense. Like, I think - so, part of the work that I do is in chronic disease self-management, and so, I try to apply not only what I learn, but kind of that - what am I trying to say - like systematic approach to be able to be like, "Okay, well, how can I make my life better? Where are the areas?" (2915) • Honestly, I feel like I'm actively working on changing that to live my best life. And that is, paying attention, listening to what my body's saying, and then responding accordingly (2915) • I have a lot of, I call it my toolbox. I have sort of like my first line, my second line, and my third line of things that I use. (3104)

3.5.5.3.1. Implications of Managing Migraine Findings for Measuring Migraine

Some coping strategies appear commonplace and strongly connected to migraine symptoms, thus are suitable for consideration as COIs. In particular, cocooning and the associated practice of voluntary avoidance, were referenced by a great many people. Measuring these concepts may provide both information that illuminates changes in the severity of migraine attacks and information that contextualizes self-reported impairments of functioning. Measurable reductions in cocooning and avoidance, for example, could indicate reduced migraine severity even if patients are still experiencing considerable impairments of specific functions. Indeed, depending on how concepts are captured in a measure, reduced cocooning and avoidance could actually accompany *increased* perceived impairment of function if patients transition to pushing through attacks instead of secluding themselves. It is also important to note that, although many people cocoon by going into a quiet, dark room to lie down, this is not the only way that people self-isolate. As a result, any PROM items aimed at capturing cocooning behaviors should be neutrally phrased to describe the behavior, rather than a specific location or environment.

Other concepts in migraine management, though very important to patients, may be poorly suited to clinical outcomes assessment or difficult to operationalize. For example, the unpredictability of migraine created havoc for interview participants and led to both ictal and interictal impacts. Although it may be possible to capture some of this concept by asking participants about how consistently an abortive medication works to alleviate symptoms in a predictable amount of time, this approach may be confounded by people's ability to recognize symptoms promptly and make consistent, accurate decisions about when to take medication. Similarly, pushing through attacks was a common practice, but one that was subject to a very wide range of individual circumstances that could vary, even for the same participant from attack to attack. Although a measure could ask about how often people find themselves pushing through attacks, it is unclear that this would be reliably related to any reduction in severity, duration, or frequency of symptoms.

3.6. CONCEPTUAL ATTRIBUTES: BOTHERSOMENESS

Two analyses were conducted to develop an understanding of how people with migraine conceptualize the bothersomeness of migraine symptoms and impairments of functioning. In the sections below, results from a secondary analysis of interviews conducted in the UG3 study are discussed, followed by a discussion of the findings from the present study.

3.6.1. UG3 Study Findings About Bothersomeness

Because UG3 interview participants were not consistently asked about which symptoms or impacts were *most* bothersome to them, secondary analysis focused on identifying references to symptoms or impacts on functioning being bothersome in general. Only 7 participants (17.5%) used the term "bothersome" or "bothers," suggesting that this term may not best reflect the ways people think about their experiences. Accordingly, besides the term bothersome itself, coding included a range of comments that specific experiences were "*the worst*," "*awful*," "*hard to deal with*," or "*just not ok*."

Analysis of coding for bothersome symptoms (Table 26) supported the validity of the existing, commonly-used outcomes for migraine (pain and the three symptoms used in most bothersome symptom (MBS) analysis: nausea, photophobia, and phonophobia). Results also aligned with research that allowed subjects to self-select their most bothersome symptom, which demonstrated that a considerable percentage of people do not choose any of the standard MBS as their most bothersome symptom.(Lipton et al., 2021) In particular, the UG3 data set suggested that the following additional symptoms were frequently bothersome: sensitivity to smells, sensitivity to touch, and altered mental acuity or "brain fog."

Table 26. Symptoms Identified as Bothersome by UG3 Study Participants

Symptom	Number of Transcripts (%) (n = 40)	Number of Coded References
Pain	24 (60%)	39
Photophobia	19 (47.5%)	28
Phonophobia	17 (42.5%)	23
Nausea	14 (35%)	24
Mental acuity	9 (22.5%)	15
Sensitivity to smell	9 (22.5%)	11
Sensitivity to touch	7 (17.5%)	7
Sensitivity to movement	4 (10%)	7
Fatigue	4 (10%)	4
Vision symptoms	2 (5%)	4
Vertigo	2 (5%)	3
Sensitivity to temp or weather	2 (5%)	2
Anxiety	2 (5%)	2

In commenting on why symptoms are bothersome, UG3 participants expressed four concepts:

- Creates physical suffering or discomfort
- Impairs function or causes disability
- Creates emotional burden
- Worsens migraine experience overall, such as making pain or brain fog worse

An analysis of the overlap of these concepts with migraine symptoms (Table 27) shows that, although the four symptoms commonly used in migraine trials consistently encompass functional impairment and discomfort, they may not sufficiently capture emotional and cognitive burdens of migraine. Notably, cognitive impairments were associated with emotional burden in 3 transcripts (UG3 transcripts 6, 16, and 27) and these were not reflected in either the nausea/emotional burden group (UG3 transcript 13) or pain/emotional burden group (UG3 transcripts 13, 14). Similarly, some symptoms were identified as bothersome, but were not described as creating suffering or discomfort (e.g., fatigue, vertigo), which is the hallmark of pain or phonophobia.

Table 27. Overlap Between Symptoms and Bothersomeness Concepts (UG3 Study)

Symptom	Creates Emotional Burden	Worsens Migraine Experience Overall	Impairs Function or Causes Disability	Creates Suffering or Discomfort
Pain	X	x	x	x
Nausea	X		x	x
Photophobia			x	x
Phonophobia			x	x
Sensitivity to Smells			x	x
Change in Mental Acuity	X	x	x	x
Visual symptoms	X		x	
Sensitivity to movement		x		x
Sensitivity to touch			x	x
Sensitivity to temperature or weather		x		x
Fatigue			x	
Anxiety	x			
Vertigo			x	

3.6.2. UH3 Study Findings About Bothersomeness

Although bothersomeness arose spontaneously on occasion, UH3 study participants addressed the concept primarily because interviewers asked about it at multiple points during the discussion to elicit perspectives on the most and least bothersome symptoms and impacts of migraine. Thus all 31 participants addressed bothersomeness during their interviews, comprising 320 coded references (see Table 28).

Coding included the use of subcodes based on the prior secondary analysis of UG3 data but without making the distinction between emotional burden and other burdens on function. This was done because reference to emotional burden never occurred in isolation in the UG3 data except for anxiety, suggesting that the distinction between types of burden was unnecessary. One additional subcode was added to capture the many participants who discussed bothersomeness in the context of their perceived ability to tolerate symptoms or impacts on function.

As demonstrated by Table 28, UH3 participants talked more often about aspects of migraine that were most bothersome compared with least bothersome. Indeed, some participants struggled to respond to questions about what was least bothersome, for example saying “*Yeah, they’re all pretty bothersome*” (2693). In this dataset, a majority of participants referenced impairment of function (71%) and exacerbation of migraine experience (64%) when talking about what was bothersome to them. Roughly half of participants discussed discomfort or their ability to tolerate symptoms.

Table 28. Coding for Bothersomeness

Code	Number of Interviews	Number of References Coded	Percent of Sample
Bothersome (any code)	31	320	100%
Can tolerate	15	34	48%
Creates suffering/discomfort/negative feelings	16	23	52%
Exacerbates migraine symptoms or impacts	20	42	64%
Impairs function	22	64	71%
Least bothersome	15	22	48%
Most bothersome	31	129	100%

Discussions of bothersomeness included references to 121 concepts, although more than half of these concepts appeared only once (n=42) or twice (n=25). To identify primary areas relevant to participant perspectives about bothersomeness, Table 29 shows the concepts referenced by a minimum of 6 people, or about 20% of all the study participants. These references include comments referencing aspects that were bothersome and aspects that were not. Of these 30 concepts, 9 capture symptoms and 14 capture concepts in the psychosocial function domain, including 4 hierarchically interrelated concepts that capture work.

Table 29. Concepts Referenced by a Minimum of 20% of Participants When Discussing Bothersomeness

Code	Number of Interviews
Symptoms\Sensitivity	22
Symptoms\Pain-head and face	20
Symptoms\Sensitivity\Light	16
Psychosocial\Predictability-control	14
Symptoms\GI-Nausea	14
Psychosocial\Coping	13
Symptoms\Pain-other	13
Psychosocial\Work	12
Psychosocial\Work\Work for pay	12
Symptoms\Mental-Foggy or Clear	11
Cognitive\Language	10
Physical\General function - Live life	10
Psychosocial\Pushing through	10
Symptoms\Sensitivity\Sound	10
Cognitive\Concentrate-Focus	9
Psychosocial\Emotion States\Irritable	9

Code	Number of Interviews
Psychosocial\Well-being	9
Psychosocial\Self-sufficiency	8
Psychosocial\Stigma	8
Cognitive\Language\Speech	7
Psychosocial\Accept-adapt	7
Psychosocial\Family relations	7
Psychosocial\Identity	7
Psychosocial\Well-being\Needs-wants to do ability	7
Symptoms\Dizziness	7
Symptoms\Fatigue	7
Physical\Ambulation	6
Physical\Housekeeping	6
Physical\Mobility Transport	6
Psychosocial\Work\Work for pay\Productivity-performance at work	6

The data provided further support for the prior finding that perspectives on what is bothersome about migraine are driven by 3 main factors: level of associated discomfort or suffering, exacerbation of migraine symptoms or impacts, and impairment of function. Across concepts, the relationships amongst Content codes and bothersomeness reflects logical associations (see Table 30). For example, the bothersomeness of impairments of ambulation is discussed more frequently with impairment of function (6 cases) than exacerbation of symptoms (1 case). Similarly, sensitivity to light was related most often to exacerbation of migraine (9 cases) and impairment of function (5 cases), and less often to discomfort or suffering (3 cases). However, it is also important to remember that these findings are contextualized by the way interviews were conducted: participants were simply asked what was most or least bothersome *to them* and why. If a participant said that impairment of ambulation was most bothersome because it impaired function, interviewers did not follow up to inquire if bending over also exacerbated symptoms.

Table 30. Crosstabulation of Content Codes with Bothersomeness Codes Showing Number of Participants

Code	Bothersome (any code)	Can Tolerate	Creates Suffering / Discomfort / Negative Feelings	Exacerbates Migraine Symptoms or Impacts	Impairs Function
Cognitive\Concentrate-Focus	9	1	1	1	1
Cognitive\Language	10	0	1	0	3
Cognitive\Language\Speech	7	0	1	0	1
Physical\Ambulation	6	1	0	1	6
Physical\General function - Live life	10	1	1	1	3
Physical\Housekeeping	6	1	0	1	1
Physical\Mobility Transport	6	0	1	2	4
Psychosocial\Accept-adapt	7	3	1	0	1

Code	Bothersome (any code)	Can Tolerate	Creates Suffering / Discomfort / Negative Feelings	Exacerbates Migraine Symptoms or Impacts	Impairs Function
Psychosocial\Coping	13	2	0	5	3
Psychosocial\Emotion States\Irritable	9	0	0	2	2
Psychosocial\Family relations	7	0	0	0	3
Psychosocial\Identity	7	1	3	0	1
Psychosocial\Predictability-control	14	0	3	5	5
Psychosocial\Pushing through	10	5	1	2	4
Psychosocial\Self-sufficiency	8	1	0	2	1
Psychosocial\Stigma	8	1	0	1	1
Psychosocial\Well-being	9	1	4	0	5
Psychosocial\Well-being\Needs-wants to do ability	7	0	2	0	3
Psychosocial\Work	12	1	2	4	6
Psychosocial\Work\Work for pay	12	1	2	4	6
Psychosocial\Work\Work for pay\Productivity-performance at work	6	0	1	1	4
Symptoms\Dizziness	7	1	0	0	3
Symptoms\Fatigue	7	1	0	0	5
Symptoms\GI-Nausea	14	7	2	5	5
Symptoms\Mental-Foggy or Clear	11	2	0	1	3
Symptoms\Pain-head and face	20	7	4	2	7
Symptoms\Pain-other	13	3	2	0	4
Symptoms\Sensitivity	22	4	3	14	8
Symptoms\Sensitivity\Light	16	4	3	9	5
Symptoms\Sensitivity\Sound	10	1	1	4	3

3.6.2.1. Most Bothersome Construct

Participants referenced 100 concepts when discussing what was *most* bothersome to them, but 74 of these appeared ≤3 times. Of the remaining 26 concepts, half (n=13) were concepts in the psychosocial domain and a further 35% (n=9) were symptom concepts, as shown in Table 31. Notably, two symptom concepts that were frequent in the UG3 data, sensitivity to smell and to touch, were not common in the UH3 coding for most bothersome experiences. This inconsistency could be attributable to differences in the way the data were collected, but it may also simply underscore the underlying wide variation in perception of bothersomeness.

Table 31. Concepts Identified as Most Bothersome

Code	Number of Interviews
Symptoms\Pain-head and face	12

Code	Number of Interviews
Psychosocial\Predictability-control	11
Symptoms\Sensitivity	11
Symptoms\Mental-Foggy or Clear	9
Cognitive\Language	8
Physical\General function - Live life	8
Symptoms\Sensitivity\Sound	8
Psychosocial\Emotion States\Irritable	7
Psychosocial\Well-being	7
Symptoms\Sensitivity\Light	7
Psychosocial\Family relations	6
Psychosocial\Identity	6
Psychosocial\Stigma	6
Psychosocial\Well-being\Needs-wants to do ability	6
Psychosocial\Work	6
Psychosocial\Work\Work for pay	6
Symptoms\Pain-other	6
Cognitive\Language\Speech	5
Symptoms\GI-Nausea	5
Cognitive\Concentrate-Focus	4
Psychosocial\Emotion States\Anger-Frustration	4
Psychosocial\Self-sufficiency	4
Psychosocial\Soc Comm Civic roles	4
Psychosocial\Work\Work for pay\Productivity-performance at work	4
Symptoms\Dizziness	4
Symptoms\Fatigue	4

There were four primary themes that applied to participants' comments about why specific symptoms or migraine impacts were most bothersome to them (Table 32). First, migraine symptoms, either singly or in combination, impaired function or caused disability. Second, migraine was physically and emotionally uncomfortable or distressing. Third, some participants were very bothered by things that worsened their migraine symptoms or impairments. Finally, some participants contextualized what was most bothersome to them by commenting on whether they could or could not tolerate or "deal with" it.

In addition to these primary themes, many participants referenced a variety of other factors that were most bothersome to them, ranging from stigma experiences to loss of employment to the need to always be prepared with medications and other therapies wherever you go. Some participants also could not, or did not wish to, pick symptoms or impairments that were most bothersome. For example, participant 2693 commented, "*I really can't say one is more bothersome when it comes to that because they seem to all kind of glom together*," and then when asked again about another domain later in the interview, said "*They're all pretty bothersome. Do you want me to pick?*"

Table 32. Themes Related to the Concept of Most Bothersome

Theme	Example Quotes
Impairs function	• Not being able to go my full day doing things that I want to do. Even if it's something mundane, like watching TV with my wife at night, not being able to do that sometimes is a real bummer. Not to get technical there. (2672) • How the pain gets in the way of doing what I want to do. Like, I'll have the best intentions when I wake up in the morning - I'm going to do this, this, this, and this. And by maybe after the first "this" or the second "this," I'm done. That's all I can do. (2711) • When I cannot move and talk, and I have that full blown experience where it just feels like I can't do anything, that is the worst. I know that's more than one symptom, but that's what I experience as the worst thing ever. (2813) • I think when it's nausea, it is still nausea because it is still prohibitive. You just - I just don't want to do or can't really do anything, so that is still like taking transportation, getting in a car, not doing anything really physical. And, that is a bother. (2830) • So, when I can't go and be around my church family - because these are people who've been with me through all the illnesses and the migraine attacks, it bothers me that I can't be there to be with them, and I miss activities that they do because I just can't do it. They go snow tubing, they go to the amusement parks and I can't do anything. So, that's the most bothersome, that I can't participate in activities all the time. (2940) • It's probably the light sensitivity. That's the one that kind of affects the day to day. (3022) • I can't enjoy anything. I can't think clearly. I can't. I can't. And it's that I can't, and I just have to go to bed, and it disrupts my life. (3184) • I think that the motion sensitivity, the vertigo, is something that really messes with me because I can't do a lot of stuff. (3214) • The light sensitivity I could really do without. Mostly because it gets in the way of my work. (3248)
Creates suffering, discomfort, or negative feelings	• It's more of the sensitivity to light and noise. Everything just feels 10 times louder, stronger smells, and it's just like, "Oh my gosh. What is going on right now? Where's my medicine? I've got to take something because this is only going to get worse." (2703) • I mean, primarily that it hurts. (2753) • I think - I mean, the crankiness sucks. It really does because then I always feel like I have to explain or apologize to people. And it just feels like another part of the sensitivity. My ears are sensitive, my skin is sensitive, and I'm sensitive, that sucks. (2830) • The headache part. The painful part … I think that's the most irritating part, because, if I'm feeling sick and I'm, like, excuse me, drooling because I'm feeling nauseous, I don't feel like eating on those days, and I just want to lay down. (2909) • I really hate the burning feeling - like, the burning sensation. It's awful … Like, get burned by, like, a flame or something, a candle or something. Yeah. That's what it feels in my brain. Like, 10 times worse. So I really hate that sensation. It's really awful. So that's the most thing that bothers me. (2913) • Not being able to digest. It means I don't want to eat, or I'm just really bloated. It's really uncomfortable. I wouldn't call it pain, but it's just super uncomfortable. (3005) • I think it's the emotional impact, for me. So, it's the results of not being able to do something, feeling like a failure, feeling lazy. (3104) • I hate throwing up, so being nauseated always is incredibly disturbing to me. (3225)

Theme	Example Quotes
Exacerbates migraine symptoms or impacts	• Weather affects a lot, the barometric pressure. So, if it's raining, that's when I feel even worse. (2703) • So, when I'm in a migraine attack, I don't know, I'll throw up three, four times a day, and it's just, it's awful. It's just constant. I can't keep anything down, and then I get dehydrated and that just makes my migraine even worse. (2798) • I can't sleep on that side. I can't really pull my hair up. And it's just annoying. But like, when it's that with a migraine attack, it amplifies everything else. (2830) • I have the hydrocollator, so I have a pack, but there's a light on there letting me know that it's on and it's working, but that'll just – like, that might be the – like, that'll just do it for me. Like, that's annoying. It's too annoying for me. Interviewer: Just the little bit of light? Does it make your headache pain worse? 2909: Yes, it does. And you know what? That's what started the pain in the eye. (2909) • When it's pounding, when I go and bend down – you know like if I'm starting to have a migraine and then I'm like, "Okay, do not make abrupt movements or else it's going to suddenly -- ." (2915) • Like sound of any kind will make the throbbing that much worse … whether it's either a sound or something visual or somebody trying to get my attention is very disturbing when I'm in the middle of a migraine and I just cannot cope with it. (3225)
Ability to tolerate	• I mean, right now, I think it would be sound and the brain fog. I've learned how to live with light sensitivity. I've learned how to live with light sensitivity. That probably used to be my number one answer, but I've learned how to live with it. (2672) • Because I can function with light sensitivity, and I can function with sound sensitivity. And I can function with the vomiting, because the Zofran works really well with the vomiting. But I can't function – I can't be present with the pain. I think that's – like, I can go throw up in the bathroom and come out and go swimming again with my kids, but when the pain is at its peak, there's no way I can do any of that, you know. (2744) • I can deal with – I've had the pain all my life, so just pain I can usually roll through. (2797) • The one that bothers me the most is the smell, the sensitivity to smell. And that's the only one I can't plug up, cover up, or hide, to prevent or to kind of taper down. So, that's the one. And you can't escape smells. Like you can sit in a dark room you can sit in the quiet room, and escape or muffle down noise by putting on an eye mask and ear plugs. That, you can do. But you can't do anything about the smell. You can't hide the smell. (2940) • I mean sound sensitive and light sensitivity, I can just turn the lights off and turn the volume down or have no volume. (3214)

3.6.2.2. Least Bothersome Construct

Participants were also asked about what was least bothersome to them. Although 27 concepts were referenced in connection with 'least bothersome,' no concept was referenced in more than 3 interviews (see Table 33).

Table 33. Concepts Identified as Least Bothersome

Code	Number of Interviews
Cognitive\Concentrate-Focus	3
Cognitive\Concentrate-Focus\Sustained attention	1
Cognitive\Info Processing/Reasoning	1
Cognitive\Language	2
Cognitive\Language\Speech	2
Cognitive\Language\Speech\Avoiding speaking, not able to speak	2
Physical\Housekeeping	1
Physical\Shopping errands	1
Psychosocial\Accept-adapt	2
Psychosocial\Coping	3
Psychosocial\Emotion States\Happy-Euphoria	1
Psychosocial\Identity	1
Psychosocial\Predictability-control	1
Psychosocial\Pushing through	2
Psychosocial\Self-sufficiency	1
Psychosocial\Social Community Civic roles	1
Psychosocial\Social Community Civic roles\Friends-family social	1
Psychosocial\Work	3
Psychosocial\Work\Work for pay	3
Psychosocial\Work\Work for pay\Productivity-performance at work	1
Psychosocial\Work\Work for pay\Working through attacks	2
Symptoms\Fatigue	2
Symptoms\GI-Nausea	1
Symptoms\Mental-Foggy or Clear	2
Symptoms\Pain-head and face	1
Symptoms\Pain-other	2
Symptoms\Tension-Stiffness	2

Several themes emerged from participant descriptions of factors that they considered when identifying symptoms or impacts that were least bothersome to them (Table 34). Participants considered the severity and frequency of experiences, selecting milder or low frequency ones as least bothersome. Participants considered their ability to treat symptoms or manage impairment, noting that things are less bothersome when they can be avoided or minimized, or if alternative ways of functioning are available. They also reflected on the relative position of specific symptoms or impacts within the whole of their migraine experience, including whether the concept at issue was something that could become extreme, suggesting that aspects of migraine may be least bothersome only because other aspects are clearly *very* bothersome or could get much worse.

Table 34. Themes Related to the Concept of Least Bothersome

Theme	Definition	Illustrative Quotations
"I can handle it"	Participants considered whether a symptom or impact was something they were used to, knew how treat, or could put off to another time	• Honestly, I think it's the pain, weirdly enough. I know how to handle pain. (2830) • The least bothersome would be the tightness in the neck. That would be the least. It's there, it's noticeable, but it's not like I can't manage it. A heat pack, ice pack, massaging something ball, something. You can kind of work with it. But then on the other things, you can't really do too much about it other than hide. (2940) • Least bothersome, just the cleaning aspect. I'm like, "You know what? I'll get to it tomorrow. I'll get to it the next day." (2703)
"I'm okay with this"		• The least. I need to think about that. Yeah, it might be the nausea, because I know I'm not going to vomit, because I haven't vomited, like, ever from it, from the headache. So maybe I know that comfort, like, it's just nausea, but I'm not really going to vomit. So maybe that's what bothers me the least. (2913) • That's a good question. That's a really good question. I don't know. I feel like I get fatigued or I get pretty sleepy sometimes, but honestly, that doesn't bother me because like I said, my sleep can be affected in some ways. So, sometimes I get happy when I get sleepy because I'm like, "Oh good, my body just needs to rest," and I will allow it to rest. (3104)
"It doesn't happen that often"	Participants considered whether they experience was infrequent	• And the speech, that happens not that often. At that point I don't feel like talking anyways, so it's fine. Like, whatever, I don't care. (3005) • Other things like fatigue and all the other weird ones, they don't bother me as much (3214)
"I have alternatives"	Participants noted that they have options or alternative ways of achieving function; this factor did not apply to symptoms.	• Social activities. I get to be social in my house and I'm okay. (2940) • Probably, believe it or not, the loss of the vocabulary because I am pretty good at pointing and gesturing. And over the years, my partner and I have refined this, to if I make a certain gesture, he'll know what it is. So, in the confines of my home, I'd say that would be the least bothersome to me. (2997)
"It's the least of my concerns"		• [Regarding cognitive impacts] They're minor compared to the other things, I guess I'll … I don't know. I guess – those are the least of my concerns. (2744) • The stiff joint – like the neck pain – like that stuff? Honestly, I don't care about that. I don't – it doesn't bother me. (3248)

3.7. CONCEPTUAL ATTRIBUTES: SEVERITY

Interviewers probed about the level of severity of symptoms and impairments, and asked participants to try to describe differences in level of severity if they could. Severity was thus described in all 31 interviews, with 327 references coded.

As described by participants, migraine severity consists of two realms of subjective judgment about migraine attacks relative to symptom experiences and time: (a) the degree of severity of the symptom or of an attack over all (typically described in terms of mild to intense, or how “bad” something is), or the degree of impairment of activities or function; and (b) waxing and waning of symptoms or impairments over time. In addition, multiple participants commented that their perceptions of severity were influenced by whether they were aware of, or noticed, their symptoms. Illustrative quotations for each of these themes within the data are provided in

Table 35. Finally, some observations on the language of severity are provided at the end of this section.

Overall, participants described four degrees of severity that can be loosely described as mild, bad, awful, and extreme. Degrees of severity applied to both symptoms and to an attack as a whole. However, although attack severity was often directly based on the severity of associated symptoms, people did also regard attacks as more severe if they experienced more or different symptoms than usual, even when those symptoms were not severe. When participants talked about the degree of an attack, they most frequently referenced pain; nausea and vomiting; mental acuity; sensitivities to light, sound, or motion; dizziness or vertigo; visual disturbances; and impairments of functioning.

- **Mild**: Symptoms are described as mild when they are difficult to recognize or easily managed. People describe symptoms as "*minor*" or "*in the background*," and report that they can ignore or be distracted from them, permitting continued function. A mild attack may involve only one or two symptoms, such as some pain and light sensitivity. Symptoms may also be localized (e.g., pain may be restricted to a small area of the head). People report making choices about whether to treat a mild attack based on how they are feeling as well as their assessment of whether the attack is likely to worsen.

- **Bad**: Bad symptoms cause distress and cannot be missed. A bad attack demands attention, requires treatment, and invariably interferes with functioning. A bad attack may also involve the development of additional symptoms only experienced during more severe migraine episodes or existing symptoms may spread or progress (e.g., pain may spread to the entire head, lightheadedness may progress to dizziness). People cannot ignore or distract themselves from their symptoms during a bad attack, but many people are able to 'push through' a bad attack to carry out essential functions. People uniformly report treating bad attacks in some way unless they have found no effective treatment at all.

- **Awful**: Symptoms are intense, cause suffering, and become overwhelming. People also describe these attacks as "*so bad that*" they must take additional treatment steps or engage in additional coping behaviors. An awful attack typically involves multiple symptoms that are simultaneously severe but can also involve just one or two symptoms at this level; however, people acknowledge that the distress caused by some symptoms may affect either recognition or subjective experience of other symptoms. For example, awful pain may make it difficult to recognize changes in mental acuity and awful nausea may make someone experience severe sensitivity to smell. During awful attacks, people sharply curtail function or can no longer function at all except for basic self-care and unavoidable responsibilities. People may use multiple medication doses, more powerful medications, or combinations of therapies in an attempt to stop or mitigate the attack.

- **Extreme**: Symptoms are extreme and unusual, causing genuine alarm or fear, and may prompt people to seek medical care or visit an emergency department. People are often unable to function much at all. Many people also described attacks that lasted a very long time (i.e., many days or weeks) as extreme. These events caused alarm, created disability, and often prompted people to seek medical care.

As described by participants, severity waxes and wanes during the course of a single attack, across attacks that fall within the range of typical experience at a given time, and over a lifetime with migraine. Participants referenced changes in the onset speed of attacks, as well as their duration, as part of their perception of waxing and waning.

- **A single attack**: Most people indicated that the severity of a specific symptom, or the severity of the attack as a whole, usually fluctuates over the course of each attack. Nausea may begin, for example, as mild discomfort and then progress to disabling nausea or vomiting before dissipating. People often described this experience in terms of symptoms '*ramping up and down*' or '*rolling in*' and '*lifting.*' When describing the changing severity of an attack, people typically linked it to the severity of associated symptoms but might also, or only, consider the accumulation of symptoms over the course of an attack. For example, people might describe an attack as mild at the beginning because they were experiencing only light and sound sensitivity and then describe it as getting worse as nausea and head pain begin. Similarly, people might describe an attack as waning because pain and nausea are lifting, even though other symptoms continue or fatigue begins.

- **Typical variation across attacks**: Most people described experiencing symptoms and attacks of varying severity over short periods of time (e.g., a few weeks or months) and were able to speak in terms of typical mild vs bad symptoms or attacks. For example, most people were able to point to specific experiences that demarcated normal severity levels for mild, bad, or awful attacks and to give an opinion about how often they experienced each type. People were also typically able to recall their worst or most extreme attacks over a short period of time, even when that worst attack might not be the worst one they had ever had.

- **Over years or a lifetime**: Most people, including those who had experienced migraine for 0-5 years, described changes in the severity of symptoms and attacks over years or in relation to major life changes (e.g., puberty or menopause, moving around the country or the world, having or not having medical care or access to effective treatments). Changes in experience could occur gradually, such as a progressive worsening or improvement in severity, but could occur abruptly without warning. People also described experiencing alternating periods of generally less or more severe migraine over time.

People noted that their perceptions of severity could vary depending on whether or when they noticed specific symptoms or impacts. For example, if a symptom began as mild and progressed slowly, people might only become aware of it when it became bad. This could be influenced by what other symptoms they were experiencing as well as their overall familiarity and knowledge of their own migraine. For example, participants noted developing the capacity over time to ignore certain symptoms (often described as '*tolerance*' for symptoms like pain or tinnitus), but also described realizing in hindsight that they had been experiencing a symptom or impact without paying attention to it.

Many participants encountered difficulty directly describing the severity of their symptoms and would shift to expressing severity in terms of functional abilities that were affected by migraine symptoms. This expository strategy was particularly common for symptoms where there are fewer English language terms available to denote experience, especially when trying to address variations in experience. There are a great many English words and phrases that can be used to denote different types and levels of pain (e.g., agony, torment, sore, tender, excruciating, ache, hurt, throb, twinge, and sting) and most people will recognize that these terms describe different types and levels of pain—tender is far milder than agony, for example, and aching is a different sensation than stinging. There are, however, comparatively few words available to describe different types or levels of mental acuity. Indeed, the term ‘acuity’ is not even specific to cognition, hence the need to add the word ‘mental.’ Acuity is also used to describe vision and hearing, for example, and some of the terms interview participants used to describe mental symptoms reflect this overlap of sensory realms (e.g., fuzzy, foggy). In the context of describing changes in mental acuity, then, participants frequently resorted to descriptive exposition of the functional or behavioral consequences they experienced. Although PROM items can be written using these functioning concepts, the difficulty this presents for a PROM is that the functional and behavioral consequences experienced could also originate in other symptoms or in environmental or personal characteristics, calling into question the reliability of items intended to capture the desired underlying symptom. For example, difficulties with concentration can be related to migraine’s impact on mental acuity but could also originate in pain so intense that people cannot concentrate on other things. Additionally, and more directly related to the construct of severity, it is not abundantly clear, at least from the qualitative record, how these functional and behavioral consequences could be used to convey levels of experience. For example, it is not clear that people experience lesser or greater severity in jumbled speech, but it is also not clear whether jumbled speech is worse/better/the same as slurred or mumbled speech.

Table 35. Themes Related to Severity Of Migraine

Theme	Quotes
Degree of an attack	• Mild case, like the imbalance – I can stand up and I can walk around the house, I may need to hold onto something. When it's bad, going from if I'm laying down on the couch, going from that prone position to just sitting up on the couch is incredibly difficult. … [about light sensitivity] So, now since that's a symptom I've lived with a long time, and I can describe it at its worst. And most people can relate to this. But imagine, 2:00 a.m., you're sleeping, a moonless night, you wake up, your room is dark, and you can make out everything in your bedroom. It's kind of this monochromatic field of view. Someone comes in and turns on the light at that point. That massive – what's the word I want – tense sensation, kind of your brain exploding from it, that's what I feel like when it's at the most severe level. So when it's mild, there's a glare off something, I'll turn my head. (2672) • When I have prolonged migraine attacks, I would say they're pretty severe, to the point where I am, you know, laying down in bed, not able to keep food down. … sometimes it'll start off I'm dizzy and then it'll get worse. Sometimes it starts off worse than other attacks, but usually I'm dizzy, and also the vertigo comes later. … if I do experience vertigo, then I'm not really able to do anything. And if – sometimes my migraines are to an intensity where I can't get out of bed, and so in those cases I feel like it impacts my ability to do anything at all, including, you know, going to the bathroom or getting the water that I need to drink and things like that. (2691) • Your attack gets so bad that you need to go to the ER … some attacks are so bad that I have to lay in bed and with my head under, like, a weighted mat, and I cannot have any sound and anything, and I just have to be completely still, can't move. And some attacks are kind of – I don't want to say lighter, the pain, but where I can just kind of, you know, watch TV, lay on the couch. They're not as bad. But sometimes they're just so awful that I just pray for sleep, you know. (2692) • Well, like, right now I know it's here. Like, right now I could feel the throbbing without paying particular attention. But when I say the background, unless, you know, it's like unless you look for something, I don't find it. Like, if I'm out doing something, it doesn't really bother me, but – let's call it if I'm slightly distracted. But if I happen to just be sitting here, all of a sudden, you know, you feel a very low-quality, let's say at a – if we used a pain scale, at, like, a level of a 1 to 2 you'll feel a slow throbbing. But if I was out – like, when I'm talking to you at times, it's just – right now it doesn't seem obvious, because I'm paying attention to the camera and the screen, but at times it's unavoidable, you know, when it goes, let's say, to a 4 or a 5 or, you know, at a higher level. (2709) • Like, a worse migraine for me pain-wise would be one that lasts three to four days and allows me not to function for three or four days. (2744) • And there have been times where it's gotten down to like a 1, maybe a 2, on the pain scale, and that's about as good as it gets. And to me, that's pretty much pain free. And then, I never say that it's all the way at a 10 because it can always get worse. That's been my experience. The pain can always get worse. Just when I think it's the worst, it'll always get worse. (2798) • The more headache I have, the more nauseous I get – like, the intensity of the pain. The worse it is, the more dizzy, the more nauseous I get. … So when it's severe, it always be flames. Like, it feels like my head is burning. … But when the headache is mild, I don't get the flames. I get pressure in my ears, but I don't get this intense flames. (2913) • I lose most of my vocabulary during a migraine. A lot of times, I'll just point and gesture. I had one episode where I actually couldn't speak. … But yeah, the whole idea of vocabulary, of communication, it goes maybe down to like a 15% level in a bad episode. (2997)

Theme	Quotes
	• A mild one still has a lot of the pain and the brain fog, but I can work through those and be functional. (3018) • The severe migraine's kind of more of a strong pain where I can kind of feel – it'll almost feel like my hair's been in too tight of a ponytail, so I'll have the – like the skin on my head feels like it's also in pain, and it'll just kind of be like a really dull throbbing. … A mild attack is usually just like a dull presence, like it feels like I can feel my brain, and it kind of just feels gross. (3022) • Most of my less-severe migraines will be – I'm trying to think of a way to say this clearly – they'll be localized, right? So, I will have them behind the ears; I will have them at the base of my skull; I will have them in a place. Now sometimes those regular migraines will crawl to a certain place. Like it will go from my neck and end up here [gesturing to the forehead] and stay there. Or it will crawl from my eyes back, but once it decides to settle somewhere for whatever reason, it stops. The more severe ones, as the pain gets worse, it will spread out and I will just feel it – like if I had a helmet on – anything covered by the helmet would hurt kind of thing. (3248)
Waxing and waning	• So the severity of the [light] sensitivity would come and go. (2672) • So I usually have a pretty progressive buildup in my migraine, so usually what will happen is I'll start to have a little bit of pain behind my eyes, and that's when I know that migraine is on its way, as well as nausea usually starts. … Usually the pain increases and concentrates on one side of my face, so I think that is distinct – I don't even know these days, but distinct, maybe, from a headache. With my migraines in particular, usually there's a lot of pain concentrated on one side of my face. And when it starts to grow from my eye to my jaw to the top of my head, then I know that it's getting worse. … sometimes it also seems like the migraine is getting better and then it'll get worse, so never really go away, but get worse and better throughout a couple of days. (2691) • If it's a fast moving attack, and the pain ramps up quickly, it can happen fast. The nausea, the vomiting, it's just kind of like you get slammed, and all of a sudden, everything is happening at once. (2693) • I wake up every day with a headache around 3 to 5, and then it just depends on how my day goes. They can go from 3 to 5, they can jump up to 8. It just depends on what I'm doing at work. If I'm around somebody that's talking very loud or I'm smelling somebody's food or cologne or perfume, it can intensify from there. (2703) • It can vary within the attack or from a different attack to a different attack. And you can probably already hear that, because I choose medicine according to my symptoms, so to speak, too, you know what I mean? (2744) • Again, mine tend to ramp up from very light to the longer they go uncontrolled, the worse they get. So, the pain gets worse, the light sensitivity gets worse, the sound sensitivity gets worse, and it's pretty much on a straight up scale if you're looking at a graph. (2753) • I'll have a period of time, maybe several years, and they would ramp up, and then they ramp down and they go away, more or less, and then a few years go by and I'll do it again. And this last time – [identifying information redacted] – last few years have been worse than before, so they're more debilitating. (2797) • Yes, they have differed over time, where they're not as severe. So, before, if a migraine attack hit me, I was down and not able to function at all. Like, that's total bed rest for however long the migraine attack would be. I could try to do something. But now, they're not as severe. I'll have some severe flare-ups but it's not constantly severe. (2940)

Theme	Quotes
	• After a period of about five years, they started to get worse and worse and more common. I would say going from maybe one every couple of months to one at least twice a month, sometimes almost one every week. (2997) • Definitely I feel like I've gotten worse this past eight years. Like I said, the symptoms have started to happen in between migraines. Fatigue is one I didn't mention, sorry. I also have a lot of exhaustion, even when I'm not in migraine, and that could just be chronic pain. But yeah, I'd say experiencing different symptoms that I hadn't experienced, so they definitely have shifted. (3005)
Subject to noticing	• [Regarding brain fog] More like the frog in the pot, the hot water, it gradually builds up and by the time I noticed it's been building up for a bit - so I think it's gradual. It takes a while for me to notice. … In terms of light and sound sensitivity, if it's minor, then it's kind of always there, but it takes light or sound to actually make me realize that it's there. (2672) • And then, when my pain's at maybe a 6 or a 7, not so bad to go home, but bad to where I'm definitely noticing it … [After the participant had COVID-19] my migraine brain fog seems - I don't want to use the term better - but it doesn't seem as severe because now I feel like I have brain fog all the time. So, it's a little bit harder to evaluate because I just feel foggy, as opposed to before then, it was like, "Oh wow, now I definitely have brain fog during my migraine," and I had something to compare it to when I didn't have brain fog. So, now constantly having brain fog it's like, oh, okay, well, I don't even - I don't know. (2798) • The migraine, when it's really - when I think it's a migraine - I realize that I'm holding my breath, I'm clenching muscles, usually my jaw and my neck, and I realize that all of a sudden, I think "This is bad." And it's been bad. Like I realize that it's been that bad for a while, and I hadn't put it together. So, there's sort of this moment when I realize, "Ugh, I should have taken it already." Or, "Oh, this has been bad, and I'm just now realizing it." (2830) • It can be a little bit of a throbbing, but not really intensely enough that I notice it or can't do anything about it. It usually doesn't present a lot more symptoms other than just the dull presence, where I'm conscious of it but it's not taking my full attention. (3022) • I live with this constant chronic background migraine at about a pain level of 3. So, I don't even start recording migraine events until they get bigger than that anymore because it's just, if it doesn't get above the background noise, I'm not even going to worry about it because I've got the background noise kind of well in hand. It's still there, but it doesn't disrupt me. So, I don't start recording a migraine until it hits over that threshold. I don't notice body pain till it gets over that threshold too. (3184) • I would say if there's one thing that I didn't really touch on in the call it's that - so, I grew up fairly poor and so didn't ever - I never grew up in a family or a community culture that prioritized taking care of yourself health wise or going to the doctor for checkups or doing things like that. I didn't even realize that I was shortsighted until I was like 15 years old and went to the doctor and they're like, "Oh, you need glasses." I just assumed that the world was blurry for everybody else. It's only in hindsight that I'm like, "That's a ridiculous thing to think." It's the same thing with my migraines. (3225)

4. LIMITATIONS OF THE STUDY

While saturation was reached (and interviews continued even after saturation was reached to ensure variability in sample demographic characteristics), the sample size necessitated by the in-depth, person-centered nature of this qualitative work may mean that atypical migraine experiences were not fully captured in the current sample.

Participants in this study were recruited by conducting outreach through CHAMP, a patient advocacy coalition. Outreach was primarily conducted through online channels, such as Facebook and Twitter. As a result, the participant sample may overrepresent people who are engaged in the migraine community, are more comfortable/experienced discussing living with migraine and their specific experiences, are sophisticated consumers of migraine-related information, and who are active on these specific channels. The participant sample also included many people over the age of 55 and many who were highly educated. This may have influenced findings, although stratification results tend to suggest it did not.

Participants' migraine diagnosis was self-reported. Although all participants referenced being given a diagnosis by a health care provider and reported symptoms consistent with migraine, it is possible that people who had other headache disorders were included in the sample. Participants were also purposively selected to represent specific health and demographic characteristics. Although routinely used for qualitative studies of this type, non-random selection procedures always include a risk of undetected bias.

Both interviewer-coders were White females. This may have influenced what BIPOC and/or male participants talked about or how they expressed themselves. It may also have affected whether coders recognized and captured concepts specific to BIPOC or male individuals. Specifically related to gender, interviewers did observe that some male participants were initially reluctant to label their headaches as pain (e.g., one referred to throbbing multiple times during the early portion of the interview). Because the interviews were long and provided ample opportunity to build rapport and trust, all of them did eventually refer to and discuss pain. Similarly, coding for some content may reflect female-specific interpretations of male speech, which may include misinterpretation. These limitations underscore the potential importance of interpreting sex-based differences in the results with some caution, since it may reflect the mismatch between interviewer and participant. For example, it is somewhat surprising that no male participants referenced issues with feeling understood by friends and family. This could be a true gender-based difference or may have resulted either from male participant discomfort discussing this topic with a female interviewer or from misinterpretation by female coders. Similarly, the failure to detect many differences based on race may reflect the universality of migraine experience at a conceptual level, but could also reflect limitations in interviews or analyses that resulted in failure to capture or recognize race-based differences.

5. DISCUSSION

Implications of the study results for developing a patient-centered PROM that captures symptoms and impairments of function were explored in subsections of Section 3.5, Concepts in Migraine. These results both elaborate and expand on findings from the UG3 study, and the two literature reviews conducted as part of the MiCOAS project and, when taken together, offer some overarching guidance for the selection or development of migraine PROMs and for expanding established principles of health measurement more broadly.

The study results provide robust evidence that the COIs typically measured in clinical trials capture outcomes that are commonly experienced, burdensome, and matter to people with migraine. However, this study identified additional symptoms and impairments that are important and whose measurement would improve the scientific understanding of experiences of people living with migraine. Some of these, including changes in mental acuity and cognitive impairments, appeared to be more common and important to people with migraine than some existing COIs. People's experience of symptoms and functions are also subject to contextual influences that can affect both the perceived severity of symptoms and the perceived degree of impairment or disability. These contextual influences cover a wide territory, ranging from access to medication to a person's surrounding social or physical environment. Similarly, interictal experiences of migraine are important to people living with the disease, but some experiences that dominate the interictal period are among the most complex, integrative concepts identified, such as life satisfaction. These concepts are difficult to operationalize and may not align well with long-standing theories and standards of health outcome measurement, which typically aim to measure discrete concepts and to infer relationships between them based on statistical relationships in collected data. The UG3 and UH3 studies showed that people with migraine have their own judgments about the relationships between discrete concepts that are integrated into a holistic, contextual outcome (e.g., life satisfaction), but it is not clear whether these judgments could be operationalized for assessment through a PROM. It is also unclear whether these judgments would align with the apparent relationship among concepts inferred from traditional health measurement strategies.

Bothersomeness is an instructive example of the integrative and contextual nature of migraine experience from the patient's perspective. Bothersomeness reflects the interdependence of symptoms and impairments of function, including exacerbations, and reflects perceived ability to tolerate burdens from migraine, a perception that is influenced by an array of contextual factors. The concept of bothersomeness is of value to people living with migraine because they experience their illness as an integrated whole in which the shifting relationship between symptoms, impairments, and contextual factors is *itself* an important, burdensome feature. This feature is often described in terms of unpredictability but is also woven into discussions of concepts such as identity, well-being, and accepting/adapting to migraine. Similarly, people living with migraine reported that they are willing to engage in daily journaling and measurement of symptoms or impacts for their healthcare professional or in the context of a clinical trial, but many also offered a pointed critique based on their experiences of using these measures. Several interview participants thought these instruments focus too narrowly on clinical topics and negative experiences, and many described abandoning their migraine diary or tracker because it did not seem useful or was depressing to fill out. This suggests that people with migraine view prevailing measurement paradigms as primarily serving clinical or regulatory interests, rather than being truly patient-centered.

Taken together, these observations about the integrated, contextual nature of migraine experiences, the value of bothersomeness in capturing that integration, and the dissatisfaction with existing migraine measures broadly suggest that a PROM for migraine would be enhanced by including items that aim to capture complex, holistic outcomes. These items may indeed be of limited value in a clinical trial aimed at narrowly evaluating the efficacy of a specific medication but could serve to improve a person-centered criterion for the PROM itself. The inclusion of these outcomes might improve the utility of the PROM to people living with migraine, for example, who will have their own aims and standards for interpreting measurements of their experiences. PROM development that supports these holistic, person-centered goals is also in line with recent shifts in principles of health measurement. These shifts include those reflected in the FDA's evolving approach to patient-reported outcome measurement for both medications and medical devices (Kluetz et al., 2016; United States Food and Drug Administration, 2009 Dec, 2020, 2022a, 2022b). The Measures Management System Blueprint includes a supplement specific to PROMs that expands the definition of "meaningful" to include a person's "achievement of personal goals," a highly contextual and complex concept (Centers for Medicare & Medicaid Services, 2021). Similarly, the National Quality Forum has challenged measure developers to implement five consensus-driven principles for patient-centered measurement that call for measures to be holistic as well as transparent and useful to patients themselves (National Quality Forum, 2018; van Terheyden, 2017).

In developing a draft PROM, the MiCOAS research team will aim to expand the available COIs by including and evaluating the measurement properties of concepts that are important to people with migraine and fit into current measurement paradigms and the specific aims of clinical trials of migraine therapies. The team will develop items, for example, that aim to capture changes in mental acuity and additional sensory sensitivities, as well as aspects of cognitive and psychosocial functioning, that may not be adequately captured by available PROMs and are likely to be responsive to effective treatment. Careful consideration will also be given to the development of items that attempt to operationalize holistic, integrated, or contextual concepts so that evidence may be gathered about the utility of these items both in clinical trials and in the value of the PROM from the perspective of people living with migraine. Finally, to improve the flexibility and adaptability of the PROM to suit different types of clinical trials, the team will aim to develop items that could be used successfully with more than one reference/recall time period and more than one set of response options. For example, in assessing an acute treatment, trial aims may be best served by measuring the severity of symptoms and degree of impairment on a 24-hour basis when attacks occur. For a preventive treatment, daily assessment of a limited number of outcomes may be important, while other outcomes could be satisfactorily captured by assessing changes in frequency over a period of two weeks. The underlying aim of this approach is to develop a set of items that promote consistency in the way that concepts are operationalized, while permitting needed flexibility in how they are assessed.

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Appendix A. Questionnaires Completed by Study Enrollees

Eligibility Screening Questionnaire

The following questions ask about you. Your answers will be used to see whether you are eligible to participate in a study about people's experience with migraine.
Please read each question carefully.
Check the box next to your answer for each question.

1. Are you an employee of the Food and Drug Administration, Albert Einstein College of Medicine, or Vector Psychometric Group?
    - Yes [INELIGIBLE]
    - No [CONTINUE, GO TO Q2]
2. Has a doctor or other health care professional ever told you that you have migraine?
    - Yes [CONTINUE, GO TO Q3]
    - No [INELIGIBLE]
3. Did you participate in an interview for the MiCOAS study in 2020?
    - Yes [INELIGIBLE]
    - No [CONTINUE, GO TO Q4]
4. Have you been interviewed or participated in a focus group for another research study about migraine in the past 12 months?
    - Yes [INELIGIBLE]
    - No [CONTINUE, GO TO Q5]
5. How old are you?
    - Less than 18 years old [INELIGIBLE]
    - 18 to 75 years old [CONTINUE, GO TO Q6]
    - 76 years old or more [INELIGIBLE]
6. Do you currently live in the United States?
    - Yes [CONTINUE, GO TO Q7]
    - No [INELIGIBLE]
7. Are you able to tell the difference between a day with migraine and days with other types of headaches?
    - Yes [CONTINUE, GO TO Q8]
    - No [INELIGIBLE]
8. Over the last 3 months, how many migraine headache days have you typically had per month?
    - 0-3 headache days per month [INELIGIBLE]
    - 4-8 headache days per month [CONTINUE, GO TO Q9]
    - 9-14 headache days per month [CONTINUE, GO TO Q9]
    - 15-20 headache days per month [CONTINUE, GO TO Q9]
    - 21-26 headache days per month [CONTINUE, GO TO Q9]
    - More than 26 headache days per month [INELIGIBLE]
9. In the last 3 months, have you limited your activities on at least 1 day because of your migraine?
    - Yes [CONTINUE, GO TO Q10]
    - No [INELIGIBLE]

10. Has a doctor or other health care professional ever told you that you have any of the following? (Please check all that apply)
    - Multiple sclerosis [INELIGIBLE]
    - Traumatic brain injury or spinal cord injury [INELIGIBLE]
    - Schizophrenia [INELIGIBLE]
    - Bi-polar disorder [INELIGIBLE]
    - Alzheimer's disease or dementia [INELIGIBLE]
    - Epilepsy [INELIGIBLE]
    - Stroke [INELIGIBLE]
    - Cognitive impairment [INELIGIBLE]
    - None of the above [CONTINUE, GO TO Q11]
11. In the last 30 days, how often have you used an opioid (e.g., Percocet or OxyContin) or barbiturate (e.g., Fioricet or Seconal) medication, either for your migraine or for something else?
    - 0 -2 days [CONTINUE, GO TO Q12]
    - 3-4 days [CONTINUE, GO TO Q12]
    - 5-7 days [INELIGIBLE]
    - 8-10 days [INELIGIBLE]
    - More than 10 days [INELIGIBLE]
12. Are you comfortable reading English, such as to read a newspaper or fill out a medical form on your own?
    - Yes [CONTINUE, GO TO Q13]
    - No [INELIGIBLE]
13. Will you be comfortable speaking English while talking to someone about your migraine for 60-90 minutes?
    - Yes [CONTINUE, GO TO Q14]
    - No [INELIGIBLE]
14. Over the past 3 months:
    [SCORE OF 0 or 1: CONTINUE, GO TO Q15]
    [SCORE OF 2 OR HIGHER: INELIGIBLE]

	Yes	No
Have you felt that you should cut down on your drinking or recreational drug use?	1	0
Have people annoyed you by criticizing your drinking or recreational drug use?	1	0
Have you felt guilty about your drinking or recreational drug use?	1	0
Have you had a drink or taken recreational drugs first thing in the morning?	1	0

15. This study involves a single interview that takes up to 90 minutes. Are you willing to have your interview audio recorded?
    - Yes [ELIGIBLE, GO TO INFORMED CONSENT]
    - No [INELIGIBLE]

HEALTH AND DEMOGRAPHIC SURVEY

We will use your answers to these questions to select people for our study with a range of migraine experiences. For example, we want to be sure that the study includes people who use preventive medications and people who don't.

There are 24 questions, but some questions have multiple parts. This survey should take about 10 minutes to fill out.

- Please read each question carefully.
- Check the box (☑) next to your answer or fill in the requested information for each question.

The following questions are about you.

1. What is your current age?

_______________ years old [DROP DOWN]

2. How old were you when you were first told by a doctor or other health care provider that you have migraine?

_______________ years old [DROP DOWN] plus an option "I don't remember"

3. In the <u>last 4 weeks</u>, how many days did you have headache of any kind (including migraine)?
______________ days with headache (including migraine) [DROP DOWN]

4. In the <u>last 4 weeks</u>, how many days were you <u>completely free</u> of headache of any kind (including migraine)?
______________ days free of headache (including migraine) [DROP DOWN]

5. Over <u>the past year</u>, have you taken <u>medication(s)</u> to treat your migraine headaches <u>when they happen</u>? (These may be over-the-counter or prescription).
☐ Yes [Continue to Question 6]
☐ No [Continue to Question 7]

6. What <u>medication(s)</u> have you taken within the <u>past year</u> to treat your migraine headaches <u>when they happen</u>? *(check **all** that apply)*

☐ Acetaminophen (generic)
☐ Acetaminophen, aspirin, caffeine (generic)
☐ Acetaminophen with codeine (generic)
☐ Advil (ibuprofen)
☐ Aleve (naproxen sodium)
☐ Almotriptan (generic)
☐ Amerge (naratriptan)
☐ Anaprox (naproxen)
☐ Ansaid (flurbiprofen)
☐ Aspirin
☐ Axert (almotriptan)
☐ Butorphanol tartrate (generic)
☐ Cambia (diclofenac)
☐ Cataflam (diclofenac)
☐ Celebrex (celecoxib)
☐ Celecoxib (generic)
☐ Compazine (prochlorperazine)
☐ Darvocet (acetaminophen and propoxyphene)
☐ Darvon (propoxyphene+ aspirin+ caffeine)
☐ Demerol (meperidine)
☐ DHE-45 injection (dihydroergotamine)
☐ Diclofenac (generic)
☐ Dihydroergotamine (generic)
☐ Duradrin (Isometheptene+ dichloralphenazone+ acetaminophen)
☐ Eletriptan (generic)
☐ Esgic (butalbital+ caffeine+ acetaminophen) with or without codeine
☐ Etodolac (generic)
☐ Excedrin (acetaminophen+ aspirin+ caffeine)
☐ Excedrin "Generic" (acetaminophen+ aspirin+ caffeine)
☐ Excedrin Migraine (acetaminophen+ aspirin+ caffeine)
☐ Fioricet (butalbital+ caffeine+ acetaminophen) with or without codeine
☐ Fiorinal (butalbital+ caffeine+ aspirin) with or without codeine
☐ Flurbiprofen (generic)

- ☐ Frova (frovatriptan)
- ☐ Frovatriptan (generic)
- ☐ Hydrocodone with or without acetaminophen (generic)
- ☐ Ibuprofen (generic)
- ☐ Imitrex (sumatriptan) nasal spray
- ☐ Imitrex (sumatriptan) pills or tablets/capsules
- ☐ Indocin (indomethacin)
- ☐ Indomethacin (generic)
- ☐ Ketoprofen (generic)
- ☐ Ketorolac (generic)
- ☐ Lasmiditan (generic)
- ☐ Lidocaine nasal spray
- ☐ Lodine (etodolac)
- ☐ Maxalt (rizatriptan)
- ☐ Meclofenamate (generic)
- ☐ Meclomen (meclofenamate)
- ☐ Meloxicam (generic)
- ☐ Meperidine (generic)
- ☐ Metoclopramide (generic)
- ☐ Midrin (Isometheptene+ dichloralphenazone+ acetaminophen)
- ☐ Migranal nasal spray (dihydorergotamine)
- ☐ Mobic (meloxicam)
- ☐ Motrin (including prescription Motrin) (ibuprofen)
- ☐ Nabumetone (generic)
- ☐ Naprosyn (naproxen)
- ☐ Naproxen (generic)
- ☐ Naproxen sodium (generic)
- ☐ Naratriptan (generic)
- ☐ Nasal spray (non-prescription) Please specify:

  ____
- ☐ Nurtec (rimegepant)
- ☐ Orudis/ Oruvail (ketoprofen)
- ☐ Oxycodone (generic)
- ☐ Percocet, Percodan (oxycodone)

☐ Phenergan (promethazine)
☐ Phrenilin or Phrenilin Forte (butalbital+ acetaminophen)
☐ Prochlorperazine (generic)
☐ Promethazine (generic)
☐ Reglan (metoclopramide)
☐ Relafen (nabumetone)
☐ Relpax (eletriptan)
☐ Reyvow (lasmiditan)
☐ Rimegepant (Nurtec)
☐ Rizatriptan (generic)
☐ Roxicodone (oxycodone)
☐ Sinus or allergy medications (e.g., Tylenol Sinus)
☐ Stadol (butorphanol tartrate)
☐ Sumatriptan (generic)
☐ Toradol (ketorolac)
☐ Tramadol compound (generic)
☐ Treximet (sumatriptan + naproxen sodium)
☐ Tylenol (acetaminophen)
☐ Tylenol with codeine
☐ Ubrelvy (ubrogepant)
☐ Ultram, Ultracet (tramadol compound)
☐ Vanquish (acetaminophen+ aspirin+ caffeine medication)
☐ Vicodin (acetaminophen and hydrocodone or other hydrocodone compound)
☐ Voltaren (diclofenac) pills or tablets/capsules
☐ Voltaren (diclofenac) topical gel
☐ Zolmitriptan (generic)
☐ Zomig (zolmitriptan) pills or tablets/capsules
☐ Zomig (zolmitriptan) nasal spray
☐ Other prescription injection Please specify______________________________
☐ Other prescription medication (pills or tablets/capsules) Please specify ______________
☐ Other prescription nasal spray Please specify _____________________________

☐ Other prescription topical Please specify

____

7. Do you currently take any medication(s) or receive any treatment(s) to prevent or reduce the frequency or severity of migraine (i.e., preventive medication)?

☐ Yes [Continue to Question 8]
☐ No [Continue to Question 9]

8. What medication(s) do you take or what treatment(s) do you receive to prevent or reduce the frequency or severity of migraine (i.e., preventive medication)? *(check **all** that apply)*

☐ AbotulinumtoxinA (generic)
☐ Acetazolamide (generic)
☐ Aimovig (erenumab)
☐ Ajovy (fremanezumab)
☐ Amitriptyline (generic)
☐ Aspirin
☐ Atacand (candesartan)
☐ Atenolol (generic)
☐ Blocadren (timolol)
☐ Botox (onabotulinumtoxin A)
☐ Calan/Covera-HS/Isoptin, Verelan (verapamil)
☐ Candesartan (generic)
☐ Clopidogrel (generic)
☐ Coenyzme Q10
☐ Corgard (nadolol)
☐ Cymbalta (duloxetine)
☐ Cyproheptadine (generic)
☐ Depakote (divalproex sodium)
☐ Desvenlafaxine (generic)
☐ Diamox (acetazolamide)
☐ Divalproex sodium (generic)
☐ Duloxetine (generic)
☐ Dysport (abotulinumtoxinA)
☐ Effexor (venlafaxine)
☐ Elavil (amitriptylline)

☐ Emgality (galcanezumab)
☐ Escitalopram oxalate (generic)
☐ Fluoxetine (generic)
☐ Gabapentin (generic)
☐ Inderal (propranolol)
☐ Lacosamide (generic)
☐ Lexapro (escitalopram oxalate)
☐ Lisinopril (generic)
☐ Lopressor (metoprolol)
☐ Lyrica (pregabalin)
☐ Magnesium
☐ Memantine (generic)
☐ Metoprolol (generic)
☐ Nadolol (generic)
☐ Namenda (memantine)
☐ Neurontin (gabapentin)
☐ Nifedipine (generic)
☐ Nortriptyline (generic)
☐ Nurtec (rimegepant)
☐ Onabotulinumtoxin A (generic)
☐ Pamelor (nortriptylline)
☐ Paroxetine (generic)
☐ Paxil (paroxetine)
☐ Periactin (cyproheptadine)
☐ Plavix (clopidogrel)
☐ Pregabalin (generic)
☐ Prinivil (lisinopril)
☐ Pristiq (desvenlafaxine)
☐ Procardia (nifedipine)
☐ Propranolol (generic)
☐ Prozac (fluoxetine)
☐ Qudexy (topiramate)
☐ Riboflavin (vitamin B2)
☐ Rimegepant (Nurtec)

☐ Sertraline (generic)
☐ Tenormin (atenolol)
☐ Timolol (generic)
☐ Tizanidine (generic)
☐ Topamax (topiramate)
☐ Topiramate (generic)
☐ Toprol XL (metoprolol)
☐ Trokendi (topiramate)
☐ Venlafaxine (generic)
☐ Verapamil (generic)
☐ Vimpat (lacosamide)
☐ Vitamin B2
☐ Vyepti (eptinezumab)
☐ Zanaflex (tizanidine)
☐ Zestril (lisinopril)
☐ Zoloft (sertraline)
☐ Other Please specify __________

9. Do you currently use <u>opioids</u> for any reason, including for your migraine attacks? For example, Tylenol with codeine (acetaminophen with codeine), Stadol [butorphanol tartrate], Percocet (oxycodone and acetaminophen), Ultram (tramadol), or Vicodin (hydrocodone and acetaminophen)

☐ Yes

In the last 4 weeks, how many days did you use opioids of any kind to treat migraine or headache _______ [DROP DOWN]

☐ No

10. Do you use <u>barbiturate containing analgesics</u> for <u>any reason</u>, including for your migraine attacks? For example, Fiorinal (butalbital-aspirin-caffeine) or Fioricet (butalbital-acetaminophen-caffeine)

☐ Yes

In the last 4 weeks, how many days did you use barbiturates to treat migraine or headache _______ [DROP DOWN]

☐ No

11. Do you <u>currently</u> use any of the following medications <u>for any reason</u>, including for your migraine? (Check any that apply)

☐ No, I don't currently use any of these medications
☐ Amitriptyline (Elavil, Vanatrip)
☐ Amoxapine (Asendin)
☐ Clomipramine (Anafranil)
☐ Desipramine (Normpramin)
☐ Divalproex sodium (Depakote)
☐ Doxepin (Sinequan)
☐ Eletriptan (Relpax)
☐ Imipramine (Tofranil)
☐ Lasmiditan (Reyvow)
☐ Nortriptyline (Pamelor, Aventyl Hydrochloride)
☐ Protriptyline (Vivactil)
☐ Topiramate (Topamax, Trokendi XR, Qudexy XR, Topiragen)
☐ Trimipramine (Surmontil)

12. Please rate how frequently you experience each symptom <u>during a migraine</u>:

	Never 1	Rarely 2	Less than Half the Time 3	Half the Time or More 4
1. The pain is worse on one side				
2. The pain is pounding, pulsating, or throbbing				
3. The pain has moderate or severe intensity				
4. The pain is made worse by routine activities such as walking or climbing stairs				
5. You feel nauseated or sick to your stomach or vomit (throw up)				
6. Light bothers you (more than when you do not have a headache)				

7. Sound bothers you (more than when you do not have a headache)				
8. Your skin is sensitive to things that are usually not painful such as taking a shower, laying your head on a pillow, brushing your hair or wearing an earring.				
9. You don't feel like eating				
10. You have neck pain				
11. You have sinus pain				
12. You feel dizzy				
13. Your vision is distorted				
14. Your thinking or memory is impaired				

13. Over the <u>past 2 weeks</u>, how often have you been bothered by the following problem?

	Not at all 0	Several days 1	More than half the days 2	Nearly every day 3
1. Feeling nervous, anxious or on edge				
2. Not being able to stop or control worrying				
3. Little interest or pleasure in doing things				
4. Feeling down, depressed or hopeless				
5. Trouble falling or staying asleep, or sleeping too much				
6. Feeling tired or having little energy				
7. Poor appetite or overeating				
8. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down				

9. Trouble concentrating on things, such as reading the newspaper or watching television				
10. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.				

14. What sex were you assigned at birth? *(check one only)*

☐ Male

☐ Female

☐ Other (please share if you would like):

____

☐ Prefer not to answer

15. What is your gender? *(check one only)*

☐ Woman

☐ Man

☐ Trans Woman

☐ Trans Man

☐ Genderqueer/ Gender Non-Binary

☐ Other (please share if you would like):____________________

☐ Prefer not to answer

16. Are you of Hispanic, Latino, or Spanish origin? *(check one only)*[1]

☐ Yes (Optional: How would you describe yourself? ____________________)

☐ No

☐ Prefer not to answer

17. What race best describes you? *(check all that apply)*[1]

☐ American Indian or Alaska Native

☐ Asian

☐ Black or African American

☐ Native Hawaiian or Other Pacific Islander

☐ White

☐ Other (please specify): ________________________

☐ Prefer not to answer

18. What language do you speak most of the time at home? *(check one only)*

☐ English

☐ Another language

Please specify ________________________

19. Are you currently married or living with a domestic partner or significant other?

☐ Yes

☐ No

20. Other than yourself, how many adults live in your household?
_________ [DROP DOWN]

21. How many children live (part-time or full-time) in your household?
_________ [DROP DOWN]

22. How would describe how much education you have completed? _________ [DROP DOWN]

Drop down options will start with
Did not attend school
Then a list of all the grades
Kindergarten through “12 or GED or equivalent”
then
Attended college, technical school, or apprenticeship
Completed college, technical school, or apprenticeship
Attended graduate or professional school
Completed graduate or professional school

23. How would you describe your current employment status? *(check **all** that apply)*

☐ Student

☐ Employed for wages or self-employed (full time or part time)

Approximate number of hours worked per week: _____ [DROP DOWN]

☐ Not currently employed and looking for work

☐ Not currently employed and not looking for work

☐ Homemaker

☐ Retired

☐ Disabled (or on disability or leave of absence)

☐ Other, please specify_______________
☐ Prefer not to answer

24. Which of these income categories comes closest to the total yearly income for your household, from all sources? *(check one only)*

☐ Under $30,000
☐ $30,000 to $59,999
☐ $60,000 to $90,000
☐ More than $90,000
☐ Prefer not to answer

APPENDIX B. CONCEPT ELICITATION INTERVIEW GUIDE

The interview guide was used to direct and manage individual concept elicitation interviews. Interviewers adapted the guide as needed to align with participant's life circumstances (e.g., when participants did not work, interviewers did not ask detailed questions about work experiences). Interviewers also adapted the guide as needed to reflect the language used by individual participants. If participants used the word throbbing to describe headache, for example, interviewers also tried to consistently use that word.

GENERAL HISTORY AND EXPERIENCE

Time: 5 – 15 minutes

Objectives for the interviewer: *In this part of the interview, you will provide some open-ended opportunities for the participant to share their individual history and experience with migraine. The questions and prompts indicate what information is desired, but in this section the primary focus should be on allowing the participant to tell their story in the way that makes sense to them.*

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1. **I'd like to start by asking you to tell me about your experience with migraine.**

Follow-ups could include asking about:

What symptoms or impacts do you typically experience now?

When do these different symptoms or impacts occur? (ictal/interictal)

What do you experience between migraine attacks?

How frequent are they? (e.g., how many times per month do you typically have migraine attacks)

How long do your migraine attacks usually last? (e.g., how many hours/days)

How long have you had migraine? Or, when did you experience your first migraine attack? (age/year/occasion)

When were you first diagnosed or told by a healthcare professional that you have migraine? (age/year)

As appropriate, depending on number of reported attacks per month or other information offered by participant:

Do they cluster together? (e.g., do you tend to have multiple attacks close together, followed by a longer period without any attacks)

Do you have menstrual migraines?

2. **Tell me a bit more about what you usually experience during your migraine attacks?**

[**ALTERNATIVES:** Tell me about your headaches. What are they like for you?]

Follow-ups could include:

How would you describe how severe or intense your symptoms are?

How have the symptoms or impacts you experience differed over time, say over the past 3 months? The past year?

3. **What has living with migraine been like for you?**

   [ALTERNATIVES: How does migraine affect your life? How does migraine affect your ability to do the things you need or want to do?]

   PROBE for both <u>during attacks and between attacks</u>

   Follow-ups could include:

   Personal life -- at home, social life

   Life at work or school

   Other aspects of your life

4. **What are some of the ways that you've figured out that help you manage your migraine?**

   [ALTERNATIVES: What sorts of things do you do when you know a migraine attack is coming on? What are some of your "go-to" things for dealing with a migraine attack?]

5. **What bothers you the most about living with migraine?**

   Follow-ups could include:

   Which symptoms?

   Which impacts on your life?

   Do these things that bother you change depending on…

   Which phase of the migraine attack? In between attacks?

   Other factors? (E.g., weather, where you are or what you are doing?)

6. **What changes have you noticed in your migraine in the time since you first started experiencing them?**

   Follow-ups could include:

   IF NEEDED: How long have you had migraines?

   In what ways have the frequency or severity of your migraine attacks changed?

   In what ways have your symptoms or the impacts on your life changed?

   Improved, worsened, or stayed the same?

   Has the thing that bothers you the most changed over time? How so?

7. **How does the medication or other treatments you use affect your migraine attacks?**

***Interviewer reminder*: Treatments may include a variety of things, so prompting may be needed.**

Examples include

    - Preventive or acute medications or products (Rx or OTC)
    - Treatments like Botox or nerve blocks
    - Neurostimulation
    - Behavioral therapies like biofeedback, mindfulness, or meditation
    - Alternative/complementary therapies like acupuncture or Reiki
    - Cold or heat packs/wraps
    - Physical or occupational therapy

- **[OPTIONAL] Are there other things you do to manage your symptoms?**

  Interviewer reminder: **Management includes a wide variety of things, so prompting may be needed.**

  Examples include

    - Keeping a migraine or headache diary
    - Rest or sleep
    - Avoiding triggers (could be a wide range of things, such as loud noises, stress, or certain foods)
    - Diet, exercise, or other self-care
    - Change your environment (e.g., dark room, wear a hat)
    - Avoiding exertion (physical or mental / cognitive)

MIGRAINE SYMPTOM & SEVERITY EXPERIENCE AND BOTHERSOME SYMPTOMS

Time: 10-15 minutes

***Objectives for the interviewer**: In this part of the interview, you will elicit details about the symptoms the participant experiences during the phases of migraine, the severity of symptoms, which symptoms are the most bothersome and why, and ability to recall. These questions do not ask about impacts, as that comes in the next section. However, do not stop the participant from sharing impacts at this time, should they choose to do so.*

Thank you so much for sharing all of that with me. This has been very helpful.

I'd like to understand in a bit more detail about the symptoms you usually have with migraine. I'd like to understand better when these different symptoms occur—for example, which ones happen before your headache pain starts and which ones happen during or after the headache pain.

Typical Symptoms, Severity, and Most Bothersome

***Interviewer instruction**:* **You will likely need to tailor this section according to what the participant has already shared. For some participants, it may work better to use a "paint me a picture" approach in which you ask the participant to describe their most recent or a typical migraine attack from beginning to end.**

8. Help me understand more about what typically happens for you now when you have a migraine attack…

Can probe for detail to help you understand the person's ictal/interictal experiences:

- What symptoms tell you that an attack is probably coming? [prodrome]
- What symptoms tell you that a headache is starting very soon (or now)? [aura/onset]
- What symptoms do you typically have during the headache period?
- What symptoms linger after the headache is over? [postdrome]
    - Are there symptoms that start after the headache is over?
- In between your headache attacks, what symptoms do you typically have? [interictal period]

Follow-ups for these questions could include

How long does [symptom] last?

How do you know whether [symptom] is getting worse or better?

What do you do? What are some ways that you manage these symptoms?

Which of these symptoms would you most want to be improved by a treatment?

9. Help me understand better…Which symptoms typically bother you the most and why?

Follow-ups could include

Could you tell me more about what it is that bothers you? (e.g., impact on function, level of suffering, triggering other symptoms)

Is there a particular time period during your migraine when this is most bothersome for you?

How does [bothersome symptom] change in [severity | intensity | frequency] over the course of your migraine?

[ALTERNATIVE: How do you know whether [symptom] is getting better or worse?]

Cycle Prompt for elaboration: Are there other symptoms that bother you a lot?

REQUIRED FOLLOW-UP IF the participant does <u>not</u> spontaneously mention these 3 symptoms:

In migraine research, scientists often focus on 3 specific symptoms as the most bothersome, other than pain. They are: nausea, being bothered by light, and being bothered by sounds.

What are your thoughts on these 3 symptoms in terms of your experience of migraine?

Which of the symptoms that are bothersome to you would you like to see scientists focus on as well?

How would you go about choosing one of these symptoms as most bothersome for you?

➔ Would you always pick the same one?

When you think about how you experience these 3 symptoms, do they change in [severity | intensity | frequency] over the course of your migraine? Or, how do you know whether [symptom] is getting better/worse?

10. In your experience [or, how do you think about]: what makes one migraine attack [better/worse | more/less severe | more/less intense] than another?

Follow-ups could include

Do you tend to think about the overall experience from beginning to end?

Are there particular symptoms you think about?

Do you think about…

Degree / amount of symptom(s)?

How long the attack lasts? How long particular symptoms last?

How long it takes to recover? Or, how much time there is between attacks?

11. In what ways does the severity | intensity of your migraine differ from attack to attack?

IF NEEDED: Ask the participant to focus on experiences in the last few months or year.

Follow-ups could include

What sorts of differences are there in what you experience?

Are there particular symptoms or impacts that vary the most? How do they vary?

12. When you think back to your migraine attacks, like you are doing now, what are the things that [stand out in your mind | you remember most clearly] about it?

Follow-ups could include

How challenging is it to remember what happened in an attack that happened a week ago? Or a month ago?

Or, what happened in between attacks?

Interviewer instruction: This question is aimed at developing an understanding of recall time frames for a PROM. It is important to probe for participant's perspectives on ability to and perceived relevance of recalling from the past week, two weeks, and month. If those time periods are not relevant to them, focus attention on determining what period of time is relevant.

13. IF NEEDED: Now I'd like to go back and focus a bit more on how severe / intense your symptoms are.

Help me understand the difference between more severe [symptom] and less severe [symptom]?

OR, how do you think about how the severity of [symptom] varies?

14. [OPTIONAL] Are there any other symptoms that you have from time to time, but not typically?

Probe around when these symptoms occur and how often.

IMPACTS ON PHYSICAL FUNCTION

Time: 10-15 minutes

Objectives for the interviewer*: In the remaining sections of the interview, you will provide an open-ended opportunity for participants to comment on aspects of function and disability experience. You will follow up by probing around the nature of the impacts experienced, when they occur, and what the consequences are. You will then refer to a table or bullet list of functional areas and probe as needed for effects on these functions. After exploring which effects the participant experiences, you will ask questions about whether medication influences these effects, explore thoughts on most bothersome effects, and ask about how things have changed over time for the participant.*

Check in with the participant – How are they doing?

Now I'd like to ask you to tell me a bit more about how living with migraine impacts your ability to do the things you need or want to do from day to day.

Physical Impacts and Disability Experiences

15. Could you tell me a bit more about how migraine affects your ability to do things that require physical activity or movement?

REQUIRED FOLLOW-UPS:

<u>What is the effect</u>(s) – For example: makes no difference / can do better / change the way you do it / can't do at all / avoid doing / do more slowly or not as well / need help from someone / use a device <u>to support function</u> (e.g., use a shower chair) / other?

<u>When</u> do these effects happen – For example, during attacks and/or in between attacks? Sometimes or with every attack? How do they change over the course of the attack (phases)?

<u>What are the consequences</u> – For example, what benefits or challenges does it create for general well-being, family life, etc.?

<u>How are symptoms or functions related</u> – For example, which symptoms result in functional impacts? Which functional impacts affect other functions?

***Interviewer instruction*: After the participant has had an opportunity to offer spontaneous thoughts on physical function impacts, use the probe topics in the table as needed to fill in any gaps and use the same follow-ups.**

PHYSICAL FUNCTION PROBE TOPICS:

Functional area	Examples
Basic movement or exertion	Moving your head, getting in and out of bed/chair, eating/feeding yourself
Mobility and ambulation	Moving around the house, bending over, picking things up, walking a short distance, using stairs
Self-care	Bathing, grooming (shaving, brushing hair, etc.), dressing yourself
Standing or sitting upright (prolonged)	Standing in line, sitting up at the table for a meal
Household tasks	Cooking, cleaning, laundry, gardening, car maintenance
Moving about in the community	Shopping, running errands, getting to and from work/school or other locations, going to doctor's appointments Driving or being in a car, using public transport
Ability to care for other people or pets	Taking care of family members (or other important people) or household animals
Physical activities at work or school	Operating a machine, shifting a chair, lifting a box, carrying a briefcase or backpack
Exercise / recreation	Walking, running, sports, dance, swimming, hiking
Ability to have a hobby that requires physical activity	Playing an instrument, sewing, woodworking, artwork, or other activities that requires physical exertion

Other aspects of experience

16. How would you say the medicine or other treatments that you use for migraine affect these physical impacts you experience?

- IF NEEDED: Does your medication/treatment makes these impacts less? Does it make them worse?

Interviewer instruction: As appropriate, inquire about acute vs. preventive treatments.

17. Which of these physical effects are bothersome to you?

  - Which is <u>most</u> bothersome?
  - Which is <u>least</u> bothersome?
- IF NEEDED: Tell me a little bit about **<u>why you chose that</u>** as the most/least bothersome.

***Interviewer instruction*:** **Probe for detail as needed. We want to know**: Is it most bothersome, e.g., due to physical discomfort, exacerbation of other symptoms, or something else? Is it least bothersome because the person has adapted or doesn't prioritize certain activities?

18. How would you say these effects on your ability to do physical things has changed over the time you have lived with migraine?

- IF NEEDED:

  If the participant has had migraine for many years, ask the participant to focus on the past year or two.

  - For example, did you always have these impacts, or have they changed over time? (If they have changed, interviewer will explore when and why)
  - Are they the same / worse / better than before?
  - What adaptations have you made in your life to manage these impacts of migraine (e.g., good routines, being prepared)? What improvements have you experienced (e.g., more support from doctors or other people, better treatment)?

19. When you think back about your migraine, how easy/challenging is it to remember these physical effects when it happened a week ago? Two weeks? A month?

- What are the things that [stand out in your mind | you remember most clearly]? Or, what is it that you remember best?
- If someone wanted to understand your experience well, what period of time would you want to describe to them?

[OPTIONAL: Ask if the participant has ever used a diary or migraine tracker and in what ways they find this helpful. Ask what information in a diary might be hard to recall or assess after a week or two or four.]

Interviewer instruction: This question is aimed at developing an understanding of recall time frames for a PROM. It is important to probe for participant's perspectives on ability to and perceived relevance of recalling from the past week, two weeks, and month. If those time periods are not relevant to them, focus attention on determining what period of time is relevant.

IMPACTS ON THINKING OR CONCENTRATION

Time: 10-15 minutes

Check in with the participant – How are they doing? Thank them for all they have contributed so far.

I'd like to ask you to switch now and focus now on the ways that migraine affects your ability to think.

Cognitive Impacts and Disability Experiences

20. Could you tell me a little bit more about how migraine affects your ability to do things that require you to [think or concentrate | use your brain]?

REQUIRED FOLLOW UPS:

What is the specific effect on ability – For example: makes no difference / can do better / change the way you do it / can't do at all / avoid doing / do more slowly or not as well / need help from someone else / use things to help you, like a notebook or calendar reminder / other

When do these effects happen – For example, during attacks and/or in between attacks? Sometimes or with every attack? How do they change over the course of the attack (phases)?

What are the consequences – For example, what challenges or benefits does it create for general well-being, family life, physical safety, etc.?

How are symptoms or functions related – For example, which symptoms result in functional impacts? Which functional impacts affect other functions?

***Interviewer instruction*: After the participant has had an opportunity to offer spontaneous thoughts on mental function impacts, use the probe topics in the table as needed to fill in any gaps and use the same follow-ups.**

COGNITIVE FUNCTION PROBE TOPICS:

Language and numbers	Ability to ○ Think of words ○ Correctly name objects ○ Speak clearly, with fluency – not halting or slurring ○ Understand what is said to you (comprehension) ○ Do or understand simple arithmetic (e.g., pay a bill)
Memory	Ability to ○ Free recall (e.g., remember people's names or

	recent events) ○ Cued recall (e.g., can recall when prompted) ○ Use working memory (e.g., what am I doing right now or what did I just do?) ○ Use long term memory (e.g., what did I do yesterday, or last year?) ○ Learn skills that require memorization (implicit learning)
Attention / Information processing	Ability to ○ Concentrate or focus on something ○ Follow a conversation, understand a question ○ Function in a group conversation or other noisy group situation ○ Process and act on information (e.g., follow directions) ○ Sustain attention for a long period (e.g., follow a lecture, work for several hours) ○ Divide attention / multi-task ○ Perform complex mental tasks, like doing your taxes
Planning / Reasoning	Ability to ○ Plan activities (e.g., plan a vacation or organize a volunteer event) ○ Solve problems ○ Engage in complex thought, reading, writing, or math
Judgment / Executive function	Ability to ○ Make decisions ○ Understand consequences of action ○ Control impulses (e.g., control frustration) ○ Be flexible (e.g., adapt plans on the fly)

Other aspects of experience

21. How would you say the treatments that you use for your migraine affect these mental effects you experience?

IF NEEDED: Does your medication/treatment makes these impacts less? Does it make them worse?

Interviewer instruction: As appropriate, inquire about acute vs. preventive treatments.

22. Which of these mental effects are bothersome to you?

- ○ Which is most bothersome?
- ○ Which is least bothersome?

○ IF NEEDED: Tell me a little bit about **why you chose that** as the most bothersome.

***Interviewer instruction*: Probe for detail as needed. We want to know**: Is it most bothersome, e.g., due to challenges of doing, challenges created in life by limitations, or because of consequences (which could range from financial costs to dealing with errors afterwards to embarrassment)?

23. How would you say these effects on your ability to do mental things has changed over the time you have lived with migraine?

- IF NEEDED:

  If the participant has had migraine for many years, ask the participant to focus on the past year or two.

  - For example, did you always have these impacts, or have they changed over time? (If they have changed, interviewer will explore when and why)
  - Are they the same / worse / better than before?
  - What improvements have you experienced (e.g., more support from doctors or other people, better treatment)? Or, what adaptations have you made in your life to manage these impacts of migraine?

24. When you think back on your migraine, how easy/challenging is it to remember these sorts of mental effects when they happened a week ago? Two weeks? A month?

  - What are the things that [stand out in your mind | you remember most clearly]? Or, what is it that you remember best?
  - If someone wanted to understand your experience well, what period of time would you want to describe to them?

[Optional: If the person has experience using a diary or tracker, inquire as before]

Interviewer instruction: This question is aimed at developing an understanding of recall time frames for a PROM. It is important to probe for participant's perspectives on ability to and perceived relevance of recalling from the past week, two weeks, and month. If those time periods are not relevant to them, focus attention on determining what period of time is relevant.

IMPACTS ON PSYCHOSOCIAL FUNCTION

Time: 10-15 minutes

Interviewer instruction: Please tailor this part of the interview to match and build from what each participant has already shared about themselves and their experiences with migraine. Mirror language used by participant to describe their family/social/personal circumstances and skip questions as appropriate.

Interviewer instruction: In this section, be alert for impacts that may have resulted from, or been worsened by, the COVID-19 pandemic. Ask participants to describe typical, non-pandemic effects.

Check in with the participant – How are they doing? Thank them for all they have contributed so far.

In the time we have left, I'd like to ask more about how migraine affects your ability to do other things that may be important to you, such as working or going to social or family events. I also want to ask about how migraine affects your mood or your emotional state.

Social Roles and Activities

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25. How would you say that migraine affects your family | home life?

Interviewer instruction: The participant should define home and family life in the way that makes most sense for them. In the unlikely event that they have not already offered information showing how they define home/family life, it is okay to ask for clarification.

- PROBE FOR:
  - **When effects happen** (ictal/interictal)
  - **How symptoms or functions are related these effects**
  - **Benefits and challenges** (e.g., helps person appreciate their family more, ruins family events)
  - **Impact on ability to carry out family roles** (e.g., being a spouse or partner, parent, sibling)
  - **Impact on others in the family** (e.g., burden created for family members, disruption of family life or family plans)

26. How would you say migraine affects your social life | community life?

Interviewer reminder: Social life could include a wide range of things. Be alert for alternative social engagements, such as Zoom calls or participating in an online support forum.

For example:

- Making or sustaining relationships with others
- Taking part in social events, such as gatherings
- Making or keeping to plans
- Attending a movie or going to the theater
- Going to a religious gathering
- Participating in community or volunteer activities (e.g., being in the PTA, serving on a community committee)

PROBE FOR:

When effects happen (ictal/interictal)

BE SURE TO PROBE for interictal experiences such as reluctance to plan or worry about having to miss things

How symptoms or functions are related these effects

Benefits and challenges

Impact on ability to carry out social roles

Impact on others

27. How would you say migraine affects your ability to work | go to school?

***Interviewer reminder*: This could include a wide range of things.**

For example:

- No effect….unable to work / go to school
- Requiring accommodations or making adaptations
- Taking more time to do things
- Limiting you or causing absences
- Feeling less productive / managing schedule to optimize "good" times
- Finding a different job / not working in the job you trained for

PROBE FOR:

When effects happen (ictal/interictal)

How symptoms or functions are related to these effects

28. When you think about these different areas of life – family | home, work | school, social activity – which of these impacts is most bothersome to you and why? Least bothersome?

29. How have these effects changed over time? What improvements have you experienced in the long run? (e.g., finding a support community, a doctor who understands you or better treatments?)

30. When you are thinking back, how easy or challenging is it to remember these sorts of effects when they happened a week ago? Two weeks? A month?

Impact on Mood

31. How would you say migraine affects your mood, or the feelings and emotions that you have?

***Interviewer reminder*: This could include a wide range of things and effects could vary over the course of migraine attack or during interictal periods.**

***Interviewer instruction*: If the participant emphasizes one dimension (e.g., headache phase, negative effects), please ask about other dimensions (e.g., other phases, positive effects).**

For example:

- Mood changes or swings, such as irritability, euphoria
- Positive feelings such as happiness, feeling energetic, feeling satisfied, feelings of acceptance or peace
- Negative feelings, such as sadness, feeling depressed, feeling hopeless, feeling a sense of loss of identity or lack of control
- Anxiety or worry, including apprehension about attacks
- Frustration or anger, either about symptoms or effects of migraine on life

32. When do these effects occur? (ictal/interictal)

BE SURE TO PROBE for interictal experiences such as happiness about being able to do things or worry about next headache.

33. Which of these impacts on your mood is most bothersome to you? Least bothersome?

34. How have these effects changed over time?

35. When thinking back, how easy/challenging is it to recall something from a week ago? Two weeks ago?

Transition Question

***Interviewer instruction:* This question is meant to be broad and to help the participant return to a broader perspective on their experience.**

36. Finally, when you think about everything you've shared with me today, what are the key things about your migraine that would have to change for you to be able to do the things you most want to do | live the life you want to live?

CLOSING

Time: ~5 minutes

- That is the end of the questions I have for you. Thank you so much for spending this time with me and sharing so much information and insight.

- Is there anything else about your experience that you think is important for me to know?

    - **Alternative**: Is there anything else I should have asked about?

APPENDIX C. FINAL CODEBOOK

The table below provides the final coding structure established for the interview data, including definitions for each code and a designation of the code type (where applicable). The coding structure is hierarchical and the level of indentation indicates thematic subcoding relationships.

Code Name	Definition and code type
Content Codes **(used to code migraine concepts)**	Parent code -- number of files and references represents aggregated results of subcoding
Cognitive Function Codes	Parent code -- number of files and references represents aggregated results of subcoding
Concentrate	Ability to pay attention or focus on something, to concentrate on the activity at hand. Concept group code -- number of files and references includes aggregated results of subcoding. This code was used for functioning impacts only. Comments describing mental clarity or fogginess were coded as Symptoms-Mental Acuity. The term "focus" was not used in coding or reporting because the word is also used to describe visual functioning.
Critical thinking	Ability to make judgments or engage in analytic activities. Subcode.
Divided attention	Ability to divide one's attention between two or more targets, including the ability to concentrate on things other than symptoms experienced during a migraine. Subcode. Concept group code -- number of files and references includes aggregated results of subcoding
Multiple inputs	Ability to concentrate in the presence of multiple inputs (e.g., a multi-person conversation). Subcode.
Pain-distraction	References to pain interference with concentration. Subcode.
Sensory-distraction	References to interference from sensory symptoms (e.g., photo- or phonophobia) with concentration. Subcode.
Sustained attention	Ability to sustain attention and concentrate for long period of time. Subcode.
Flexibility, multitasking	Ability to be flexible and adaptive in one's thinking, consider alternatives, and to multi-task.
Impulse & behavior management	Ability to control impulses and reactions.
Information processing & reasoning	Ability to process information and make sense of things, form or respond to abstract thoughts/ideas, to categorize, to learn new things, etc.
Language	Ability to receive and comprehend spoken and non-verbal messages, to speak, to carry on a conversation, and to use numbers. Concept group code -- number of files and references includes aggregated results of subcoding
Comprehension	Ability to understand spoken language. Subcode.
Expression	Ability to express one's thoughts. Subcode.
Numbers	Ability to understand and use numbers, do simple math. Subcode.
Speech	Ability to speak. Concept group code -- number of files and references includes aggregated results of subcoding

Code Name	Definition and code type
Avoiding speaking, not able to speak	Inability to speak or choosing to avoid speaking. Subcode.
Jumbled	Experience of jumbled speech or jumbled words. Subcode.
Slowed	Experiencing slowed, hesitant speech. Subcode.
Slurred, mumbled	Experiencing slurred or mumbled speech. Subcode.
Word finding	Ability to recall and say the intended word. Subcode
Medication management	Ability to taking medication properly and on schedule or when needed.
Memory	Parent code -- number of files and references represents aggregated results of subcoding
Memory free recall	Ability to create working memory, to encode and hold information in memory. Subcode.
Memory working	Ability to create working memory, to encode and hold information in memory. Subcode.
Recall of attacks	Ability to recall symptoms and impacts from a specific attack over a period of time (e.g., a few days, a week, two weeks). Subcode.
Money management	Ability to handle basic financial activities, such as managing income and taxes, planning a budget, writing checks, paying bills, communicating with banks.
Problem solving	Ability to identify/recognize problems and engage in problem solving behaviors.
Read Write	Ability to read and write, in any and all forms. Concept group code -- number of files and references includes aggregated results of subcoding
Read	Ability to read. Concept group code -- number of files and references includes aggregated results of subcoding
Concentrate	Effects on reading ability that result from ability to concentrate. Subcode.
Visual disturbances	Effects on reading ability that result from visual disturbances. Subcode.
Write	Ability to write. Concept group code -- number of files and references includes aggregated results of subcoding
Assistive writing	Use of writing during a migraine attack as a means to support function (as a contrast to impairments of writing ability). Subcode.
Technology	Comments referring to use of technology while writing during a migraine attack. Subcode.
Physical Function Codes	Parent code -- number of files and references represents aggregated results of subcoding
Ambulation	Ability to sit, stand, and walk by oneself, to move one's body or parts of the body. Ability to transfer in and out of a chair, bed, or vehicle. Concept group code -- number of files and references includes aggregated results of subcoding.
Head-limb movements	Ability to move the head or limbs. Subcode.
Immobility	Inability to move. Subcode.
Postural transitions	Ability to move the body from one posture to another, such as getting up out of a chair. Subcode.
Stand-sit prolonged	Ability to sit or stand for a prolonged period of time. Subcode.

Code Name	Definition and code type
Walk	Ability to walk. Subcode.
Basic self-care	Ability to carry out basic self-care, such as dressing, grooming, and eating. Concept group code -- number of files and references includes aggregated results of subcoding
Bathing	Ability to bathe completely by oneself or need assistance only with cleaning a single part of the body. Subcode.
Dressing	Ability to select and retrieve clothing, put them on by oneself. Subcode.
Eating & drinking	Ability to use utensils and containers to feed oneself (does not include food preparation or clean up; these activities are classified under Meals). Subcode.
Grooming	Ability to take care of hair, skin, teeth, including activities like shaving or applying makeup. Subcode.
Toileting	Ability to go to the toilet by oneself. Subcode.
Communications systems	Ability to use communication devices such as phones, computer email, etc.
Exercise	Ability to engage in exercise activities, such as running, lifting weights, taking an exercise class, doing yoga.
Fine motor	Ability to engage in small motor activities, such as picking up small objects or opening packages.
General function - Live life	Ability to carry out normal life or daily functions when not specified or referred to in an aggregate, general way.
Health maintenance	Ability to schedule and attend medical appointments and look after one's health.
Housekeeping	Ability to carry out home care activities such as cleaning, making beds, laundry, gardening, taking out the trash, etc.
Lift carry	Ability to pick up and carry an object of any weight.
Meals	Ability to carry out meal preparation activities such as meal planning, retrieving ingredients, washing and chopping, lifting filled pots and pans, operating appliances, safely managing risks of fire or burns, and cleaning up after meals (e.g., dishwashing, putting away food). Ability to avoid trigger foods and maintain adequate nutrition.
Mobility Transport	Concept group code -- number of files and references includes aggregated results of subcoding
Driving in a car	Ability to drive a car or be a passenger. Subcode.
Medication prevents driving	Used for references to inability to drive as a result of medication use. Subcode.
Public transportation	Ability to use public transportation such as buses or subways. Subcode.
Travel	Ability to travel long distance, such as by plane. Subcode.
Shopping & running errands	Ability to shop in stores or run errands.
Sleep impacts	Effects of migraine on ability to sleep.
Psychosocial Function Codes	Parent code -- number of files and references represents aggregated results of subcoding

Code Name	Definition and code type
Accept-adapt	Ability to accept or adapt to life with migraine, develop a sense of tolerance about one's experiences, or to find a "new normal."
Care of others or pets	Ability to provide care and fulfill any familial/household roles such as parenting, taking care of elders, taking care of pets, including selecting and supervising other caregivers as needed.
Coping	Ability to engage in strategies designed to cope with or prevent the occurrence of undesirable symptoms, impacts, or consequences. Concept group code -- number of files and references include aggregated results of subcoding
Cocooning	Withdrawing, self-isolating, or avoiding stimuli and activity during a migraine attack. Subcode.
Voluntary avoidance	Choosing not to engage in specific activities or interactions due to a migraine attack, which may be independent or simultaneous with cocooning. Subcode.
Lifestyle changes-adjustments	Choosing to change or adopt a lifestyle that minimizes risk of migraine attacks, builds health and well-being, or prioritizes one's own health and welfare needs. Subcode.
Maintaining	Using strategies aimed at limiting the progression or stopping the worsening of a migraine attack. Subcode.
Non-pharmaceutical therapies	Use of non-pharmaceutical therapies and strategies to cope with migraine attacks (e.g., meditation, ice/heat packs, massage). Subcode.
Sensory control	Use of devices and strategies to control or reduce sensory inputs (e.g., light-blocking glasses, earplugs, blackout curtains). Subcode.
Direct costs	Comments about the direct costs of migraine, such as out-of-pocket medical costs or time spent obtaining medical care or dealing with insurance companies.
Emotion States	Parent code -- number of files and references represents aggregated results of subcoding
Anger-Frustration	Feelings of anger or frustration. Subcode.
Anxiety	Feelings of worry, anxiety, or apprehension. Subcode.
Depression	Feelings of sadness or depression. Subcode.
Embarrassment	Feelings of embarrassment. Subcode.
Energy and drive	Feelings of having energy and drive to do things, feeling motivated. Subcode.
Grief	Feelings of grief and loss. Subcode.
Guilt	Feelings of guilt. Subcode.
Happy-Euphoria	Feelings of happiness or euphoria. Subcode.
Irritable	Feelings of irritability, being short-tempered or easily bothered. Subcode.
Other negative thoughts	Used to capture other negative moods or thoughts not covered by other codes. Subcode.
Other positive thoughts	Used to capture other positive moods or thoughts not covered by other codes. Subcode.
Relief-invigorated	Feelings of relief or being invigorated, typically as a result of migraine treatment. Subcode.

Code Name	Definition and code type
Skepticism	Feelings of skepticism or mistrust, often regarding whether medication will work as desired. Subcode.
Family relations	Impacts of migraine on family relationships or on one's ability to participate in family relationships (other than partner/spouse relationships). Family can include anyone in the household relevant to the interview participant, such as roommates.
Feeling heard	Ability to feel like others, including health care providers, hear and understand you, that they take you seriously and don't dismiss your experience or burden. Ability to feel that you are not invisible. Concept group code -- number of files and references includes aggregated results of subcoding
Friends-family	Ability to feel heard and understood by family and friends. Subcode.
Healthcare providers	Ability to feel heard and understood by healthcare providers. Subcode.
Work-school-society	Ability to feel heard and understood by employers, colleagues, educational institutions, or society at large. Subcode.
Identity	Ability to feel that you are who you really are— being your best self, being the good or normal person you usually are or used to be.
Interpersonal relations	Ability to form and maintain personal relations and engage in interpersonal interactions with non-family members or people outside the household.
Intimate relations	Ability to have intimate relationships with a partner or spouse, with or without sex.
Life satisfaction and meaning	Ability to feel that your life has meaning and purpose, that you have satisfaction, joy, or fulfillment.
Predictability-control	Ability to predict how you will feel and function over a given period of time, that you can make plans and have a reasonable chance of being able to stick to them. Ability to feel that you have control over your life and circumstances.
Pushing through	Concept group code -- number of files and references includes aggregated results of subcoding
Care for others	References to pushing through in order to provide care for others, such as children or parents. Subcode.
Desire to live life	References to pushing through because one wishes to live life and not be held back by migraine. Subcode.
Maintain self-image	References to pushing through in order to maintain one's self-image or social role image. Subcode.
No choice-no other alternative	References to pushing through because one has no choice, such as when one must drive home, or when there is no one else to take care of responsibilities or roles. Subcode.
Scheduled plans-obligations	References to pushing through because one has made a commitment or promise and feels obligated to follow through. Subcode.
Recreation-leisure	Ability to engage in recreational or leisure activities, such as going to a movie or theater, going to the beach or an amusement park, or sightseeing.

Code Name	Definition and code type
School	Ability to attend classes/days of school and complete required schoolwork. Full time or part time. Online or in person.
Self-sufficiency	Ability to be or feel self-sufficient, have the sense that one can manage one's health condition.
Social community & civic roles	Ability to participate in social gatherings with friends or family, participate in community life (e.g., town meetings), or civic and political events (e.g., rallies, festivals, voting in person). Concept group code -- number of files and references includes aggregated results of subcoding
Civic roles-events	Ability to participate in roles or activities with a civic aim, including political or community activism and short-term volunteer activities. Subcode.
Community life	Ability to participate in community events beyond immediate friends and family, or to be in a large, busy community environment. Subcode.
Friends-family social	Ability to participate in social events and activities with family and friends. Subcode.
Social support-isolation	Ability to access social support—either from family, friends, community, colleagues, or a support group or organization. Ability to feel not alone or isolated.
Spiritual life	Ability to attend religious meetings or engage in routine religious activity at home (e.g., praying, fasting, preparing for holidays).
Stigma	Ability to live without shame or stigma. Experiences and perceptions of stigma related to migraine.
Well-being	Ability to achieve a sense of feeling well and good or of having the life one desires, to do the things one needs and wants to do, to enjoy life. Concept group code -- number of files and references includes aggregated results of subcoding
Enjoy life	Ability to enjoy life. Subcode.
Missing out on life	Feelings of missing out on life, including missing out on relationships, roles, and activities. Subcode.
Needs-wants to do ability	Ability to do the things one needs or wants to do. Subcode.
Work	Ability to work in any capacity, paid or unpaid. Concept group code -- number of files and references include aggregated results of subcoding
Work for pay	Ability to engage in paid employment or operate a personal business, including ability to work in a chosen occupation; ability to fulfill work responsibilities as intended, including being present for workdays/hours. Subcode.
Accommodations	Experiences with needing or obtaining accommodations at work. Subcode.
Job-career loss	Experiences with losing a job or changing careers due to migraine. Subcode.
Missed work-leave	Experiences with missing work or taking leave due to migraine. Subcode.
Productivity-performance at work	Experiences with effects of migraine on work performance or productivity. Subcode.
Working through attacks	Experiences with working through attacks. Subcode.

Code Name	Definition and code type
Work stress, workload	Experiences with relationships between work-related stress or workload and migraine attacks. Subcode.
Work unpaid-volunteer	Ability to engage in unpaid work, such as unpaid internships, or volunteer activities, such as for community organizations, schools (including home school), or events. Subcode.
Symptom Codes	Parent code -- number of files and references represents aggregated results of subcoding
Appetite	Experiences of change in appetite as a symptom, including increase, decrease or loss of appetite.
Clumsiness	Experiences of being clumsy, having problems with coordination.
Dizziness	Experiences of dizziness or vertigo.
Fatigue	Experiences of fatigue, exhaustion, lethargy, or tiredness due to migraine.
GI-Nausea	Experiences of nausea or vomiting due to migraine.
GI-Other	Experiences of other GI symptoms, such as bloating, constipation, or diarrhea.
Mental Acuity (clarity or fogginess)	Concept group code -- number of files and references includes aggregated results of subcoding
Brain fog	Term used to denote experience of mental fogginess or reduced mental acuity. Subcode.
Brain not working, migraine brain	Term used to denote experience of mental fogginess or reduced mental acuity. Subcode.
Confusion	Term used to denote experience of mental fogginess or reduced mental acuity. Subcode.
Feel stupid, less smart	Term used to denote experience of mental fogginess or reduced mental acuity. Subcode.
Not as sharp, clear	Term used to denote experience of mental fogginess or reduced mental acuity. Subcode.
Slowed, delayed	Term used to denote experience of mental fogginess or reduced mental acuity. Subcode.
Spaced out	Term used to denote experience of mental fogginess or reduced mental acuity. Subcode.
Mood change	Experiences of abrupt changes in mood associated with migraine.
Pain-head and face	Experiences of pain in the head or face associated with migraine.
Pain-other	Experiences of any other pain associated with migraine.
Sensitivity	Experiences of sensitivity to stimulus. Concept group code -- number of files and references includes aggregated results of subcoding
Light	Experiences of sensitivity to light. Subcode.
Other	Experience of any other sensitivity not included in another code, such as sensitivity to motion, temperature, or weather. Subcode.
Smell	Experiences of sensitivity to smells. Subcode.
Sound	Experiences of sensitivity to sound. Subcode.
Touch	Experiences of sensitivity to touch. Subcode.
Sensory disturbance	Experiences of unusual or disturbed perception of sensory inputs. Experience of unusual, disturbed, or unexplainable reflex activity, such as yawning,

Code Name	Definition and code type
	associated with migraine. Concept group code -- number of files and references include aggregated results of subcoding
Eye symptoms	Experiences with eye symptoms such as eye watering, twitching, or trouble focusing. Subcode.
Other	Descriptions of unique or unusual sensory or physical disturbances, such as hand tremors, dry sinuses, or the feeling of getting an electric shock. Subcode.
Skin sensations	Experiences of allodynia or other unusual skin sensations associated with migraine. Subcode.
Taste or smell symptoms	Experiences of unusual or disturbed tastes or smells. Subcode.
Tinnitus, aural disturbances	Experience of ringing in the ears or ear fullness, etc., associated with migraine. Subcode.
Visual disturbances	Experiences of disturbed vision, such as spots, "snow," sparkles, or loss of visual field associated with migraine. Subcode.
Yawning	Experiences of yawning as a migraine symptoms. Subcode.
Sleep symptoms	Use for sleep symptoms such as insomnia, difficulty staying asleep (frequent waking), or sleep that is unrefreshing (wake up tired, poor quality sleep) that are associated with migraine. May be difficult to distinguish from sleep impacts.
Symptoms- General	Used for comments that do not identify specific symptoms or refer to symptoms in the aggregate. Concept group code -- number of files and references includes aggregated results of subcoding
Relief of symptoms-impacts	Used for comments referring to the relief of symptoms or impacts at the end of a migraine attack (as distinct from "no symptoms" which is the absence of symptoms). Subcode.
Tension-Stiffness	Experiences of tension or stiffness in the body associated with migraine.
Weakness	Experiences of muscle weakness associated with migraine.
Context Codes **(Used for dual coding with concept codes)**	Parent code -- not aggregated
Bothersome	Concept group code -- number of files and references includes aggregated results of subcoding
Can tolerate	Used to code comments regarding bothersomeness that expressed a connection to a person's ability to tolerate symptoms or impacts. Subcode.
Creates suffering	Used to code comments regarding bothersomeness that expressed a connection to whether the symptom or impact created suffering or discomfort. Subcode.
Exacerbates migraine symptoms or impacts	Used to code comments regarding bothersomeness that expressed a connection to exacerbation of other symptoms or impacts. Subcode.
Impairs function	Used to code comments regarding bothersomeness that expressed a connection to impairment of functioning. Subcode.
Least bothersome	Used to code responses to questions asking participants which symptoms or impacts they found least bothersome. Subcode.

Code Name	Definition and code type
Most bothersome	Used to code responses to questions asking participants which symptoms or impacts they found most bothersome. Subcode.
Change over time	Used to code references to how migraine symptoms or experiences have changed over time.
Comorbidity	Used to code references to comorbidities by interview participants.
Duration	Used to code references to the duration of symptoms or impacts (e.g., hours, days, weeks)
Expectations influence	Used to code references to how a participant's expectations about migraine and/or treatment are a factor in their experience or influence the way they think about priorities (e.g., expectation that medication won't work well may influence coping decisions or willingness to plan ahead).
Frequency	Used to code references to the frequency of migraine attacks or symptoms.
General inability to function	Used to code references to a general inability to function associated with migraine.
Get help from people or pets	Used to code references to getting help from other people or from pets.
Ictal	Concept group code -- number of files and references includes aggregated results of subcoding
Aura	Used to code references to aura by interview participants. Subcode.
Post headache	Used to code references to the time period following headache but still part of the migraine attack. Subcode.
Pre headache	Used to code references to the time period leading up to the onset of headache. Subcode.
Interdependence	Used to code references to participants' perceptions of how symptoms, functions, and preferences may be interdependent (e.g., a person who is unable to drive or use public transportation may link that limitation to feelings of isolation).
Interictal	Used to code references to the time period in between migraine attacks.
Medication impact	Used to code references to the ways in which medication impacts migraine symptoms or functioning.
Preferences	Used to code references to preferences of priorities for outcomes or treatments.
Recall	Used to code references to ability to recall; this code was replaced by a concept code for Recall of Attacks. Legacy code.
Severity	Used to code references to the severity of migraine symptoms or impacts on functioning.
Speed	Used to code references to the speed with which migraine symptoms or impacts occur, such as how quickly loss of function begins or subsides.
Stress	Used to code references to stress as a trigger or exacerbator of migraine.
Tradeoffs	Used to code references to making tradeoffs in relation to migraine, such as accepting medication side effects to achieve pain relief or weighing the pros and cons of exposure to triggers.

Code Name	Definition and code type
Use assistive device	Used to code references to use of assistive devices or strategies intended to support physical or cognitive function. This includes items such as walkers or shower chairs, technologies such as calendar alerts, and pragmatic strategies such as using sticky notes or lists to support memory or leaning on furniture to support walking.

APPENDIX D. SATURATION TABLES

Table D-1 provides data relevant to assessing the saturation of concepts within and across interviews. Table D-2 provides an analysis of probed vs. spontaneous occurrence of the concepts within coded interview content.

Table D-1 demonstrates that concept saturation was reached in interview #14 of 31 interviews conducted. In the coding structure shown in the table below, thematic subcodes are included in addition to concept codes. In some cases, thematic subcoding revealed variations or nuances in participant expression in interviews later than #14, but this was uncommon. For example, within the thematic subcoding for “Write,” references to specific aspects of writing with technology (e.g., preferring to use an iPad with a dimmed screen) first arose in interview #24 and this nuance is now the final new subcode in this codebook. However, this subcode does not represent a new concept, as the content of the subcode still reflects impacts of migraine on ability to write, which was first encountered in interview #3.

Table D-1. Saturation and Endorsement of Concepts

Code	First Occurrence	# Cases Coded	% Of Cases Coded	2672	2689	2691	2692	2693	2703	2709	2711	2744	2753	2797	2798	2813	2830	2850	2882	2909	2913	2915	2940	2997	3005	3013	3018	3022	3104	3184	3214	3225	3233	3248
Cognitive Function Codes	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Concentrate	2	29	94%		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x
Critical thinking	2	5	16%		x			x			x										x											x		
Divided attention	3	18	58%			x		x					x	x		x	x	x	x	x	x	x	x		x	x		x		x	x	x		
Multiple inputs	5	6	19%					x					x	x					x									x			x			
Pain-distraction	3	11	35%			x							x					x	x	x	x				x	x				x	x	x		
Sensory-distraction	13	10	32%													x	x		x	x		x			x			x		x	x	x		
Sustained attention	5	13	42%					x	x	x		x		x					x	x		x			x		x	x		x	x			
Flexibility, multitasking	2	10	32%		x			x	x	x				x		x			x								x					x		x
Impulse & behavior management	7	9	29%							x		x	x	x			x			x					x				x	x				

Code	First Occurrence	# Cases Coded	% Of Cases Coded	2672	2689	2691	2692	2693	2703	2709	2711	2744	2753	2797	2798	2813	2830	2850	2882	2909	2913	2915	2940	2997	3005	3013	3018	3022	3104	3184	3214	3225	3233	3248
Information processing & reasoning	2	18	58%		x	x			x	x	x	x	x	x		x	x			x				x	x			x	x	x		x	x	
Language	1	28	90%	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x		x	x	x	x	x	x	x	
Comprehension	2	4	13%		x						x					x											x							
Expression	1	5	16%	x		x			x																				x	x				
Numbers	2	8	26%		x						x		x	x						x				x			x						x	
Speech	1	22	71%	x	x	x		x	x		x	x		x	x	x	x		x	x	x	x		x	x		x	x	x			x	x	
Avoiding speaking, not able to speak	1	6	19%	x	x																			x	x		x					x		
Jumbled	2	9	29%		x	x		x	x						x				x	x		x					x							
Slowed	14	2	6%														x												x					
Slurred, mumbled	1	6	19%	x							x	x				x									x			x						
Word finding	1	18	58%	x	x	x	x	x		x		x			x	x	x		x	x	x	x	x		x			x			x			
Medication management	1	6	19%	x		x			x					x						x										x				
Memory	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Memory free recall	3	20	65%			x	x		x	x	x	x				x		x	x	x	x	x	x	x		x	x	x	x	x			x	
Memory working	2	21	68%		x	x	x	x	x	x	x				x	x			x	x	x	x	x		x	x			x	x	x		x	x
Recall of attacks	1	28	90%	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x		x	x	x	x	x	x		x
Money management	9	3	10%									x								x			x											
Problem solving	1	6	19%	x			x			x			x	x															x					
Read Write	3	21	68%			x		x	x		x			x	x	x			x	x	x	x			x	x	x	x	x	x	x	x	x	x
Read	5	17	55%					x	x		x			x		x			x	x	x	x			x	x	x	x		x		x	x	x
Concentrate	5	10	32%					x	x		x					x			x	x							x	x				x	x	

Code	First Occurrence	# Cases Coded	% Of Cases Coded	2672	2689	2691	2692	2693	2703	2709	2711	2744	2753	2797	2798	2813	2830	2850	2882	2909	2913	2915	2940	2997	3005	3013	3018	3022	3104	3184	3214	3225	3233	3248
Visual disturbances	17	5	16%																	x	x				x					x		x		
Write	3	10	32%			x			x						x	x			x		x					x	x		x		x			
Assistive writing	3	5	16%			x			x							x										x					x			
Technology	24	3	10%																								x		x		x			
Physical Function Codes	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Ambulation	1	27	87%	x	x	x	x	x	x	x	x	x		x	x	x	x		x	x	x	x	x		x		x	x	x	x	x	x	x	x
Head-limb movements	7	6	19%							x									x		x	x					x		x					
Immobility	3	7	23%			x	x									x	x		x			x										x		
Postural transitions	1	10	32%	x	x	x				x						x					x				x		x		x		x			
Stand-sit prolonged	5	10	32%					x	x		x								x		x	x			x				x		x		x	
Walk	1	17	55%	x	x	x	x				x			x	x	x			x		x		x		x		x		x	x		x		x
Basic self-care	3	15	48%			x		x			x				x	x	x		x		x						x		x	x	x	x	x	x
Bathing	5	9	29%					x			x				x	x			x		x								x		x		x	
Dressing	14	2	6%														x																x	
Eating & drinking	3	4	13%			x																					x		x					x
Grooming	12	4	13%												x	x					x						x							
Toileting	3	4	13%			x										x					x									x				
Communications systems	4	10	32%				x			x					x	x		x	x		x	x			x		x							
Exercise	1	22	71%	x	x	x	x	x	x	x	x		x	x		x		x			x	x		x	x	x	x	x	x			x		x
Fine motor	9	8	26%									x	x			x			x					x			x			x		x		
General function - Live life	1	21	68%	x	x	x		x	x	x	x		x	x		x	x	x	x	x			x	x			x			x	x	x	x	

Code	First Occurrence	# Cases Coded	% Of Cases Coded	2672	2689	2691	2692	2693	2703	2709	2711	2744	2753	2797	2798	2813	2830	2850	2882	2909	2913	2915	2940	2997	3005	3013	3018	3022	3104	3184	3214	3225	3233	3248
Health maintenance	2	21	68%		x	x	x		x	x		x	x	x	x	x	x		x	x	x	x			x	x		x	x				x	x
Housekeeping	2	19	61%		x	x		x	x		x	x	x			x		x	x	x	x		x		x	x		x	x			x	x	
Lift carry	2	7	23%		x											x					x	x			x		x			x				
Meals	1	22	71%	x	x	x			x	x	x	x	x		x		x	x	x	x		x		x	x				x	x	x	x	x	x
Mobility Transport	2	27	87%		x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		
Driving in a car	2	26	84%		x	x		x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		
Medication prevents driving	2	2	6%		x		x																											
Public transportation	3	5	16%			x									x	x	x								x									
Travel	4	3	10%				x													x			x											
Shopping & running errands	4	13	42%				x		x					x		x			x		x		x		x		x		x		x		x	x
Sleep impacts	7	12	39%							x	x	x				x						x		x		x		x	x		x	x		x
Psychosocial Function Codes	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Accept-adapt	1	23	74%	x	x	x	x		x	x		x		x	x				x	x	x	x	x	x	x	x	x	x	x	x			x	x
Care of others or pets	4	16	52%				x	x	x		x	x			x	x			x	x			x			x	x	x			x	x	x	
Coping	1	30	97%	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Cocooning	1	29	94%	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x
Voluntary avoidance	1	17	55%	x	x		x		x	x			x	x		x					x				x	x	x	x	x			x	x	x
Lifestyle changes-adjustments	1	11	35%	x	x	x	x			x			x	x	x	x	x					x												
Maintaining	2	5	16%		x				x				x														x						x	
Non-pharmaceutical therapies	2	12	39%		x	x	x	x	x	x	x	x	x	x	x	x																		
Sensory control	1	10	32%	x	x	x	x		x	x		x		x	x	x																		

Code	First Occurrence	# Cases Coded	% Of Cases Coded	2672	2689	2691	2692	2693	2703	2709	2711	2744	2753	2797	2798	2813	2830	2850	2882	2909	2913	2915	2940	2997	3005	3013	3018	3022	3104	3184	3214	3225	3233	3248
Direct costs	1	21	68%	x	x	x	x	x	x	x	x	x			x	x	x		x		x	x	x		x	x				x	x		x	
Emotion States	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Anger-Frustration	1	24	77%	x	x	x		x	x	x	x	x	x	x	x	x	x		x	x	x	x			x		x	x	x	x		x	x	
Anxiety	1	25	81%	x	x	x	x		x		x	x	x	x	x	x	x		x	x	x	x		x	x		x	x	x		x	x	x	x
Depression	2	19	61%		x	x		x			x	x				x		x	x	x	x			x	x		x	x	x	x	x	x	x	
Embarrassment	1	10	32%	x	x	x	x							x			x			x	x	x			x									
Energy and drive	1	16	52%	x	x				x	x				x	x	x	x	x			x	x			x	x	x		x		x			
Grief	12	3	10%												x						x			x										
Guilt	2	12	39%		x	x	x		x						x				x		x			x	x	x			x					x
Happy-Euphoria	2	12	39%		x	x			x										x		x	x			x	x	x		x			x	x	
Irritable	1	18	58%	x		x		x		x	x	x			x	x	x		x	x	x	x	x		x	x	x	x						
Other negative thoughts	3	10	32%			x		x		x		x								x	x	x		x		x			x					
Other positive thoughts	3	5	16%			x				x												x				x				x				
Relief-invigorated	2	18	58%		x	x		x	x	x						x	x			x		x	x		x	x	x	x	x		x		x	x
Skepticism	1	15	48%	x	x				x	x		x			x	x	x			x	x				x		x	x	x				x	
Family relations	1	26	84%	x	x	x	x	x	x	x	x	x	x	x	x	x			x	x	x	x	x		x	x	x	x	x		x		x	x
Feeling heard	1	29	94%	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x
Friends-family	12	12	39%												x	x	x		x		x	x		x	x	x	x	x	x					
Healthcare providers	1	19	61%	x	x		x		x	x		x	x		x	x	x		x	x	x	x			x	x	x						x	x
Work-school-society	12	15	48%												x		x	x	x	x		x	x	x	x		x	x	x	x	x			x
Identity	1	26	84%	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x		x	x	x	x	x	x				x	x

Code	First Occurrence	# Cases Coded	% Of Cases Coded	2672	2689	2691	2692	2693	2703	2709	2711	2744	2753	2797	2798	2813	2830	2850	2882	2909	2913	2915	2940	2997	3005	3013	3018	3022	3104	3184	3214	3225	3233	3248
Interpersonal relations	1	28	90%	x	x	x	x		x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x		x	x
Intimate relations	1	17	55%	x	x	x	x	x	x	x		x			x						x	x		x	x				x			x	x	x
Life satisfaction and meaning	1	16	52%	x	x	x	x			x		x	x	x	x	x	x			x	x	x							x				x	
Predictability-control	1	30	97%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x
Pushing through	1	26	84%	x	x	x		x	x	x	x	x	x	x	x		x		x	x	x	x	x	x	x	x	x	x	x			x	x	x
Care for others	6	7	23%						x		x	x			x				x	x							x							
Desire to live life	7	6	19%							x			x		x										x	x								x
Maintain self-image	3	5	16%			x								x							x		x						x					
No choice-no other alternative	2	10	32%		x				x			x		x	x		x						x				x					x	x	
Scheduled plans-obligations	1	5	16%	x						x		x			x																	x		
Recreation-leisure	1	28	90%	x	x	x	x	x	x	x	x			x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x
School	3	10	32%			x	x		x					x	x						x	x			x		x	x						
Self-sufficiency	1	21	68%	x	x	x	x		x	x		x	x	x	x	x	x		x	x	x	x				x		x	x				x	x
Social community & civic roles	1	28	90%	x		x	x	x	x	x	x		x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Civic roles-events	4	14	45%				x	x	x		x			x					x				x	x	x		x	x	x		x		x	
Community life	3	10	32%			x	x		x	x								x						x	x	x	x						x	
Friends-family social	1	19	61%	x		x		x	x		x			x		x	x		x			x	x	x	x	x	x	x		x		x		x
Social support-isolation	1	22	71%	x	x	x	x		x	x		x	x	x	x	x	x		x		x	x			x	x		x	x		x		x	x
Spiritual life	11	5	16%											x					x			x	x										x	
Stigma	1	23	74%	x	x	x	x	x	x	x		x	x	x			x	x	x		x	x		x	x	x	x			x	x		x	x
Well-being	1	27	87%	x	x	x	x	x	x	x		x	x	x	x		x		x	x	x	x	x		x	x	x	x	x	x	x	x	x	x

Code	First Occurrence	# Cases Coded	% Of Cases Coded	2672	2689	2691	2692	2693	2703	2709	2711	2744	2753	2797	2798	2813	2830	2850	2882	2909	2913	2915	2940	2997	3005	3013	3018	3022	3104	3184	3214	3225	3233	3248
Enjoy life	2	16	52%		x	x		x		x		x			x				x	x	x		x			x	x	x	x				x	x
Missing out on life	2	9	29%		x	x	x			x		x	x		x						x							x						
Needs-wants to do ability	1	20	65%	x	x	x			x	x		x		x	x		x		x	x	x	x			x	x	x	x	x		x	x		
Work	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Work for pay	1	29	94%	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x
Accommodations	1	16	52%	x	x	x	x		x							x			x			x	x	x	x		x	x	x	x				x
Job-career loss	3	13	42%			x	x	x			x	x				x			x		x	x			x				x	x			x	
Missed work-leave	3	17	55%			x	x	x	x		x				x	x		x	x		x	x	x	x		x			x		x	x		
Productivity-performance at work	1	16	52%	x	x	x		x	x				x				x	x				x		x			x	x	x	x		x		x
Working through attacks	3	14	45%			x			x			x		x	x		x					x		x	x	x	x	x	x					x
Work-stress, workload	1	10	32%	x		x		x	x		x			x	x	x						x						x						
Work unpaid-volunteer	4	6	19%				x													x					x		x	x			x			
Symptom Codes	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Appetite	3	12	39%			x			x	x										x	x			x	x	x			x	x		x		x
Clumsiness	1	6	19%	x												x				x				x						x				x
Dizziness	1	17	55%	x		x			x	x				x	x	x	x	x			x		x	x	x			x	x		x			x
Fatigue	1	23	74%	x	x	x		x	x	x			x		x	x	x		x	x	x	x	x	x	x		x	x	x	x	x			x
GI-Nausea	2	28	90%		x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x		x	x	x
GI-Other	3	6	19%			x								x								x		x	x				x					
Mental Acuity (Mental clarity/fogginess)	1	30	97%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x
Brain fog	1	21	68%	x		x	x	x	x	x		x	x	x	x	x	x	x	x		x			x	x		x		x		x		x	

Code	First Occurrence	# Cases Coded	% Of Cases Coded	2672	2689	2691	2692	2693	2703	2709	2711	2744	2753	2797	2798	2813	2830	2850	2882	2909	2913	2915	2940	2997	3005	3013	3018	3022	3104	3184	3214	3225	3233	3248
Brain not working, migraine brain	13	6	19%													x	x	x	x	x									x					
Confusion	21	1	3%																					x										
Feel stupid, less smart	2	6	19%		x		x				x						x					x								x				
Not as sharp, clear	4	9	29%				x		x	x		x	x	x																x	x	x		
Slowed, delayed	2	12	39%		x				x	x				x			x					x		x		x	x	x	x					x
Spaced out	17	2	6%																	x	x													
Mood change	1	18	58%	x	x	x	x	x	x			x		x			x		x	x				x	x	x	x	x		x				x
Pain-head and face	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Pain-other	1	24	77%	x	x	x	x	x	x	x		x	x		x	x			x	x	x	x	x	x	x	x	x		x	x		x		x
Sensitivity	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Light	1	30	97%	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Other	1	15	48%	x	x					x	x				x	x	x				x			x			x	x	x	x	x	x		
Smell	2	14	45%		x	x		x	x		x	x				x					x		x	x	x				x				x	x
Sound	1	29	94%	x	x	x	x	x	x	x	x		x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Touch	3	11	35%			x	x								x		x				x	x		x	x	x		x		x				
Sensory disturbance	1	29	94%	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x		x	x	x
Eye symptoms	2	3	10%		x										x										x									
Other	6	6	19%						x											x	x						x			x				x
Skin sensations	3	10	32%			x	x	x						x	x		x			x		x							x					x
Taste or smell symptoms	17	2	6%																	x		x												
Tinnitus, aural disturbances	1	4	13%	x					x						x															x				

Code	First Occurrence	# Cases Coded	% Of Cases Coded	2672	2689	2691	2692	2693	2703	2709	2711	2744	2753	2797	2798	2813	2830	2850	2882	2909	2913	2915	2940	2997	3005	3013	3018	3022	3104	3184	3214	3225	3233	3248
Visual disturbances	2	24	77%		x			x	x		x	x	x	x	x	x			x	x	x	x	x	x	x	x	x	x	x	x		x	x	x
Yawning	2	2	6%		x									x																				
Sleep symptoms	6	8	26%						x	x				x			x					x				x			x				x	
Symptoms- General	1	31	100%	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Relief of symptoms-impacts	2	11	35%		x				x							x			x		x	x				x	x	x	x				x	
Tension-Stiffness	3	17	55%			x		x	x		x	x			x	x	x			x	x	x	x					x	x	x		x		x
Weakness	11	10	32%											x	x	x							x	x			x			x	x	x		x

Table D-2. Data that Was Probed vs. Not Probed by the Interviewer

Code	Not Probed (number of references coded)	Probed (number of references coded)	Percent of total that is Probed
Content Codes (used to code migraine experience concepts)	2118	440	17%
Cognitive Function Codes	293	108	27%
Concentrate	76	27	26%
Critical thinking	3	2	40%
Divided attention	18	11	38%
Multiple inputs	3	5	63%
Pain-distraction	10	2	17%
Sensory-distraction	7	3	30%
Sustained attention	14	5	26%
Flexibility, multitasking	9	10	53%
Impulse & behavior management	15	2	12%
Information processing & reasoning	28	15	35%
Language	73	37	34%
Comprehension	3	6	67%
Expression	8	3	27%
Numbers	4	5	56%
Speech	31	13	30%
Avoiding speaking, not able to speak	5	2	29%
Jumbled	11	5	31%
Slowed	2	0	0%
Slurred, mumbled	3	3	50%
Word finding	19	10	34%
Medication management	7	0	0%
Memory	114	37	25%
Memory free recall	28	19	40%
Memory working	44	22	33%
Money management	2	3	60%
Problem solving	6	1	14%
Read Write	34	13	28%
Read	22	4	15%

Code	Not Probed (number of references coded)	Probed (number of references coded)	Percent of total that is Probed
Concentrate	10	2	17%
Visual disturbances	5	2	29%
Write	14	8	36%
Assistive writing	5	4	44%
Technology	5	1	17%
Physical Function Codes	338	123	27%
Ambulation	51	29	36%
Head-limb movements	7	3	30%
Immobility	8	2	20%
Postural transitions	15	3	17%
Stand-sit prolonged	4	8	67%
Walk	18	9	33%
Basic self-care	16	18	53%
Bathing	5	9	64%
Dressing	3	1	25%
Eating & drinking	5	2	29%
Grooming	1	5	83%
Toileting	3	2	40%
Communications systems	17	8	32%
Exercise	47	11	19%
Fine motor	10	3	23%
General function - Live life	57	3	5%
Health maintenance	39	8	17%
Housekeeping	33	10	23%
Lift carry	7	1	13%
Meals	35	14	29%
Mobility Transport	46	27	37%
Driving in a car	23	15	39%
Medication prevents driving	1	3	75%
Public transportation	6	3	33%
Travel	4	1	20%
Shopping & running errands	15	9	38%
Sleep impacts	20	4	17%
Psychosocial Function Codes	1249	226	15%

Code	Not Probed (number of references coded)	Probed (number of references coded)	Percent of total that is Probed
Accept-adapt	58	6	9%
Care of others or pets	31	14	31%
Coping	229	54	19%
Cocooning	86	24	22%
Voluntary avoidance	27	11	29%
Lifestyle changes-adjustments	18	6	25%
Maintaining	9	1	10%
Non-pharmaceutical therapies	27	7	21%
Sensory control	18	6	25%
Direct costs	50	3	6%
Emotion States	324	54	14%
Anger-Frustration	60	7	10%
Anxiety	63	14	18%
Depression	52	2	4%
Embarrassment	10	1	9%
Energy and drive	35	6	15%
Grief	6	0	0%
Guilt	20	3	13%
Happy-Euphoria	11	7	39%
Irritable	43	8	16%
Other negative thoughts	11	3	21%
Other positive thoughts	6	0	0%
Relief-invigorated	22	8	27%
Skepticism	34	3	8%
Family relations	78	17	18%
Feeling heard	142	17	11%
Friends-family	24	5	17%
Healthcare providers	53	1	2%
Work-school-society	25	6	19%
Identity	86	2	2%
Interpersonal relations	64	16	20%
Intimate relations	26	4	13%
Life satisfaction and meaning	28	5	15%
Predictability-control	224	40	15%

Code	Not Probed (number of references coded)	Probed (number of references coded)	Percent of total that is Probed
Pushing through	85	26	23%
Care for others	10	3	23%
Desire to live life	7	1	13%
Maintain self-image	3	3	50%
No choice-no other alternative	10	4	29%
Scheduled plans-obligations	4	3	43%
Recreation-leisure	64	24	27%
School	24	3	11%
Self-sufficiency	64	12	16%
Social community & civic roles	73	25	26%
Civic roles-events	11	6	35%
Community life	8	6	43%
Friends-family social	24	5	17%
Social support-isolation	55	15	21%
Spiritual life	5	1	17%
Stigma	56	4	7%
Well-being	107	7	6%
Enjoy life	25	1	4%
Missing out on life	13	0	0%
Needs-wants to do ability	49	6	11%
Work	162	40	20%
Work for pay	142	34	19%
Accommodations	25	8	24%
Job-career loss	18	5	22%
Missed work-leave	26	5	16%
Productivity-performance at work	30	13	30%
Working through attacks	20	8	29%
Work-stress, workload	23	1	4%
Work unpaid-volunteer	11	4	27%
Symptom Codes	1028	161	14%
Appetite	23	1	4%
Clumsiness	10	1	9%
Dizziness	60	7	10%
Fatigue	61	10	14%

Code	Not Probed (number of references coded)	Probed (number of references coded)	Percent of total that is Probed
GI-Nausea	120	13	10%
GI-Other	16	3	16%
Mental Acuity (Mental clarity or fogginess)	132	27	17%
Brain fog	42	9	18%
Brain not working, migraine brain	5	3	38%
Confusion	2	0	0%
Feel stupid, less smart	8	1	11%
Not as sharp, clear	11	2	15%
Slowed, delayed	11	4	27%
Spaced out	3	0	0%
Mood change	43	6	12%
Pain-head and face	253	29	10%
Pain-other	85	7	8%
Sensitivity	244	64	21%
Light	135	33	20%
Other	35	10	22%
Smell	33	9	21%
Sound	96	25	21%
Touch	17	6	26%
Sensory disturbance	87	13	13%
Eye symptoms	2	1	33%
Other	10	1	9%
Skin sensations	18	2	10%
Taste or smell symptoms	3	0	0%
Tinnitus, aural disturbances	7	0	0%
Visual disturbances	39	9	19%
Yawning	2	0	0%
Sleep symptoms	11	2	15%
Symptoms- General	173	11	6%
Relief of symptoms-impacts	17	2	11%
Tension-Stiffness	33	3	8%
Weakness	11	1	8%

APPENDIX E. STRATIFICATION TABLES

Contents

Table E- 1. Stratification of Migraine Experience Concepts By Sex

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Cognitive Function (any code)	9	100%	22	100%
Cognitive\Concentrate-Focus	8	89%	21	95%
Cognitive\Concentrate-Focus\Critical thinking	1	11%	4	18%
Cognitive\Concentrate-Focus\Divided attn	4	44%	14	64%
Cognitive\Concentrate-Focus\Divided attn\Multiple inputs	3	33%	3	14%
Cognitive\Concentrate-Focus\Divided attn\Pain-distraction	3	33%	8	36%
Cognitive\Concentrate-Focus\Divided attn\Sensory-distraction	2	22%	8	36%
Cognitive\Concentrate-Focus\Sustained attn	4	44%	9	41%
Cognitive\Flexibility, multitasking	4	44%	6	27%
Cognitive\Impulse-Behavior	4	44%	5	23%
Cognitive\Info Proc Reasoning	6	67%	12	55%
Cognitive\Language	8	89%	20	91%
Cognitive\Language\Comprehension	0	0%	4	18%
Cognitive\Language\Expression	1	11%	4	18%
Cognitive\Language\Numbers	3	33%	5	23%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Cognitive\Language\Speech	5	56%	17	77%
Cognitive\Language\Speech\Avoiding speaking, not able to speak	2	22%	4	18%
Cognitive\Language\Speech\Jumbled	0	0%	9	41%
Cognitive\Language\Speech\Slowed	0	0%	2	9%
Cognitive\Language\Speech\Slurred, mumbled	2	22%	4	18%
Cognitive\Language\Word finding	4	44%	14	64%
Cognitive\Meds mgmt	2	22%	4	18%
Cognitive\Memory	9	100%	22	100%
Cognitive\Memory\Memory free recall	3	33%	17	77%
Cognitive\Memory\Memory working	4	44%	17	77%
Cognitive\Memory\Recall of attacks	8	89%	20	91%
Cognitive\Money mgmt	1	11%	2	9%
Cognitive\Problem solve	4	44%	2	9%
Cognitive\Read Write	4	44%	16	73%
Cognitive\Read Write\Read	4	44%	13	59%
Cognitive\Read Write\Read\Concentrate	2	22%	8	36%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Cognitive\Read Write\Read\Visual disturbances	1	11%	4	18%
Cognitive\Read Write\Write	1	11%	9	41%
Cognitive\Read Write\Write\Assistive writing	1	11%	4	18%
Cognitive\Read Write\Write\Technology	1	11%	2	9%
Physical Function (any code)	9	100%	22	100%
Physical\Ambulation	8	89%	19	86%
Physical\Ambulation\Head-limb movements	1	11%	5	23%
Physical\Ambulation\Immobility	1	11%	6	27%
Physical\Ambulation\Postural transitions	3	33%	7	32%
Physical\Ambulation\Stand-sit prolonged	2	22%	8	36%
Physical\Ambulation\Walk	4	44%	12	55%
Physical\Basic self-care	4	44%	11	50%
Physical\Basic self-care\Bathing	2	22%	7	32%
Physical\Basic self-care\Dressing	1	11%	1	5%
Physical\Basic self-care\Eat drink	1	11%	3	14%
Physical\Basic self-care\Grooming	0	0%	4	18%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Physical\Basic self-care\Toileting	0	0%	4	18%
Physical\Comms systems	1	11%	9	41%
Physical\Exercise	6	67%	16	73%
Physical\Fine motor	3	33%	5	23%
Physical\General function - Live life	7	78%	14	64%
Physical\Health maintenance	6	67%	15	68%
Physical\Housekeeping	4	44%	15	68%
Physical\Lift carry	0	0%	7	32%
Physical\Meals	8	89%	14	64%
Physical\Mobility Transport	6	67%	21	95%
Physical\Mobility Transport\Driving a car	6	67%	20	91%
Physical\Mobility Transport\Driving a car\Medication prevents driving	0	0%	2	9%
Physical\Mobility Transport\Public transportation	0	0%	4	18%
Physical\Mobility Transport\Travel	0	0%	3	14%
Physical\Shopping errands	4	44%	9	41%
Physical\Sleep impacts	5	56%	7	32%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Psychosocial Function (any code)	9	100%	22	100%
Psychosocial\Accept-adapt	6	67%	17	77%
Psychosocial\Care of others or pets	4	44%	12	55%
Psychosocial\Coping	9	100%	21	95%
Psychosocial\Coping\Cocooning	8	89%	21	95%
Psychosocial\Coping\Cocooning\Voluntary avoidance	7	78%	10	45%
Psychosocial\Coping\Lifestyle changes-adjmts	4	44%	7	32%
Psychosocial\Coping\Maintaining	2	22%	3	14%
Psychosocial\Coping\Non-pharmaceutical therapies	4	44%	8	36%
Psychosocial\Coping\Sensory control	4	44%	6	27%
Psychosocial\Direct costs	5	56%	16	73%
Psychosocial\Emotion States	9	100%	22	100%
Psychosocial\Emotion States\Anger-Frustration	7	78%	17	77%
Psychosocial\Emotion States\Anxiety	8	89%	17	77%
Psychosocial\Emotion States\Depression	4	44%	15	68%
Psychosocial\Emotion States\Embarrassment	2	22%	8	36%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Psychosocial\Emotion States\Energy and drive	4	44%	12	55%
Psychosocial\Emotion States\Grief	0	0%	3	14%
Psychosocial\Emotion States\Guilt	1	11%	11	50%
Psychosocial\Emotion States\Happy-Euphoria	2	22%	10	45%
Psychosocial\Emotion States\Irritable	3	33%	15	68%
Psychosocial\Emotion States\Other negative thoughts	2	22%	8	36%
Psychosocial\Emotion States\Other positive thoughts	1	11%	4	18%
Psychosocial\Emotion States\Relief-invigorated	4	44%	14	64%
Psychosocial\Emotion States\Skepticism	4	44%	11	50%
Psychosocial\Family relations	8	89%	18	82%
Psychosocial\Feeling heard	8	89%	21	95%
Psychosocial\Feeling heard\Friends-family	0	0%	12	55%
Psychosocial\Feeling heard\Healthcare providers	6	67%	13	59%
Psychosocial\Feeling heard\Work-school-society	2	22%	13	59%
Psychosocial\Identity	7	78%	19	86%
Psychosocial\Interpersonal relations	8	89%	20	91%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Psychosocial\Intimate relations	6	67%	11	50%
Psychosocial\Life satisfaction and meaning	6	67%	10	45%
Psychosocial\Predictability-control	9	100%	21	95%
Psychosocial\Pushing through	8	89%	18	82%
Psychosocial\Pushing through\Care for others	1	11%	6	27%
Psychosocial\Pushing through\Desire to live life	3	33%	3	14%
Psychosocial\Pushing through\Maintain self-image	1	11%	4	18%
Psychosocial\Pushing through\No choice-no other alt.	4	44%	6	27%
Psychosocial\Pushing through\Scheduled plans-obligations	4	44%	1	5%
Psychosocial\Recreation-leisure	7	78%	21	95%
Psychosocial\School	1	11%	9	41%
Psychosocial\Self-sufficiency	7	78%	14	64%
Psychosocial\Soc Comm Civic roles	8	89%	20	91%
Psychosocial\Soc Comm Civic roles\Civic roles-events	3	33%	11	50%
Psychosocial\Soc Comm Civic roles\Community life	2	22%	8	36%
Psychosocial\Soc Comm Civic roles\Friends-family social	4	44%	15	68%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Psychosocial\Social support-isolation	8	89%	14	64%
Psychosocial\Spiritual	2	22%	3	14%
Psychosocial\Stigma	8	89%	15	68%
Psychosocial\Well-being	9	100%	18	82%
Psychosocial\Well-being\Enjoy life	4	44%	12	55%
Psychosocial\Well-being\Missing out on life	3	33%	6	27%
Psychosocial\Well-being\Needs-wants to do ability	6	67%	14	64%
Psychosocial\Work	9	100%	22	100%
Psychosocial\Work\Work for pay	8	89%	21	95%
Psychosocial\Work\Work for pay\Accom.-adjmts	2	22%	14	64%
Psychosocial\Work\Work for pay\Job-career loss	2	22%	11	50%
Psychosocial\Work\Work for pay\Missed work-leave	2	22%	15	68%
Psychosocial\Work\Work for pay\Productivity-performance at work	4	44%	12	55%
Psychosocial\Work\Work for pay\Working through attacks	3	33%	11	50%
Psychosocial\Work\Work for pay\Work-stress, tasks, workload	2	22%	8	36%
Psychosocial\Work\Work unpaid-volunteer	1	11%	5	23%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Symptoms (any code)	9	100%	22	100%
Symptoms\Appetite	3	33%	9	41%
Symptoms\Clumsiness	2	22%	4	18%
Symptoms\Dizziness	5	56%	12	55%
Symptoms\Fatigue	5	56%	18	82%
Symptoms\GI-Nausea	7	78%	21	95%
Symptoms\GI-Other	1	11%	5	23%
Symptoms\Mental-Foggy or Clear	9	100%	21	95%
Symptoms\Mental-Foggy or Clear\Brain fog	7	78%	14	64%
Symptoms\Mental-Foggy or Clear\Brain not working, migraine brain	0	0%	6	27%
Symptoms\Mental-Foggy or Clear\Confusion	0	0%	1	5%
Symptoms\Mental-Foggy or Clear\Feel stupid, less smart	0	0%	6	27%
Symptoms\Mental-Foggy or Clear\Not as sharp, clear	6	67%	3	14%
Symptoms\Mental-Foggy or Clear\Slowed, delayed	3	33%	9	41%
Symptoms\Mental-Foggy or Clear\Spaced out	0	0%	2	9%
Symptoms\Mood change	4	44%	14	64%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Symptoms\Pain-head and face	9	100%	22	100%
Symptoms\Pain-other	6	67%	18	82%
Symptoms\Sensitivity	9	100%	22	100%
Symptoms\Sensitivity\Light	9	100%	21	95%
Symptoms\Sensitivity\Other	4	44%	11	50%
Symptoms\Sensitivity\Smell	3	33%	11	50%
Symptoms\Sensitivity\Sound	8	89%	21	95%
Symptoms\Sensitivity\Touch	0	0%	11	50%
Symptoms\Sensory disturbance	8	89%	21	95%
Symptoms\Sensory disturbance\Eye symptoms	0	0%	3	14%
Symptoms\Sensory disturbance\Other	1	11%	5	23%
Symptoms\Sensory disturbance\Skin sensations	2	22%	8	36%
Symptoms\Sensory disturbance\Taste or smell symptoms	0	0%	2	9%
Symptoms\Sensory disturbance\Tinnitus, aural disturbances	1	11%	3	14%
Symptoms\Sensory disturbance\Visual disturbances	6	67%	18	82%
Symptoms\Sensory disturbance\Yawning	1	11%	1	5%

Code	Male (n=9)	Percent Male	Female (n=22)	Percent Female
Symptoms\Sleep symptoms	3	33%	5	23%
Symptoms\Symptoms- General	9	100%	22	100%
Symptoms\Symptoms- General\Relief of symptoms-impacts	1	11%	10	45%
Symptoms\Tension-Stiffness	3	33%	14	64%
Symptoms\Weakness	4	44%	6	27%

Table E- 2. Stratification of Migraine Experience Concepts by Age

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Cognitive Function (any code)	10	100%	16	100%	5	100%
Cognitive\Concentrate-Focus	10	100%	15	94%	4	80%
Cognitive\Concentrate-Focus\Critical thinking	1	10%	2	13%	2	40%
Cognitive\Concentrate-Focus\Divided attn	8	80%	9	56%	1	20%
Cognitive\Concentrate-Focus\Divided attn\Multiple inputs	2	20%	3	19%	1	20%
Cognitive\Concentrate-Focus\Divided attn\Pain-distraction	4	40%	7	44%	0	0%
Cognitive\Concentrate-Focus\Divided attn\Sensory-distraction	5	50%	5	31%	0	0%
Cognitive\Concentrate-Focus\Sustained attn	3	30%	8	50%	2	40%
Cognitive\Flexibility, multitasking	1	10%	6	38%	3	60%
Cognitive\Impulse-Behavior	2	20%	5	31%	2	40%
Cognitive\Info Proc Reasoning	5	50%	8	50%	5	100%
Cognitive\Language	9	90%	14	88%	5	100%
Cognitive\Language\Comprehension	1	10%	1	6%	2	40%
Cognitive\Language\Expression	2	20%	3	19%	0	0%
Cognitive\Language\Numbers	0	0%	4	25%	4	80%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Cognitive\Language\Speech	8	80%	10	63%	4	80%
Cognitive\Language\Speech\Avoiding speaking, not able to speak	0	0%	4	25%	2	40%
Cognitive\Language\Speech\Jumbled	3	30%	5	31%	1	20%
Cognitive\Language\Speech\Slowed	2	20%	0	0%	0	0%
Cognitive\Language\Speech\Slurred, mumbled	2	20%	3	19%	1	20%
Cognitive\Language\Word finding	8	80%	8	50%	2	40%
Cognitive\Meds mgmt	1	10%	4	25%	1	20%
Cognitive\Memory	9	90%	13	81%	4	80%
Cognitive\Memory\Memory free recall	7	70%	10	63%	3	60%
Cognitive\Memory\Memory working	7	70%	11	69%	3	60%
Cognitive\Memory\Recall of attacks	0	0%	3	19%	0	0%
Cognitive\Money mgmt	1	10%	3	19%	2	40%
Cognitive\Problem solve	8	80%	11	69%	2	40%
Cognitive\Read Write	4	40%	11	69%	2	40%
Cognitive\Read Write\Read	2	20%	7	44%	1	20%
Cognitive\Read Write\Read\Concentrate	1	10%	4	25%	0	0%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Cognitive\Read Write\Read\Visual disturbances	6	60%	4	25%	0	0%
Cognitive\Read Write\Write	3	30%	2	13%	0	0%
Cognitive\Read Write\Write\Assistive writing	2	20%	1	6%	0	0%
Cognitive\Read Write\Write\Technology	9	90%	14	88%	5	100%
Physical Function (any code)	10	100%	16	100%	5	100%
Physical\Ambulation	9	90%	14	88%	4	80%
Physical\Ambulation\Head-limb movements	3	30%	2	13%	1	20%
Physical\Ambulation\Immobility	4	40%	3	19%	0	0%
Physical\Ambulation\Postural transitions	5	50%	3	19%	2	40%
Physical\Ambulation\Stand-sit prolonged	4	40%	5	31%	1	20%
Physical\Ambulation\Walk	5	50%	9	56%	3	60%
Physical\Basic self-care	7	70%	7	44%	1	20%
Physical\Basic self-care\Bathing	5	50%	3	19%	1	20%
Physical\Basic self-care\Dressing	1	10%	1	6%	0	0%
Physical\Basic self-care\Eat drink	2	20%	2	13%	0	0%
Physical\Basic self-care\Grooming	3	30%	1	6%	0	0%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Physical\Basic self-care\Toileting	3	30%	1	6%	0	0%
Physical\Comms systems	5	50%	4	25%	1	20%
Physical\Exercise	7	70%	10	63%	5	100%
Physical\Fine motor	1	10%	6	38%	1	20%
Physical\General function - Live life	5	50%	11	69%	5	100%
Physical\Health maintenance	8	80%	10	63%	3	60%
Physical\Housekeeping	6	60%	11	69%	2	40%
Physical\Lift carry	3	30%	3	19%	1	20%
Physical\Meals	7	70%	11	69%	4	80%
Physical\Mobility Transport	10	100%	13	81%	4	80%
Physical\Mobility Transport\Driving a car	10	100%	12	75%	4	80%
Physical\Mobility Transport\Driving a car\Medication prevents driving	0	0%	1	6%	1	20%
Physical\Mobility Transport\Public transportation	4	40%	1	6%	0	0%
Physical\Mobility Transport\Travel	0	0%	3	19%	0	0%
Physical\Shopping errands	4	40%	8	50%	1	20%
Physical\Sleep impacts	5	50%	4	25%	3	60%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Psychosocial Function (any code)	10	100%	16	100%	5	100%
Psychosocial\Accept-adapt	6	60%	13	81%	4	80%
Psychosocial\Care of others or pets	4	40%	11	69%	1	20%
Psychosocial\Coping	10	100%	15	94%	5	100%
Psychosocial\Coping\Cocooning	10	100%	14	88%	5	100%
Psychosocial\Coping\Cocooning\Voluntary avoidance	4	40%	10	63%	3	60%
Psychosocial\Coping\Lifestyle changes-adjmts	5	50%	3	19%	3	60%
Psychosocial\Coping\Maintaining	0	0%	4	25%	1	20%
Psychosocial\Coping\Non-pharmaceutical therapies	3	30%	5	31%	4	80%
Psychosocial\Coping\Sensory control	3	30%	4	25%	3	60%
Psychosocial\Direct costs	7	70%	11	69%	3	60%
Psychosocial\Emotion States	10	100%	16	100%	5	100%
Psychosocial\Emotion States\Anger-Frustration	8	80%	12	75%	4	80%
Psychosocial\Emotion States\Anxiety	9	90%	12	75%	4	80%
Psychosocial\Emotion States\Depression	7	70%	9	56%	3	60%
Psychosocial\Emotion States\Embarrassment	4	40%	4	25%	2	40%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Psychosocial\Emotion States\Energy and drive	8	80%	5	31%	3	60%
Psychosocial\Emotion States\Grief	2	20%	0	0%	1	20%
Psychosocial\Emotion States\Guilt	4	40%	6	38%	2	40%
Psychosocial\Emotion States\Happy-Euphoria	4	40%	7	44%	1	20%
Psychosocial\Emotion States\Irritable	7	70%	9	56%	2	40%
Psychosocial\Emotion States\Other negative thoughts	4	40%	4	25%	2	40%
Psychosocial\Emotion States\Other positive thoughts	2	20%	2	13%	1	20%
Psychosocial\Emotion States\Relief-invigorated	7	70%	9	56%	2	40%
Psychosocial\Emotion States\Skepticism	6	60%	7	44%	2	40%
Psychosocial\Family relations	8	80%	14	88%	4	80%
Psychosocial\Feeling heard	10	100%	14	88%	5	100%
Psychosocial\Feeling heard\Friends-family	7	70%	4	25%	1	20%
Psychosocial\Feeling heard\Healthcare providers	5	50%	12	75%	2	40%
Psychosocial\Feeling heard\Work-school-society	7	70%	7	44%	1	20%
Psychosocial\Identity	8	80%	13	81%	5	100%
Psychosocial\Interpersonal relations	9	90%	14	88%	5	100%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Psychosocial\Intimate relations	5	50%	9	56%	3	60%
Psychosocial\Life satisfaction and meaning	7	70%	6	38%	3	60%
Psychosocial\Predictability-control	10	100%	15	94%	5	100%
Psychosocial\Pushing through	7	70%	14	88%	5	100%
Psychosocial\Pushing through\Care for others	1	10%	5	31%	1	20%
Psychosocial\Pushing through\Desire to live life	1	10%	4	25%	1	20%
Psychosocial\Pushing through\Maintain self-image	3	30%	1	6%	1	20%
Psychosocial\Pushing through\No choice-no other alt.	2	20%	6	38%	2	40%
Psychosocial\Pushing through\Scheduled plans-obligations	1	10%	3	19%	1	20%
Psychosocial\Recreation-leisure	9	90%	14	88%	5	100%
Psychosocial\School	5	50%	4	25%	1	20%
Psychosocial\Self-sufficiency	8	80%	10	63%	3	60%
Psychosocial\Soc Comm Civic roles	9	90%	15	94%	4	80%
Psychosocial\Soc Comm Civic roles\Civic roles-events	3	30%	8	50%	3	60%
Psychosocial\Soc Comm Civic roles\Community life	2	20%	6	38%	2	40%
Psychosocial\Soc Comm Civic roles\Friends-family social	5	50%	11	69%	3	60%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Psychosocial\Social support-isolation	9	90%	10	63%	3	60%
Psychosocial\Spiritual	1	10%	3	19%	1	20%
Psychosocial\Stigma	6	60%	13	81%	4	80%
Psychosocial\Well-being	8	80%	16	100%	3	60%
Psychosocial\Well-being\Enjoy life	5	50%	9	56%	2	40%
Psychosocial\Well-being\Missing out on life	4	40%	3	19%	2	40%
Psychosocial\Well-being\Needs-wants to do ability	8	80%	9	56%	3	60%
Psychosocial\Work	10	100%	16	100%	5	100%
Psychosocial\Work\Work for pay	10	100%	15	94%	4	80%
Psychosocial\Work\Work for pay\Accom.-adjmts	5	50%	9	56%	2	40%
Psychosocial\Work\Work for pay\Job-career loss	5	50%	7	44%	1	20%
Psychosocial\Work\Work for pay\Missed work-leave	8	80%	7	44%	2	40%
Psychosocial\Work\Work for pay\Productivity-performance at work	6	60%	8	50%	2	40%
Psychosocial\Work\Work for pay\Working through attacks	6	60%	6	38%	2	40%
Psychosocial\Work\Work for pay\Work-stress, tasks, workload	5	50%	3	19%	2	40%
Psychosocial\Work\Work unpaid-volunteer	2	20%	4	25%	0	0%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Symptoms (any code)	10	100%	16	100%	5	100%
Symptoms\Appetite	3	30%	7	44%	2	40%
Symptoms\Clumsiness	1	10%	4	25%	1	20%
Symptoms\Dizziness	9	90%	5	31%	3	60%
Symptoms\Fatigue	9	90%	11	69%	3	60%
Symptoms\GI-Nausea	8	80%	15	94%	5	100%
Symptoms\GI-Other	3	30%	1	6%	2	40%
Symptoms\Mental-Foggy or Clear	10	100%	15	94%	5	100%
Symptoms\Mental-Foggy or Clear\Brain fog	8	80%	10	63%	3	60%
Symptoms\Mental-Foggy or Clear\Brain not working, migraine brain	4	40%	2	13%	0	0%
Symptoms\Mental-Foggy or Clear\Confusion	0	0%	0	0%	1	20%
Symptoms\Mental-Foggy or Clear\Feel stupid, less smart	2	20%	2	13%	2	40%
Symptoms\Mental-Foggy or Clear\Not as sharp, clear	1	10%	6	38%	2	40%
Symptoms\Mental-Foggy or Clear\Slowed, delayed	4	40%	4	25%	4	80%
Symptoms\Mental-Foggy or Clear\Spaced out	1	10%	1	6%	0	0%
Symptoms\Mood change	3	30%	12	75%	3	60%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Symptoms\Pain-head and face	10	100%	16	100%	5	100%
Symptoms\Pain-other	6	60%	15	94%	3	60%
Symptoms\Sensitivity	10	100%	16	100%	5	100%
Symptoms\Sensitivity\Light	10	100%	15	94%	5	100%
Symptoms\Sensitivity\Other	7	70%	4	25%	4	80%
Symptoms\Sensitivity\Smell	4	40%	7	44%	3	60%
Symptoms\Sensitivity\Sound	9	90%	15	94%	5	100%
Symptoms\Sensitivity\Touch	6	60%	4	25%	1	20%
Symptoms\Sensory disturbance	8	80%	16	100%	5	100%
Symptoms\Sensory disturbance\Eye symptoms	1	10%	1	6%	1	20%
Symptoms\Sensory disturbance\Other	1	10%	5	31%	0	0%
Symptoms\Sensory disturbance\Skin sensations	5	50%	4	25%	1	20%
Symptoms\Sensory disturbance\Taste or smell symptoms	1	10%	1	6%	0	0%
Symptoms\Sensory disturbance\Tinnitus, aural disturbances	1	10%	3	19%	0	0%
Symptoms\Sensory disturbance\Visual disturbances	6	60%	14	88%	4	80%
Symptoms\Sensory disturbance\Yawning	0	0%	0	0%	2	40%

Code	Ages 18-40 (n=10)	Percent 18-40	Ages 41-60 (n=16)	Percent 41-60	Ages 61-75 (n=5)	Percent 61-75
Symptoms\Sleep symptoms	3	30%	3	19%	2	40%
Symptoms\Symptoms- General	10	100%	16	100%	5	100%
Symptoms\Symptoms- General\Relief of symptoms-impacts	5	50%	5	31%	1	20%
Symptoms\Tension-Stiffness	8	80%	8	50%	1	20%
Symptoms\Weakness	3	30%	5	31%	2	40%

Table E- 3. Stratification of Migraine Experience Concepts by Race and Ethnicity

Numbers may sum to more than 31 because participants could select more than one race category.

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Cognitive Function (any code)	13	100%	18	100%	5	100%
Cognitive\Concentrate-Focus	13	100%	16	89%	4	80%
Cognitive\Concentrate-Focus\Critical thinking	2	15%	3	17%	0	0%
Cognitive\Concentrate-Focus\Divided attn	11	85%	7	39%	4	80%
Cognitive\Concentrate-Focus\Divided attn\Multiple inputs	1	8%	5	28%	1	20%
Cognitive\Concentrate-Focus\Divided attn\Pain-distraction	8	62%	3	17%	1	20%
Cognitive\Concentrate-Focus\Divided attn\Sensory-distraction	6	46%	4	22%	4	80%
Cognitive\Concentrate-Focus\Sustained attn	6	46%	7	39%	3	60%
Cognitive\Flexibility, multitasking	4	31%	6	33%	0	0%
Cognitive\Impulse-Behavior	3	23%	6	33%	2	40%
Cognitive\Info Proc Reasoning	8	62%	10	56%	4	80%
Cognitive\Language	11	85%	17	94%	5	100%
Cognitive\Language\Comprehension	2	15%	2	11%	0	0%
Cognitive\Language\Expression	3	23%	2	11%	0	0%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Cognitive\Language\Numbers	2	15%	6	33%	1	20%
Cognitive\Language\Speech	9	69%	13	72%	5	100%
Cognitive\Language\Speech\Avoiding speaking, not able to speak	3	23%	3	17%	2	40%
Cognitive\Language\Speech\Jumbled	4	31%	5	28%	1	20%
Cognitive\Language\Speech\Slowed	0	0%	2	11%	1	20%
Cognitive\Language\Speech\Slurred, mumbled	3	23%	3	17%	2	40%
Cognitive\Language\Word finding	7	54%	11	61%	4	80%
Cognitive\Meds mgmt	4	31%	2	11%	0	0%
Cognitive\Memory	13	100%	18	100%	5	100%
Cognitive\Memory\Memory free recall	11	85%	9	50%	3	60%
Cognitive\Memory\Memory working	9	69%	12	67%	2	40%
Cognitive\Memory\Recall of attacks	11	85%	17	94%	5	100%
Cognitive\Money mgmt	2	15%	1	6%	0	0%
Cognitive\Problem solve	0	0%	6	33%	0	0%
Cognitive\Read Write	11	85%	9	50%	3	60%
Cognitive\Read Write\Read	10	77%	7	39%	3	60%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Cognitive\Read Write\Read\Concentrate	6	46%	4	22%	1	20%
Cognitive\Read Write\Read\Visual disturbances	5	38%	0	0%	1	20%
Cognitive\Read Write\Write	6	46%	4	22%	0	0%
Cognitive\Read Write\Write\Assistive writing	4	31%	1	6%	0	0%
Cognitive\Read Write\Write\Technology	1	8%	2	11%	0	0%
Physical Function (any code)	13	100%	18	100%	5	100%
Physical\Ambulation	11	85%	16	89%	4	80%
Physical\Ambulation\Head-limb movements	2	15%	4	22%	1	20%
Physical\Ambulation\Immobility	3	23%	4	22%	2	40%
Physical\Ambulation\Postural transitions	5	38%	5	28%	1	20%
Physical\Ambulation\Stand-sit prolonged	3	23%	7	39%	2	40%
Physical\Ambulation\Walk	8	62%	8	44%	1	20%
Physical\Basic self-care	6	46%	9	50%	1	20%
Physical\Basic self-care\Bathing	2	15%	7	39%	0	0%
Physical\Basic self-care\Dressing	0	0%	2	11%	1	20%
Physical\Basic self-care\Eat drink	2	15%	2	11%	0	0%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Physical\Basic self-care\Grooming	3	23%	1	6%	0	0%
Physical\Basic self-care\Toileting	4	31%	0	0%	0	0%
Physical\Comms systems	5	38%	5	28%	2	40%
Physical\Exercise	10	77%	12	67%	4	80%
Physical\Fine motor	4	31%	4	22%	1	20%
Physical\General function - Live life	9	69%	12	67%	2	40%
Physical\Health maintenance	8	62%	13	72%	4	80%
Physical\Housekeeping	11	85%	8	44%	2	40%
Physical\Lift carry	5	38%	2	11%	2	40%
Physical\Meals	7	54%	15	83%	4	80%
Physical\Mobility Transport	13	100%	14	78%	5	100%
Physical\Mobility Transport\Driving a car	13	100%	13	72%	5	100%
Physical\Mobility Transport\Driving a car\Medication prevents driving	0	0%	2	11%	0	0%
Physical\Mobility Transport\Public transportation	2	15%	2	11%	2	40%
Physical\Mobility Transport\Travel	2	15%	1	6%	0	0%
Physical\Shopping errands	6	46%	7	39%	1	20%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Physical\Sleep impacts	4	31%	8	44%	3	60%
Psychosocial Function (any code)	13	100%	18	100%	5	100%
Psychosocial\Accept-adapt	10	77%	13	72%	4	80%
Psychosocial\Care of others or pets	8	62%	8	44%	1	20%
Psychosocial\Coping	13	100%	17	94%	5	100%
Psychosocial\Coping\Cocooning	12	92%	17	94%	5	100%
Psychosocial\Coping\Cocooning\Voluntary avoidance	8	62%	9	50%	2	40%
Psychosocial\Coping\Lifestyle changes-adjmts	2	15%	9	50%	2	40%
Psychosocial\Coping\Maintaining	2	15%	3	17%	0	0%
Psychosocial\Coping\Non-pharmaceutical therapies	3	23%	9	50%	0	0%
Psychosocial\Coping\Sensory control	3	23%	7	39%	0	0%
Psychosocial\Direct costs	8	62%	13	72%	3	60%
Psychosocial\Emotion States	13	100%	18	100%	5	100%
Psychosocial\Emotion States\Anger-Frustration	10	77%	14	78%	4	80%
Psychosocial\Emotion States\Anxiety	9	69%	16	89%	5	100%
Psychosocial\Emotion States\Depression	10	77%	9	50%	3	60%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Psychosocial\Emotion States\Embarrassment	4	31%	6	33%	3	60%
Psychosocial\Emotion States\Energy and drive	7	54%	9	50%	3	60%
Psychosocial\Emotion States\Grief	1	8%	2	11%	1	20%
Psychosocial\Emotion States\Guilt	5	38%	7	39%	2	40%
Psychosocial\Emotion States\Happy-Euphoria	7	54%	5	28%	2	40%
Psychosocial\Emotion States\Irritable	9	69%	9	50%	4	80%
Psychosocial\Emotion States\Other negative thoughts	4	31%	6	33%	2	40%
Psychosocial\Emotion States\Other positive thoughts	3	23%	2	11%	1	20%
Psychosocial\Emotion States\Relief-invigorated	9	69%	9	50%	4	80%
Psychosocial\Emotion States\Skepticism	7	54%	8	44%	3	60%
Psychosocial\Family relations	10	77%	16	89%	3	60%
Psychosocial\Feeling heard	12	92%	17	94%	5	100%
Psychosocial\Feeling heard\Friends-family	6	46%	6	33%	5	100%
Psychosocial\Feeling heard\Healthcare providers	7	54%	12	67%	3	60%
Psychosocial\Feeling heard\Work-school-society	7	54%	8	44%	5	100%
Psychosocial\Identity	9	69%	17	94%	5	100%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Psychosocial\Interpersonal relations	11	85%	17	94%	5	100%
Psychosocial\Intimate relations	5	38%	12	67%	3	60%
Psychosocial\Life satisfaction and meaning	4	31%	12	67%	2	40%
Psychosocial\Predictability-control	12	92%	18	100%	5	100%
Psychosocial\Pushing through	10	77%	16	89%	5	100%
Psychosocial\Pushing through\Care for others	3	23%	4	22%	0	0%
Psychosocial\Pushing through\Desire to live life	2	15%	4	22%	1	20%
Psychosocial\Pushing through\Maintain self-image	3	23%	2	11%	0	0%
Psychosocial\Pushing through\No choice-no other alt.	4	31%	6	33%	1	20%
Psychosocial\Pushing through\Scheduled plans-obligations	1	8%	4	22%	0	0%
Psychosocial\Recreation-leisure	13	100%	15	83%	5	100%
Psychosocial\School	6	46%	4	22%	3	60%
Psychosocial\Self-sufficiency	7	54%	14	78%	3	60%
Psychosocial\Soc Comm Civic roles	13	100%	15	83%	5	100%
Psychosocial\Soc Comm Civic roles\Civic roles-events	5	38%	9	50%	3	60%
Psychosocial\Soc Comm Civic roles\Community life	6	46%	4	22%	2	40%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Psychosocial\Soc Comm Civic roles\Friends-family social	10	77%	9	50%	5	100%
Psychosocial\Social support-isolation	7	54%	15	83%	4	80%
Psychosocial\Spiritual	1	8%	4	22%	1	20%
Psychosocial\Stigma	8	62%	15	83%	4	80%
Psychosocial\Well-being	11	85%	16	89%	4	80%
Psychosocial\Well-being\Enjoy life	7	54%	9	50%	1	20%
Psychosocial\Well-being\Missing out on life	3	23%	6	33%	1	20%
Psychosocial\Well-being\Needs-wants to do ability	9	69%	11	61%	4	80%
Psychosocial\Work	13	100%	18	100%	5	100%
Psychosocial\Work\Work for pay	12	92%	17	94%	5	100%
Psychosocial\Work\Work for pay\Accom.-adjmts	8	62%	8	44%	4	80%
Psychosocial\Work\Work for pay\Job-career loss	5	38%	8	44%	2	40%
Psychosocial\Work\Work for pay\Missed work-leave	8	62%	9	50%	2	40%
Psychosocial\Work\Work for pay\Productivity-performance at work	7	54%	9	50%	4	80%
Psychosocial\Work\Work for pay\Working through attacks	6	46%	8	44%	5	100%
Psychosocial\Work\Work for pay\Work-stress, tasks, workload	4	31%	6	33%	2	40%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Psychosocial\Work\Work unpaid-volunteer	4	31%	2	11%	2	40%
Symptoms (any code)	13	100%	18	100%	5	100%
Symptoms\Appetite	8	62%	4	22%	2	40%
Symptoms\Clumsiness	3	23%	3	17%	1	20%
Symptoms\Dizziness	8	62%	9	50%	4	80%
Symptoms\Fatigue	10	77%	13	72%	5	100%
Symptoms\GI-Nausea	12	92%	16	89%	5	100%
Symptoms\GI-Other	2	15%	4	22%	3	60%
Symptoms\Mental-Foggy or Clear	12	92%	18	100%	5	100%
Symptoms\Mental-Foggy or Clear\Brain fog	7	54%	14	78%	3	60%
Symptoms\Mental-Foggy or Clear\Brain not working, migraine brain	3	23%	3	17%	1	20%
Symptoms\Mental-Foggy or Clear\Confusion	0	0%	1	6%	1	20%
Symptoms\Mental-Foggy or Clear\Feel stupid, less smart	1	8%	5	28%	2	40%
Symptoms\Mental-Foggy or Clear\Not as sharp, clear	3	23%	6	33%	0	0%
Symptoms\Mental-Foggy or Clear\Slowed, delayed	4	31%	8	44%	4	80%
Symptoms\Mental-Foggy or Clear\Spaced out	2	15%	0	0%	0	0%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Symptoms\Mood change	8	62%	10	56%	4	80%
Symptoms\Pain-head and face	13	100%	17	94%	5	100%
Symptoms\Pain-other	11	85%	13	72%	3	60%
Symptoms\Sensitivity	13	100%	18	100%	5	100%
Symptoms\Sensitivity\Light	13	100%	17	94%	5	100%
Symptoms\Sensitivity\Other	6	46%	9	50%	3	60%
Symptoms\Sensitivity\Smell	6	46%	8	44%	2	40%
Symptoms\Sensitivity\Sound	12	92%	17	94%	5	100%
Symptoms\Sensitivity\Touch	6	46%	5	28%	5	100%
Symptoms\Sensory disturbance	12	92%	17	94%	5	100%
Symptoms\Sensory disturbance\Eye symptoms	1	8%	2	11%	1	20%
Symptoms\Sensory disturbance\Other	5	38%	1	6%	0	0%
Symptoms\Sensory disturbance\Skin sensations	2	15%	8	44%	2	40%
Symptoms\Sensory disturbance\Taste or smell symptoms	1	8%	1	6%	1	20%
Symptoms\Sensory disturbance\Tinnitus, aural disturbances	2	15%	2	11%	0	0%
Symptoms\Sensory disturbance\Visual disturbances	11	85%	13	72%	4	80%

Code	BIPOC (n=13)	Percent of BIPOC	White (n=18)	Percent of White	Hispanic (n=5)	Percent of Hispanic
Symptoms\Sensory disturbance\Yawning	0	0%	2	11%	0	0%
Symptoms\Sleep symptoms	2	15%	6	33%	2	40%
Symptoms\Symptoms- General	13	100%	18	100%	5	100%
Symptoms\Symptoms- General\Relief of symptoms-impacts	6	46%	5	28%	2	40%
Symptoms\Tension-Stiffness	9	69%	8	44%	3	60%
Symptoms\Weakness	5	38%	5	28%	1	20%

Table E- 4. Stratification of Migraine Experience Concepts by Level of Education

Code	Some College or Less (n=7)	Percent Some College or Less	Completed College (n=12)	Percent College	More than College (n=12)	Percent More than college
Cognitive Function (any code)	7	100%	12	100%	12	100%
Cognitive\Concentrate-Focus	6	86%	12	100%	11	92%
Cognitive\Concentrate-Focus\Critical thinking	0	0%	3	25%	2	17%
Cognitive\Concentrate-Focus\Divided attn	3	43%	7	58%	8	67%
Cognitive\Concentrate-Focus\Divided attn\Multiple inputs	3	43%	2	17%	1	8%
Cognitive\Concentrate-Focus\Divided attn\Pain-distraction	2	29%	5	42%	4	33%
Cognitive\Concentrate-Focus\Divided attn\Sensory-distraction	3	43%	2	17%	5	42%
Cognitive\Concentrate-Focus\Sustained attn	4	57%	5	42%	4	33%
Cognitive\Flexibility, multitasking	1	14%	5	42%	4	33%
Cognitive\Impulse-Behavior	1	14%	4	33%	4	33%
Cognitive\Info Proc Reasoning	4	57%	7	58%	7	58%
Cognitive\Language	7	100%	11	92%	10	83%
Cognitive\Language\Comprehension	0	0%	2	17%	2	17%
Cognitive\Language\Expression	0	0%	4	33%	1	8%
Cognitive\Language\Numbers	2	29%	3	25%	3	25%
Cognitive\Language\Speech	6	86%	8	67%	8	67%
Cognitive\Language\Speech\Avoiding speaking, not able to speak	1	14%	3	25%	2	17%
Cognitive\Language\Speech\Jumbled	2	29%	5	42%	2	17%
Cognitive\Language\Speech\Slowed	0	0%	1	8%	1	8%
Cognitive\Language\Speech\Slurred, mumbled	2	29%	1	8%	3	25%

Code	Some College or Less (n=7)	Percent Some College or Less	Completed College (n=12)	Percent College	More than College (n=12)	Percent More than college
Cognitive\Language\Word finding	5	71%	6	50%	7	58%
Cognitive\Meds mgmt	0	0%	3	25%	3	25%
Cognitive\Memory	7	100%	12	100%	12	100%
Cognitive\Memory\Memory free recall	5	71%	7	58%	8	67%
Cognitive\Memory\Memory working	4	57%	10	83%	7	58%
Cognitive\Memory\Recall of attacks	6	86%	12	100%	10	83%
Cognitive\Money mgmt	1	14%	1	8%	1	8%
Cognitive\Problem solve	0	0%	2	17%	4	33%
Cognitive\Read Write	5	71%	9	75%	7	58%
Cognitive\Read Write\Read	3	43%	7	58%	7	58%
Cognitive\Read Write\Read\Concentrate	3	43%	3	25%	4	33%
Cognitive\Read Write\Read\Visual disturbances	0	0%	3	25%	2	17%
Cognitive\Read Write\Write	3	43%	5	42%	2	17%
Cognitive\Read Write\Write\Assistive writing	1	14%	2	17%	2	17%
Cognitive\Read Write\Write\Technology	1	14%	2	17%	0	0%
Physical Function (any code)	7	100%	12	100%	12	100%
Physical\Ambulation	6	86%	11	92%	10	83%
Physical\Ambulation\Head-limb movements	1	14%	3	25%	2	17%
Physical\Ambulation\Immobility	1	14%	1	8%	5	42%
Physical\Ambulation\Postural transitions	1	14%	6	50%	3	25%
Physical\Ambulation\Stand-sit prolonged	3	43%	5	42%	2	17%

Code	Some College or Less (n=7)	Percent Some College or Less	Completed College (n=12)	Percent College	More than College (n=12)	Percent More than college
Physical\Ambulation\Walk	2	29%	9	75%	5	42%
Physical\Basic self-care	4	57%	7	58%	4	33%
Physical\Basic self-care\Bathing	4	57%	3	25%	2	17%
Physical\Basic self-care\Dressing	1	14%	0	0%	1	8%
Physical\Basic self-care\Eat drink	0	0%	4	33%	0	0%
Physical\Basic self-care\Grooming	1	14%	2	17%	1	8%
Physical\Basic self-care\Toileting	0	0%	3	25%	1	8%
Physical\Comms systems	2	29%	3	25%	5	42%
Physical\Exercise	2	29%	10	83%	10	83%
Physical\Fine motor	3	43%	3	25%	2	17%
Physical\General function - Live life	4	57%	8	67%	9	75%
Physical\Health maintenance	5	71%	8	67%	8	67%
Physical\Housekeeping	4	57%	9	75%	6	50%
Physical\Lift carry	0	0%	5	42%	2	17%
Physical\Meals	6	86%	8	67%	8	67%
Physical\Mobility Transport	6	86%	11	92%	10	83%
Physical\Mobility Transport\Driving a car	6	86%	11	92%	9	75%
Physical\Mobility Transport\Driving a car\Medication prevents driving	0	0%	1	8%	1	8%
Physical\Mobility Transport\Public transportation	1	14%	2	17%	1	8%
Physical\Mobility Transport\Travel	0	0%	1	8%	2	17%
Physical\Shopping errands	3	43%	7	58%	3	25%

Code	Some College or Less (n=7)	Percent Some College or Less	Completed College (n=12)	Percent College	More than College (n=12)	Percent More than college
Physical\Sleep impacts	4	57%	2	17%	6	50%
Psychosocial Function (any code)	7	100%	12	100%	12	100%
Psychosocial\Accept-adapt	6	86%	10	83%	7	58%
Psychosocial\Care of others or pets	6	86%	4	33%	6	50%
Psychosocial\Coping	7	100%	11	92%	12	100%
Psychosocial\Coping\Cocooning	6	86%	12	100%	11	92%
Psychosocial\Coping\Cocooning\Voluntary avoidance	2	29%	8	67%	7	58%
Psychosocial\Coping\Lifestyle changes-adjmts	1	14%	3	25%	7	58%
Psychosocial\Coping\Maintaining	1	14%	4	33%	0	0%
Psychosocial\Coping\Non-pharmaceutical therapies	2	29%	5	42%	5	42%
Psychosocial\Coping\Sensory control	2	29%	3	25%	5	42%
Psychosocial\Direct costs	5	71%	8	67%	8	67%
Psychosocial\Emotion States	7	100%	12	100%	12	100%
Psychosocial\Emotion States\Anger-Frustration	5	71%	10	83%	9	75%
Psychosocial\Emotion States\Anxiety	7	100%	9	75%	9	75%
Psychosocial\Emotion States\Depression	6	86%	8	67%	5	42%
Psychosocial\Emotion States\Embarrassment	0	0%	4	33%	6	50%
Psychosocial\Emotion States\Energy and drive	2	29%	6	50%	8	67%
Psychosocial\Emotion States\Grief	2	29%	1	8%	0	0%
Psychosocial\Emotion States\Guilt	3	43%	7	58%	2	17%
Psychosocial\Emotion States\Happy-Euphoria	2	29%	7	58%	3	25%

Code	Some College or Less (n=7)	Percent Some College or Less	Completed College (n=12)	Percent College	More than College (n=12)	Percent More than college
Psychosocial\Emotion States\Irritable	4	57%	6	50%	8	67%
Psychosocial\Emotion States\Other negative thoughts	2	29%	4	33%	4	33%
Psychosocial\Emotion States\Other positive thoughts	0	0%	2	17%	3	25%
Psychosocial\Emotion States\Relief-invigorated	3	43%	9	75%	6	50%
Psychosocial\Emotion States\Skepticism	4	57%	6	50%	5	42%
Psychosocial\Family relations	6	86%	11	92%	9	75%
Psychosocial\Feeling heard	7	100%	11	92%	11	92%
Psychosocial\Feeling heard\Friends-family	4	57%	4	33%	4	33%
Psychosocial\Feeling heard\Healthcare providers	4	57%	7	58%	8	67%
Psychosocial\Feeling heard\Work-school-society	5	71%	6	50%	4	33%
Psychosocial\Identity	6	86%	10	83%	10	83%
Psychosocial\Interpersonal relations	7	100%	11	92%	10	83%
Psychosocial\Intimate relations	4	57%	8	67%	5	42%
Psychosocial\Life satisfaction and meaning	3	43%	5	42%	8	67%
Psychosocial\Predictability-control	7	100%	11	92%	12	100%
Psychosocial\Pushing through	6	86%	11	92%	9	75%
Psychosocial\Pushing through\Care for others	3	43%	2	17%	2	17%
Psychosocial\Pushing through\Desire to live life	1	14%	3	25%	2	17%
Psychosocial\Pushing through\Maintain self-image	0	0%	4	33%	1	8%
Psychosocial\Pushing through\No choice-no other alt.	3	43%	4	33%	3	25%
Psychosocial\Pushing through\Scheduled plans-obligations	2	29%	0	0%	3	25%

Code	Some College or Less (n=7)	Percent Some College or Less	Completed College (n=12)	Percent College	More than College (n=12)	Percent More than college
Psychosocial\Recreation-leisure	6	86%	10	83%	12	100%
Psychosocial\School	2	29%	5	42%	3	25%
Psychosocial\Self-sufficiency	5	71%	7	58%	9	75%
Psychosocial\Soc Comm Civic roles	5	71%	11	92%	12	100%
Psychosocial\Soc Comm Civic roles\Civic roles-events	5	71%	6	50%	3	25%
Psychosocial\Soc Comm Civic roles\Community life	2	29%	4	33%	4	33%
Psychosocial\Soc Comm Civic roles\Friends-family social	3	43%	8	67%	8	67%
Psychosocial\Social support-isolation	6	86%	8	67%	8	67%
Psychosocial\Spiritual	2	29%	1	8%	2	17%
Psychosocial\Stigma	5	71%	10	83%	8	67%
Psychosocial\Well-being	6	86%	12	100%	9	75%
Psychosocial\Well-being\Enjoy life	5	71%	8	67%	3	25%
Psychosocial\Well-being\Missing out on life	3	43%	4	33%	2	17%
Psychosocial\Well-being\Needs-wants to do ability	5	71%	7	58%	8	67%
Psychosocial\Work	7	100%	12	100%	12	100%
Psychosocial\Work\Work for pay	7	100%	12	100%	10	83%
Psychosocial\Work\Work for pay\Accom.-adjmts	3	43%	9	75%	4	33%
Psychosocial\Work\Work for pay\Job-career loss	3	43%	6	50%	4	33%
Psychosocial\Work\Work for pay\Missed work-leave	4	57%	6	50%	7	58%
Psychosocial\Work\Work for pay\Productivity-performance at work	2	29%	9	75%	5	42%
Psychosocial\Work\Work for pay\Working through attacks	4	57%	6	50%	4	33%

Code	Some College or Less (n=7)	Percent Some College or Less	Completed College (n=12)	Percent College	More than College (n=12)	Percent More than college
Psychosocial\Work\Work for pay\Work-stress, tasks, workload	2	29%	3	25%	5	42%
Psychosocial\Work\Work unpaid-volunteer	2	29%	2	17%	2	17%
Symptoms (any code)	7	100%	12	100%	12	100%
Symptoms\Appetite	1	14%	7	58%	4	33%
Symptoms\Clumsiness	1	14%	2	17%	3	25%
Symptoms\Dizziness	4	57%	7	58%	6	50%
Symptoms\Fatigue	5	71%	12	100%	6	50%
Symptoms\GI-Nausea	6	86%	12	100%	10	83%
Symptoms\GI-Other	1	14%	3	25%	2	17%
Symptoms\Mental-Foggy or Clear	7	100%	11	92%	12	100%
Symptoms\Mental-Foggy or Clear\Brain fog	6	86%	8	67%	7	58%
Symptoms\Mental-Foggy or Clear\Brain not working, migraine brain	1	14%	1	8%	4	33%
Symptoms\Mental-Foggy or Clear\Confusion	1	14%	0	0%	0	0%
Symptoms\Mental-Foggy or Clear\Feel stupid, less smart	0	0%	2	17%	4	33%
Symptoms\Mental-Foggy or Clear\Not as sharp, clear	2	29%	3	25%	4	33%
Symptoms\Mental-Foggy or Clear\Slowed, delayed	2	29%	5	42%	5	42%
Symptoms\Mental-Foggy or Clear\Spaced out	0	0%	1	8%	1	8%
Symptoms\Mood change	4	57%	8	67%	6	50%
Symptoms\Pain-head and face	7	100%	12	100%	12	100%
Symptoms\Pain-other	4	57%	12	100%	8	67%
Symptoms\Sensitivity	7	100%	12	100%	12	100%

Code	Some College or Less (n=7)	Percent Some College or Less	Completed College (n=12)	Percent College	More than College (n=12)	Percent More than college
Symptoms\Sensitivity\Light	7	100%	11	92%	12	100%
Symptoms\Sensitivity\Other	4	57%	5	42%	6	50%
Symptoms\Sensitivity\Smell	3	43%	9	75%	2	17%
Symptoms\Sensitivity\Sound	6	86%	12	100%	11	92%
Symptoms\Sensitivity\Touch	3	43%	4	33%	4	33%
Symptoms\Sensory disturbance	6	86%	12	100%	11	92%
Symptoms\Sensory disturbance\Eye symptoms	1	14%	2	17%	0	0%
Symptoms\Sensory disturbance\Other	0	0%	5	42%	1	8%
Symptoms\Sensory disturbance\Skin sensations	1	14%	4	33%	5	42%
Symptoms\Sensory disturbance\Taste or smell symptoms	0	0%	0	0%	2	17%
Symptoms\Sensory disturbance\Tinnitus, aural disturbances	1	14%	2	17%	1	8%
Symptoms\Sensory disturbance\Visual disturbances	6	86%	11	92%	7	58%
Symptoms\Sensory disturbance\Yawning	0	0%	1	8%	1	8%
Symptoms\Sleep symptoms	1	14%	2	17%	5	42%
Symptoms\Symptoms- General	7	100%	12	100%	12	100%
Symptoms\Symptoms- General\Relief of symptoms-impacts	3	43%	5	42%	3	25%
Symptoms\Tension-Stiffness	3	43%	8	67%	6	50%
Symptoms\Weakness	3	43%	4	33%	3	25%

Table E- 5. Stratification of Migraine Experience Concepts by Employment Status

Numbers do not sum to 31 because one participant preferred not to answer this question.

Code	Employed (n=20)	Percent Employed	Not Employed (n=10)	Percent Not Employed
Cognitive Function (any code)	20	100%	10	100%
Cognitive\Concentrate-Focus	18	90%	10	100%
Cognitive\Concentrate-Focus\Critical thinking	3	15%	2	20%
Cognitive\Concentrate-Focus\Divided attn	12	60%	5	50%
Cognitive\Concentrate-Focus\Divided attn\Multiple inputs	3	15%	2	20%
Cognitive\Concentrate-Focus\Divided attn\Pain-distraction	6	30%	4	40%
Cognitive\Concentrate-Focus\Divided attn\Sensory-distraction	6	30%	3	30%
Cognitive\Concentrate-Focus\Sustained attn	6	30%	6	60%
Cognitive\Flexibility, multitasking	7	35%	3	30%
Cognitive\Impulse-Behavior	4	20%	5	50%
Cognitive\Info Proc Reasoning	11	55%	7	70%
Cognitive\Language	17	85%	10	100%
Cognitive\Language\Comprehension	3	15%	1	10%
Cognitive\Language\Expression	4	20%	1	10%
Cognitive\Language\Numbers	5	25%	3	30%
Cognitive\Language\Speech	15	75%	7	70%
Cognitive\Language\Speech\Avoiding speaking, not able to speak	5	25%	1	10%
Cognitive\Language\Speech\Jumbled	8	40%	1	10%
Cognitive\Language\Speech\Slowed	2	10%	0	0%

Code	Employed (n=20)	Percent Employed	Not Employed (n=10)	Percent Not Employed
Cognitive\Language\Speech\Slurred, mumbled	3	15%	3	30%
Cognitive\Language\Word finding	11	55%	6	60%
Cognitive\Meds mgmt	4	20%	2	20%
Cognitive\Memory	20	100%	10	100%
Cognitive\Memory\Memory free recall	12	60%	8	80%
Cognitive\Memory\Memory working	12	60%	8	80%
Cognitive\Memory\Recall of attacks	18	90%	9	90%
Cognitive\Money mgmt	2	10%	1	10%
Cognitive\Problem solve	3	15%	3	30%
Cognitive\Read Write	13	65%	7	70%
Cognitive\Read Write\Read	10	50%	7	70%
Cognitive\Read Write\Read\Concentrate	7	35%	3	30%
Cognitive\Read Write\Read\Visual disturbances	2	10%	3	30%
Cognitive\Read Write\Write	7	35%	2	20%
Cognitive\Read Write\Write\Assistive writing	4	20%	0	0%
Cognitive\Read Write\Write\Technology	2	10%	0	0%
Physical Function (any code)	20	100%	10	100%
Physical\Ambulation	16	80%	10	100%
Physical\Ambulation\Head-limb movements	3	15%	3	30%
Physical\Ambulation\Immobility	5	25%	2	20%
Physical\Ambulation\Postural transitions	6	30%	3	30%
Physical\Ambulation\Stand-sit prolonged	4	20%	5	50%

Code	Employed (n=20)	Percent Employed	Not Employed (n=10)	Percent Not Employed
Physical\Ambulation\Walk	10	50%	6	60%
Physical\Basic self-care	9	45%	5	50%
Physical\Basic self-care\Bathing	4	20%	4	40%
Physical\Basic self-care\Dressing	1	5%	1	10%
Physical\Basic self-care\Eat drink	4	20%	0	0%
Physical\Basic self-care\Grooming	3	15%	1	10%
Physical\Basic self-care\Toileting	2	10%	2	20%
Physical\Comms systems	5	25%	5	50%
Physical\Exercise	16	80%	6	60%
Physical\Fine motor	5	25%	3	30%
Physical\General function - Live life	14	70%	6	60%
Physical\Health maintenance	13	65%	8	80%
Physical\Housekeeping	13	65%	6	60%
Physical\Lift carry	4	20%	3	30%
Physical\Meals	14	70%	7	70%
Physical\Mobility Transport	18	90%	8	80%
Physical\Mobility Transport\Driving a car	18	90%	7	70%
Physical\Mobility Transport\Driving a car\Medication prevents driving	1	5%	1	10%
Physical\Mobility Transport\Public transportation	3	15%	1	10%
Physical\Mobility Transport\Travel	2	10%	1	10%
Physical\Shopping errands	6	30%	6	60%
Physical\Sleep impacts	8	40%	3	30%

Code	Employed (n=20)	Percent Employed	Not Employed (n=10)	Percent Not Employed
Psychosocial Function (any code)	20	100%	10	100%
Psychosocial\Accept-adapt	14	70%	9	90%
Psychosocial\Care of others or pets	10	50%	5	50%
Psychosocial\Coping	19	95%	10	100%
Psychosocial\Coping\Cocooning	19	95%	9	90%
Psychosocial\Coping\Cocooning\Voluntary avoidance	11	55%	6	60%
Psychosocial\Coping\Lifestyle changes-adjmts	8	40%	3	30%
Psychosocial\Coping\Maintaining	4	20%	1	10%
Psychosocial\Coping\Non-pharmaceutical therapies	7	35%	5	50%
Psychosocial\Coping\Sensory control	6	30%	4	40%
Psychosocial\Direct costs	11	55%	9	90%
Psychosocial\Emotion States	20	100%	10	100%
Psychosocial\Emotion States\Anger-Frustration	15	75%	9	90%
Psychosocial\Emotion States\Anxiety	16	80%	8	80%
Psychosocial\Emotion States\Depression	11	55%	7	70%
Psychosocial\Emotion States\Embarrassment	6	30%	4	40%
Psychosocial\Emotion States\Energy and drive	11	55%	4	40%
Psychosocial\Emotion States\Grief	2	10%	1	10%
Psychosocial\Emotion States\Guilt	8	40%	4	40%
Psychosocial\Emotion States\Happy-Euphoria	8	40%	4	40%
Psychosocial\Emotion States\Irritable	12	60%	6	60%
Psychosocial\Emotion States\Other negative thoughts	7	35%	3	30%

Code	Employed (n=20)	Percent Employed	Not Employed (n=10)	Percent Not Employed
Psychosocial\Emotion States\Other positive thoughts	3	15%	2	20%
Psychosocial\Emotion States\Relief-invigorated	14	70%	3	30%
Psychosocial\Emotion States\Skepticism	10	50%	5	50%
Psychosocial\Family relations	16	80%	9	90%
Psychosocial\Feeling heard	18	90%	10	100%
Psychosocial\Feeling heard\Friends-family	9	45%	3	30%
Psychosocial\Feeling heard\Healthcare providers	12	60%	7	70%
Psychosocial\Feeling heard\Work-school-society	11	55%	3	30%
Psychosocial\Identity	17	85%	9	90%
Psychosocial\Interpersonal relations	17	85%	10	100%
Psychosocial\Intimate relations	11	55%	6	60%
Psychosocial\Life satisfaction and meaning	10	50%	6	60%
Psychosocial\Predictability-control	20	100%	9	90%
Psychosocial\Pushing through	18	90%	8	80%
Psychosocial\Pushing through\Care for others	4	20%	3	30%
Psychosocial\Pushing through\Desire to live life	4	20%	2	20%
Psychosocial\Pushing through\Maintain self-image	3	15%	2	20%
Psychosocial\Pushing through\No choice-no other alt.	7	35%	3	30%
Psychosocial\Pushing through\Scheduled plans-obligations	3	15%	2	20%
Psychosocial\Recreation-leisure	18	90%	9	90%
Psychosocial\School	6	30%	4	40%
Psychosocial\Self-sufficiency	14	70%	7	70%

Code	Employed (n=20)	Percent Employed	Not Employed (n=10)	Percent Not Employed
Psychosocial\Soc Comm Civic roles	18	90%	9	90%
Psychosocial\Soc Comm Civic roles\Civic roles-events	7	35%	6	60%
Psychosocial\Soc Comm Civic roles\Community life	6	30%	4	40%
Psychosocial\Soc Comm Civic roles\Friends-family social	14	70%	5	50%
Psychosocial\Social support-isolation	13	65%	8	80%
Psychosocial\Spiritual	2	10%	3	30%
Psychosocial\Stigma	13	65%	9	90%
Psychosocial\Well-being	17	85%	9	90%
Psychosocial\Well-being\Enjoy life	11	55%	5	50%
Psychosocial\Well-being\Missing out on life	5	25%	4	40%
Psychosocial\Well-being\Needs-wants to do ability	13	65%	6	60%
Psychosocial\Work	20	100%	10	100%
Psychosocial\Work\Work for pay	19	95%	9	90%
Psychosocial\Work\Work for pay\Accom.-adjmts	12	60%	4	40%
Psychosocial\Work\Work for pay\Job-career loss	5	25%	8	80%
Psychosocial\Work\Work for pay\Missed work-leave	12	60%	4	40%
Psychosocial\Work\Work for pay\Productivity-performance at work	15	75%	1	10%
Psychosocial\Work\Work for pay\Working through attacks	11	55%	3	30%
Psychosocial\Work\Work for pay\Work-stress, tasks, workload	8	40%	2	20%
Psychosocial\Work\Work unpaid-volunteer	3	15%	2	20%
Symptoms (any code)	20	100%	10	100%
Symptoms\Appetite	8	40%	4	40%

Code	Employed (n=20)	Percent Employed	Not Employed (n=10)	Percent Not Employed
Symptoms\Clumsiness	5	25%	1	10%
Symptoms\Dizziness	12	60%	4	40%
Symptoms\Fatigue	17	85%	5	50%
Symptoms\GI-Nausea	18	90%	10	100%
Symptoms\GI-Other	4	20%	2	20%
Symptoms\Mental-Foggy or Clear	19	95%	10	100%
Symptoms\Mental-Foggy or Clear\Brain fog	12	60%	8	80%
Symptoms\Mental-Foggy or Clear\Brain not working, migraine brain	5	25%	1	10%
Symptoms\Mental-Foggy or Clear\Confusion	1	5%	0	0%
Symptoms\Mental-Foggy or Clear\Feel stupid, less smart	3	15%	3	30%
Symptoms\Mental-Foggy or Clear\Not as sharp, clear	3	15%	5	50%
Symptoms\Mental-Foggy or Clear\Slowed, delayed	10	50%	2	20%
Symptoms\Mental-Foggy or Clear\Spaced out	1	5%	1	10%
Symptoms\Mood change	12	60%	6	60%
Symptoms\Pain-head and face	20	100%	10	100%
Symptoms\Pain-other	17	85%	7	70%
Symptoms\Sensitivity	20	100%	10	100%
Symptoms\Sensitivity\Light	19	95%	10	100%
Symptoms\Sensitivity\Other	10	50%	4	40%
Symptoms\Sensitivity\Smell	9	45%	5	50%
Symptoms\Sensitivity\Sound	19	95%	9	90%
Symptoms\Sensitivity\Touch	7	35%	4	40%

Code	Employed (n=20)	Percent Employed	Not Employed (n=10)	Percent Not Employed
Symptoms\Sensory disturbance	19	95%	10	100%
Symptoms\Sensory disturbance\Eye symptoms	2	10%	1	10%
Symptoms\Sensory disturbance\Other	4	20%	2	20%
Symptoms\Sensory disturbance\Skin sensations	8	40%	2	20%
Symptoms\Sensory disturbance\Taste or smell symptoms	2	10%	0	0%
Symptoms\Sensory disturbance\Tinnitus, aural disturbances	3	15%	1	10%
Symptoms\Sensory disturbance\Visual disturbances	16	80%	8	80%
Symptoms\Sensory disturbance\Yawning	1	5%	1	10%
Symptoms\Sleep symptoms	5	25%	3	30%
Symptoms\Symptoms- General	20	100%	10	100%
Symptoms\Symptoms- General\Relief of symptoms-impacts	8	40%	3	30%
Symptoms\Tension-Stiffness	13	65%	4	40%
Symptoms\Weakness	7	35%	2	20%

Table E- 6. Stratification of Migraine Experience Concepts by Income

Numbers do not sum to 31 because two participants preferred not to answer this question.

Code	< $30K (n=7)	Percent <30K	Betw $30K and $59K (n=6)	Percent $30-59K	Betw $60K and $90K (n=5)	Percent $60-90K	>$90K (n=11)	Percent >$90K
Cognitive Function (any code)	7	100%	6	100%	5	100%	11	100%
Cognitive\Concentrate-Focus	7	100%	6	100%	5	100%	9	82%
Cognitive\Concentrate-Focus\Critical thinking	0	0%	2	33%	1	20%	2	18%
Cognitive\Concentrate-Focus\Divided attn	4	57%	5	83%	2	40%	6	55%
Cognitive\Concentrate-Focus\Divided attn\Multiple inputs	2	29%	2	33%	0	0%	1	9%
Cognitive\Concentrate-Focus\Divided attn\Pain-distraction	4	57%	2	33%	2	40%	2	18%
Cognitive\Concentrate-Focus\Divided attn\Sensory-distraction	4	57%	2	33%	1	20%	3	27%
Cognitive\Concentrate-Focus\Sustained attn	5	71%	3	50%	1	20%	3	27%
Cognitive\Flexibility, multitasking	1	14%	2	33%	1	20%	5	45%
Cognitive\Impulse-Behavior	4	57%	1	17%	1	20%	2	18%
Cognitive\Info Proc Reasoning	4	57%	2	33%	4	80%	6	55%
Cognitive\Language	7	100%	5	83%	4	80%	10	91%
Cognitive\Language\Comprehension	0	0%	1	17%	1	20%	2	18%
Cognitive\Language\Expression	2	29%	0	0%	1	20%	1	9%
Cognitive\Language\Numbers	1	14%	1	17%	2	40%	3	27%
Cognitive\Language\Speech	5	71%	5	83%	4	80%	7	64%
Cognitive\Language\Speech\Avoiding speaking, not able to speak	0	0%	1	17%	1	20%	4	36%
Cognitive\Language\Speech\Jumbled	3	43%	2	33%	1	20%	2	18%

Code	< $30K (n=7)	Percent <30K	Betw $30K and $59K (n=6)	Percent $30-59K	Betw $60K and $90K (n=5)	Percent $60-90K	>$90K (n=11)	Percent >$90K
Cognitive\Language\Speech\Slowed	1	14%	1	17%	0	0%	0	0%
Cognitive\Language\Speech\Slurred, mumbled	1	14%	1	17%	2	40%	2	18%
Cognitive\Language\Word finding	5	71%	4	67%	2	40%	7	64%
Cognitive\Meds mgmt	2	29%	0	0%	1	20%	2	18%
Cognitive\Memory	7	100%	5	83%	5	100%	8	73%
Cognitive\Memory\Memory free recall	5	71%	4	67%	3	60%	7	64%
Cognitive\Memory\Memory working	6	86%	3	50%	5	100%	6	55%
Cognitive\Memory\Recall of attacks	2	29%	0	0%	0	0%	1	9%
Cognitive\Money mgmt	1	14%	0	0%	0	0%	4	36%
Cognitive\Problem solve	6	86%	5	83%	5	100%	4	36%
Cognitive\Read Write	3	43%	5	83%	4	80%	4	36%
Cognitive\Read Write\Read	2	29%	3	50%	2	40%	2	18%
Cognitive\Read Write\Read\Concentrate	2	29%	1	17%	1	20%	1	9%
Cognitive\Read Write\Read\Visual disturbances	4	57%	3	50%	1	20%	1	9%
Cognitive\Read Write\Write	1	14%	1	17%	1	20%	1	9%
Cognitive\Read Write\Write\Assistive writing	2	29%	1	17%	0	0%	0	0%
Cognitive\Read Write\Write\Technology	7	100%	5	83%	4	80%	10	91%
Physical Function (any code)	7	100%	6	100%	5	100%	11	100%
Physical\Ambulation	7	100%	5	83%	5	100%	9	82%
Physical\Ambulation\Head-limb movements	2	29%	2	33%	0	0%	2	18%
Physical\Ambulation\Immobility	1	14%	1	17%	1	20%	4	36%

Code	< $30K (n=7)	Percent <30K	Betw $30K and $59K (n=6)	Percent $30-59K	Betw $60K and $90K (n=5)	Percent $60-90K	>$90K (n=11)	Percent >$90K
Physical\Ambulation\Postural transitions	2	29%	2	33%	2	40%	4	36%
Physical\Ambulation\Stand-sit prolonged	3	43%	2	33%	3	60%	1	9%
Physical\Ambulation\Walk	4	57%	2	33%	4	80%	7	64%
Physical\Basic self-care	5	71%	4	67%	4	80%	2	18%
Physical\Basic self-care\Bathing	4	57%	2	33%	2	40%	1	9%
Physical\Basic self-care\Dressing	0	0%	1	17%	1	20%	0	0%
Physical\Basic self-care\Eat drink	1	14%	1	17%	2	40%	0	0%
Physical\Basic self-care\Grooming	1	14%	2	33%	0	0%	1	9%
Physical\Basic self-care\Toileting	1	14%	1	17%	1	20%	1	9%
Physical\Comms systems	2	29%	2	33%	1	20%	5	45%
Physical\Exercise	1	14%	5	83%	4	80%	10	91%
Physical\Fine motor	3	43%	1	17%	0	0%	3	27%
Physical\General function - Live life	4	57%	3	50%	3	60%	9	82%
Physical\Health maintenance	5	71%	4	67%	4	80%	6	55%
Physical\Housekeeping	4	57%	4	67%	4	80%	5	45%
Physical\Lift carry	1	14%	2	33%	1	20%	3	27%
Physical\Meals	7	100%	1	17%	5	100%	7	64%
Physical\Mobility Transport	7	100%	6	100%	2	40%	10	91%
Physical\Mobility Transport\Driving a car	7	100%	6	100%	2	40%	9	82%
Physical\Mobility Transport\Driving a car\Medication prevents driving	0	0%	0	0%	0	0%	2	18%
Physical\Mobility Transport\Public transportation	1	14%	1	17%	2	40%	1	9%

Code	< $30K (n=7)	Percent <30K	Betw $30K and $59K (n=6)	Percent $30-59K	Betw $60K and $90K (n=5)	Percent $60-90K	>$90K (n=11)	Percent >$90K
Physical\Mobility Transport\Travel	1	14%	0	0%	0	0%	2	18%
Physical\Shopping errands	3	43%	2	33%	3	60%	4	36%
Physical\Sleep impacts	3	43%	2	33%	2	40%	5	45%
Psychosocial Function (any code)	7	100%	6	100%	5	100%	11	100%
Psychosocial\Accept-adapt	6	86%	4	67%	4	80%	8	73%
Psychosocial\Care of others or pets	5	71%	4	67%	2	40%	4	36%
Psychosocial\Coping	7	100%	5	83%	5	100%	11	100%
Psychosocial\Coping\Cocooning	5	71%	6	100%	5	100%	11	100%
Psychosocial\Coping\Cocooning\Voluntary avoidance	1	14%	4	67%	3	60%	7	64%
Psychosocial\Coping\Lifestyle changes-adjmts	1	14%	1	17%	1	20%	7	64%
Psychosocial\Coping\Maintaining	0	0%	1	17%	1	20%	1	9%
Psychosocial\Coping\Non-pharmaceutical therapies	2	29%	1	17%	2	40%	5	45%
Psychosocial\Coping\Sensory control	2	29%	0	0%	1	20%	6	55%
Psychosocial\Direct costs	5	71%	4	67%	4	80%	7	64%
Psychosocial\Emotion States	7	100%	6	100%	5	100%	11	100%
Psychosocial\Emotion States\Anger-Frustration	6	86%	5	83%	4	80%	7	64%
Psychosocial\Emotion States\Anxiety	6	86%	4	67%	5	100%	8	73%
Psychosocial\Emotion States\Depression	6	86%	4	67%	4	80%	5	45%
Psychosocial\Emotion States\Embarrassment	1	14%	2	33%	2	40%	5	45%
Psychosocial\Emotion States\Energy and drive	3	43%	4	67%	1	20%	7	64%
Psychosocial\Emotion States\Grief	1	14%	1	17%	0	0%	1	9%

Code	< $30K (n=7)	Percent <30K	Betw $30K and $59K (n=6)	Percent $30-59K	Betw $60K and $90K (n=5)	Percent $60-90K	>$90K (n=11)	Percent >$90K
Psychosocial\Emotion States\Guilt	3	43%	2	33%	3	60%	3	27%
Psychosocial\Emotion States\Happy-Euphoria	2	29%	3	50%	3	60%	3	27%
Psychosocial\Emotion States\Irritable	4	57%	6	100%	3	60%	5	45%
Psychosocial\Emotion States\Other negative thoughts	3	43%	3	50%	1	20%	3	27%
Psychosocial\Emotion States\Other positive thoughts	1	14%	1	17%	1	20%	2	18%
Psychosocial\Emotion States\Relief-invigorated	3	43%	5	83%	4	80%	5	45%
Psychosocial\Emotion States\Skepticism	4	57%	4	67%	2	40%	4	36%
Psychosocial\Family relations	6	86%	5	83%	5	100%	8	73%
Psychosocial\Feeling heard	7	100%	5	83%	5	100%	10	91%
Psychosocial\Feeling heard\Friends-family	3	43%	5	83%	1	20%	3	27%
Psychosocial\Feeling heard\Healthcare providers	4	57%	4	67%	3	60%	6	55%
Psychosocial\Feeling heard\Work-school-society	6	86%	3	50%	2	40%	4	36%
Psychosocial\Identity	5	71%	6	100%	5	100%	8	73%
Psychosocial\Interpersonal relations	7	100%	5	83%	5	100%	9	82%
Psychosocial\Intimate relations	3	43%	2	33%	4	80%	7	64%
Psychosocial\Life satisfaction and meaning	4	57%	2	33%	2	40%	7	64%
Psychosocial\Predictability-control	6	86%	6	100%	5	100%	11	100%
Psychosocial\Pushing through	5	71%	6	100%	5	100%	8	73%
Psychosocial\Pushing through\Care for others	4	57%	1	17%	1	20%	0	0%
Psychosocial\Pushing through\Desire to live life	1	14%	1	17%	2	40%	1	9%
Psychosocial\Pushing through\Maintain self-image	1	14%	1	17%	1	20%	2	18%

Code	< $30K (n=7)	Percent <30K	Betw $30K and $59K (n=6)	Percent $30-59K	Betw $60K and $90K (n=5)	Percent $60-90K	>$90K (n=11)	Percent >$90K
Psychosocial\Pushing through\No choice-no other alt.	2	29%	2	33%	1	20%	4	36%
Psychosocial\Pushing through\Scheduled plans-obligations	2	29%	0	0%	0	0%	3	27%
Psychosocial\Recreation-leisure	5	71%	6	100%	5	100%	11	100%
Psychosocial\School	1	14%	3	50%	2	40%	3	27%
Psychosocial\Self-sufficiency	5	71%	4	67%	3	60%	7	64%
Psychosocial\Soc Comm Civic roles	5	71%	6	100%	5	100%	10	91%
Psychosocial\Soc Comm Civic roles\Civic roles-events	3	43%	3	50%	3	60%	4	36%
Psychosocial\Soc Comm Civic roles\Community life	0	0%	2	33%	3	60%	4	36%
Psychosocial\Soc Comm Civic roles\Friends-family social	2	29%	5	83%	4	80%	7	64%
Psychosocial\Social support-isolation	5	71%	4	67%	4	80%	7	64%
Psychosocial\Spiritual	1	14%	0	0%	1	20%	3	27%
Psychosocial\Stigma	4	57%	5	83%	4	80%	8	73%
Psychosocial\Well-being	7	100%	6	100%	4	80%	8	73%
Psychosocial\Well-being\Enjoy life	5	71%	5	83%	3	60%	3	27%
Psychosocial\Well-being\Missing out on life	2	29%	2	33%	1	20%	3	27%
Psychosocial\Well-being\Needs-wants to do ability	6	86%	5	83%	2	40%	6	55%
Psychosocial\Work	7	100%	6	100%	5	100%	11	100%
Psychosocial\Work\Work for pay	6	86%	6	100%	5	100%	10	91%
Psychosocial\Work\Work for pay\Accom.-adjmts	3	43%	2	33%	3	60%	7	64%
Psychosocial\Work\Work for pay\Job-career loss	4	57%	2	33%	4	80%	3	27%
Psychosocial\Work\Work for pay\Missed work-leave	4	57%	3	50%	2	40%	7	64%

Code	< $30K (n=7)	Percent <30K	Betw $30K and $59K (n=6)	Percent $30-59K	Betw $60K and $90K (n=5)	Percent $60-90K	>$90K (n=11)	Percent >$90K
Psychosocial\Work\Work for pay\Productivity-performance at work	2	29%	4	67%	2	40%	6	55%
Psychosocial\Work\Work for pay\Working through attacks	3	43%	4	67%	3	60%	3	27%
Psychosocial\Work\Work for pay\Work-stress, tasks, workload	1	14%	2	33%	2	40%	4	36%
Psychosocial\Work\Work unpaid-volunteer	2	29%	2	33%	1	20%	1	9%
Symptoms (any code)	7	100%	6	100%	5	100%	11	100%
Symptoms\Appetite	3	43%	2	33%	3	60%	3	27%
Symptoms\Clumsiness	2	29%	0	0%	1	20%	3	27%
Symptoms\Dizziness	3	43%	3	50%	3	60%	7	64%
Symptoms\Fatigue	6	86%	5	83%	3	60%	7	64%
Symptoms\GI-Nausea	6	86%	6	100%	5	100%	9	82%
Symptoms\GI-Other	1	14%	0	0%	2	40%	3	27%
Symptoms\Mental-Foggy or Clear	7	100%	6	100%	5	100%	10	91%
Symptoms\Mental-Foggy or Clear\Brain fog	5	71%	4	67%	3	60%	7	64%
Symptoms\Mental-Foggy or Clear\Brain not working, migraine brain	3	43%	1	17%	0	0%	2	18%
Symptoms\Mental-Foggy or Clear\Confusion	0	0%	0	0%	0	0%	1	9%
Symptoms\Mental-Foggy or Clear\Feel stupid, less smart	1	14%	1	17%	1	20%	3	27%
Symptoms\Mental-Foggy or Clear\Not as sharp, clear	3	43%	0	0%	0	0%	4	36%
Symptoms\Mental-Foggy or Clear\Slowed, delayed	1	14%	4	67%	1	20%	5	45%
Symptoms\Mental-Foggy or Clear\Spaced out	1	14%	1	17%	0	0%	0	0%
Symptoms\Mood change	4	57%	5	83%	3	60%	5	45%
Symptoms\Pain-head and face	7	100%	6	100%	5	100%	11	100%

Code	< $30K (n=7)	Percent <30K	Betw $30K and $59K (n=6)	Percent $30-59K	Betw $60K and $90K (n=5)	Percent $60-90K	>$90K (n=11)	Percent >$90K
Symptoms\Pain-other	6	86%	4	67%	3	60%	9	82%
Symptoms\Sensitivity	7	100%	6	100%	5	100%	11	100%
Symptoms\Sensitivity\Light	7	100%	5	83%	5	100%	11	100%
Symptoms\Sensitivity\Other	4	57%	4	67%	1	20%	6	55%
Symptoms\Sensitivity\Smell	2	29%	2	33%	5	100%	4	36%
Symptoms\Sensitivity\Sound	6	86%	6	100%	5	100%	10	91%
Symptoms\Sensitivity\Touch	2	29%	4	67%	2	40%	3	27%
Symptoms\Sensory disturbance	6	86%	6	100%	5	100%	10	91%
Symptoms\Sensory disturbance\Eye symptoms	1	14%	0	0%	1	20%	1	9%
Symptoms\Sensory disturbance\Other	2	29%	2	33%	1	20%	0	0%
Symptoms\Sensory disturbance\Skin sensations	3	43%	2	33%	2	40%	3	27%
Symptoms\Sensory disturbance\Taste or smell symptoms	1	14%	0	0%	0	0%	1	9%
Symptoms\Sensory disturbance\Tinnitus, aural disturbances	2	29%	0	0%	0	0%	1	9%
Symptoms\Sensory disturbance\Visual disturbances	6	86%	5	83%	4	80%	7	64%
Symptoms\Sensory disturbance\Yawning	0	0%	0	0%	0	0%	2	18%
Symptoms\Sleep symptoms	1	14%	2	33%	1	20%	3	27%
Symptoms\Symptoms- General	7	100%	6	100%	5	100%	11	100%
Symptoms\Symptoms- General\Relief of symptoms-impacts	2	29%	4	67%	1	20%	3	27%
Symptoms\Tension-Stiffness	5	71%	4	67%	3	60%	4	36%
Symptoms\Weakness	3	43%	1	17%	1	20%	5	45%

Table E- 7. Stratification of Migraine Experience Concepts by Headache Days

Headache days were self-reported. Participants were asked to indicate how many headache days per month they had on average over the prior 3 months.

Code	4-8 Headache Days (n=8)	Percent of 4-8 Days	9-14 Headache Days (n=10)	Percent of 9-14 Days	15-20 Headache Days (n=8)	Percent of 15-20 Days	21-26 headache days (n=5)	Percent of 21-26 Days
Cognitive Function (any code)	8	100%	10	100%	8	100%	5	100%
Cognitive\Concentrate-Focus	7	88%	10	100%	7	88%	5	100%
Cognitive\Concentrate-Focus\Critical thinking	3	38%	2	20%	0	0%	0	0%
Cognitive\Concentrate-Focus\Divided attn	5	63%	7	70%	4	50%	2	40%
Cognitive\Concentrate-Focus\Divided attn\Multiple inputs	2	25%	2	20%	1	13%	1	20%
Cognitive\Concentrate-Focus\Divided attn\Pain-distraction	4	50%	5	50%	1	13%	1	20%
Cognitive\Concentrate-Focus\Divided attn\Sensory-distraction	1	13%	4	40%	3	38%	2	40%
Cognitive\Concentrate-Focus\Sustained attn	1	13%	6	60%	4	50%	2	40%
Cognitive\Flexibility, multitasking	3	38%	2	20%	2	25%	3	60%
Cognitive\Impulse-Behavior	3	38%	3	30%	2	25%	1	20%
Cognitive\Info Proc Reasoning	6	75%	5	50%	4	50%	3	60%
Cognitive\Language	7	88%	8	80%	8	100%	5	100%
Cognitive\Language\Comprehension	1	13%	1	10%	1	13%	1	20%
Cognitive\Language\Expression	1	13%	2	20%	2	25%	0	0%
Cognitive\Language\Numbers	4	50%	2	20%	1	13%	1	20%
Cognitive\Language\Speech	6	75%	6	60%	6	75%	4	80%
Cognitive\Language\Speech\Avoiding speaking, not able to speak	3	38%	0	0%	3	38%	0	0%
Cognitive\Language\Speech\Jumbled	1	13%	4	40%	2	25%	2	40%

Code	4-8 Headache Days (n=8)	Percent of 4-8 Days	9-14 Headache Days (n=10)	Percent of 9-14 Days	15-20 Headache Days (n=8)	Percent of 15-20 Days	21-26 headache days (n=5)	Percent of 21-26 Days
Cognitive\Language\Speech\Slowed	1	13%	0	0%	1	13%	0	0%
Cognitive\Language\Speech\Slurred, mumbled	0	0%	2	20%	3	38%	1	20%
Cognitive\Language\Word finding	2	25%	6	60%	6	75%	4	80%
Cognitive\Meds mgmt	1	13%	3	30%	2	25%	0	0%
Cognitive\Memory	8	100%	10	100%	8	100%	5	100%
Cognitive\Memory\Memory free recall	4	50%	7	70%	5	63%	4	80%
Cognitive\Memory\Memory working	3	38%	9	90%	4	50%	5	100%
Cognitive\Memory\Recall of attacks	7	88%	9	90%	8	100%	4	80%
Cognitive\Money mgmt	0	0%	2	20%	1	13%	0	0%
Cognitive\Problem solve	3	38%	0	0%	2	25%	1	20%
Cognitive\Read Write	4	50%	8	80%	4	50%	4	80%
Cognitive\Read Write\Read	3	38%	7	70%	4	50%	3	60%
Cognitive\Read Write\Read\Concentrate	1	13%	3	30%	3	38%	3	60%
Cognitive\Read Write\Read\Visual disturbances	2	25%	2	20%	1	13%	0	0%
Cognitive\Read Write\Write	2	25%	3	30%	2	25%	3	60%
Cognitive\Read Write\Write\Assistive writing	0	0%	3	30%	1	13%	1	20%
Cognitive\Read Write\Write\Technology	1	13%	1	10%	1	13%	0	0%
Physical Function (any code)	8	100%	10	100%	8	100%	5	100%
Physical\Ambulation	5	63%	9	90%	8	100%	5	100%
Physical\Ambulation\Head-limb movements	2	25%	1	10%	1	13%	2	40%
Physical\Ambulation\Immobility	1	13%	2	20%	2	25%	2	40%

Code	4-8 Headache Days (n=8)	Percent of 4-8 Days	9-14 Headache Days (n=10)	Percent of 9-14 Days	15-20 Headache Days (n=8)	Percent of 15-20 Days	21-26 headache days (n=5)	Percent of 21-26 Days
Physical\Ambulation\Postural transitions	3	38%	2	20%	3	38%	2	40%
Physical\Ambulation\Stand-sit prolonged	2	25%	4	40%	2	25%	2	40%
Physical\Ambulation\Walk	5	63%	3	30%	5	63%	3	60%
Physical\Basic self-care	3	38%	6	60%	2	25%	4	80%
Physical\Basic self-care\Bathing	2	25%	3	30%	0	0%	4	80%
Physical\Basic self-care\Dressing	0	0%	0	0%	1	13%	1	20%
Physical\Basic self-care\Eat drink	1	13%	2	20%	1	13%	0	0%
Physical\Basic self-care\Grooming	1	13%	0	0%	1	13%	2	40%
Physical\Basic self-care\Toileting	1	13%	2	20%	0	0%	1	20%
Physical\Comms systems	2	25%	1	10%	3	38%	4	80%
Physical\Exercise	8	100%	6	60%	6	75%	2	40%
Physical\Fine motor	3	38%	2	20%	1	13%	2	40%
Physical\General function - Live life	6	75%	6	60%	5	63%	4	80%
Physical\Health maintenance	5	63%	6	60%	5	63%	5	100%
Physical\Housekeeping	6	75%	6	60%	4	50%	3	60%
Physical\Lift carry	2	25%	2	20%	2	25%	1	20%
Physical\Meals	6	75%	8	80%	4	50%	4	80%
Physical\Mobility Transport	8	100%	8	80%	7	88%	4	80%
Physical\Mobility Transport\Driving a car	8	100%	8	80%	6	75%	4	80%
Physical\Mobility Transport\Driving a car\Medication prevents driving	1	13%	0	0%	1	13%	0	0%
Physical\Mobility Transport\Public transportation	0	0%	1	10%	2	25%	1	20%

Code	4-8 Headache Days (n=8)	Percent of 4-8 Days	9-14 Headache Days (n=10)	Percent of 9-14 Days	15-20 Headache Days (n=8)	Percent of 15-20 Days	21-26 headache days (n=5)	Percent of 21-26 Days
Physical\Mobility Transport\Travel	0	0%	1	10%	2	25%	0	0%
Physical\Shopping errands	3	38%	2	20%	5	63%	3	60%
Physical\Sleep impacts	3	38%	6	60%	1	13%	2	40%
Psychosocial Function (any code)	8	100%	10	100%	8	100%	5	100%
Psychosocial\Accept-adapt	5	63%	7	70%	7	88%	4	80%
Psychosocial\Care of others or pets	1	13%	6	60%	5	63%	4	80%
Psychosocial\Coping	8	100%	9	90%	8	100%	5	100%
Psychosocial\Coping\Cocooning	8	100%	8	80%	8	100%	5	100%
Psychosocial\Coping\Cocooning\Voluntary avoidance	6	75%	2	20%	6	75%	3	60%
Psychosocial\Coping\Lifestyle changes-adjmts	3	38%	2	20%	3	38%	3	60%
Psychosocial\Coping\Maintaining	2	25%	0	0%	2	25%	1	20%
Psychosocial\Coping\Non-pharmaceutical therapies	3	38%	4	40%	2	25%	3	60%
Psychosocial\Coping\Sensory control	2	25%	2	20%	3	38%	3	60%
Psychosocial\Direct costs	2	25%	8	80%	6	75%	5	100%
Psychosocial\Emotion States	8	100%	10	100%	8	100%	5	100%
Psychosocial\Emotion States\Anger-Frustration	6	75%	7	70%	6	75%	5	100%
Psychosocial\Emotion States\Anxiety	7	88%	7	70%	7	88%	4	80%
Psychosocial\Emotion States\Depression	6	75%	7	70%	3	38%	3	60%
Psychosocial\Emotion States\Embarrassment	3	38%	3	30%	4	50%	0	0%
Psychosocial\Emotion States\Energy and drive	5	63%	3	30%	5	63%	3	60%
Psychosocial\Emotion States\Grief	2	25%	0	0%	0	0%	1	20%

Code	4-8 Headache Days (n=8)	Percent of 4-8 Days	9-14 Headache Days (n=10)	Percent of 9-14 Days	15-20 Headache Days (n=8)	Percent of 15-20 Days	21-26 headache days (n=5)	Percent of 21-26 Days
Psychosocial\Emotion States\Guilt	4	50%	3	30%	3	38%	2	40%
Psychosocial\Emotion States\Happy-Euphoria	4	50%	3	30%	3	38%	2	40%
Psychosocial\Emotion States\Irritable	1	13%	7	70%	6	75%	4	80%
Psychosocial\Emotion States\Other negative thoughts	3	38%	6	60%	0	0%	1	20%
Psychosocial\Emotion States\Other positive thoughts	0	0%	4	40%	0	0%	1	20%
Psychosocial\Emotion States\Relief-invigorated	2	25%	7	70%	6	75%	3	60%
Psychosocial\Emotion States\Skepticism	3	38%	2	20%	6	75%	4	80%
Psychosocial\Family relations	5	63%	9	90%	7	88%	5	100%
Psychosocial\Feeling heard	7	88%	9	90%	8	100%	5	100%
Psychosocial\Feeling heard\Friends-family	3	38%	2	20%	4	50%	3	60%
Psychosocial\Feeling heard\Healthcare providers	3	38%	5	50%	6	75%	5	100%
Psychosocial\Feeling heard\Work-school-society	3	38%	5	50%	5	63%	2	40%
Psychosocial\Identity	6	75%	8	80%	7	88%	5	100%
Psychosocial\Interpersonal relations	6	75%	9	90%	8	100%	5	100%
Psychosocial\Intimate relations	5	63%	5	50%	4	50%	3	60%
Psychosocial\Life satisfaction and meaning	5	63%	4	40%	3	38%	4	80%
Psychosocial\Predictability-control	8	100%	9	90%	8	100%	5	100%
Psychosocial\Pushing through	7	88%	8	80%	7	88%	4	80%
Psychosocial\Pushing through\Care for others	0	0%	3	30%	2	25%	2	40%
Psychosocial\Pushing through\Desire to live life	1	13%	2	20%	1	13%	2	40%
Psychosocial\Pushing through\Maintain self-image	3	38%	1	10%	1	13%	0	0%

Code	4-8 Headache Days (n=8)	Percent of 4-8 Days	9-14 Headache Days (n=10)	Percent of 9-14 Days	15-20 Headache Days (n=8)	Percent of 15-20 Days	21-26 headache days (n=5)	Percent of 21-26 Days
Psychosocial\Pushing through\No choice-no other alt.	3	38%	1	10%	4	50%	2	40%
Psychosocial\Pushing through\Scheduled plans-obligations	1	13%	1	10%	1	13%	2	40%
Psychosocial\Recreation-leisure	6	75%	9	90%	8	100%	5	100%
Psychosocial\School	2	25%	2	20%	5	63%	1	20%
Psychosocial\Self-sufficiency	5	63%	6	60%	5	63%	5	100%
Psychosocial\Soc Comm Civic roles	7	88%	9	90%	8	100%	4	80%
Psychosocial\Soc Comm Civic roles\Civic roles-events	3	38%	3	30%	6	75%	2	40%
Psychosocial\Soc Comm Civic roles\Community life	2	25%	2	20%	4	50%	2	40%
Psychosocial\Soc Comm Civic roles\Friends-family social	3	38%	7	70%	7	88%	2	40%
Psychosocial\Social support-isolation	5	63%	6	60%	6	75%	5	100%
Psychosocial\Spiritual	1	13%	1	10%	1	13%	2	40%
Psychosocial\Stigma	6	75%	8	80%	6	75%	3	60%
Psychosocial\Well-being	6	75%	9	90%	8	100%	4	80%
Psychosocial\Well-being\Enjoy life	3	38%	6	60%	3	38%	4	80%
Psychosocial\Well-being\Missing out on life	3	38%	2	20%	2	25%	2	40%
Psychosocial\Well-being\Needs-wants to do ability	5	63%	6	60%	6	75%	3	60%
Psychosocial\Work	8	100%	10	100%	8	100%	5	100%
Psychosocial\Work\Work for pay	8	100%	9	90%	8	100%	4	80%
Psychosocial\Work\Work for pay\Accom.-adjmts	3	38%	4	40%	7	88%	2	40%
Psychosocial\Work\Work for pay\Job-career loss	2	25%	6	60%	2	25%	3	60%
Psychosocial\Work\Work for pay\Missed work-leave	5	63%	6	60%	3	38%	3	60%

Code	4-8 Headache Days (n=8)	Percent of 4-8 Days	9-14 Headache Days (n=10)	Percent of 9-14 Days	15-20 Headache Days (n=8)	Percent of 15-20 Days	21-26 headache days (n=5)	Percent of 21-26 Days
Psychosocial\Work\Work for pay\Productivity-performance at work	6	75%	5	50%	5	63%	0	0%
Psychosocial\Work\Work for pay\Working through attacks	3	38%	5	50%	5	63%	1	20%
Psychosocial\Work\Work for pay\Work-stress, tasks, workload	1	13%	4	40%	3	38%	2	40%
Psychosocial\Work\Work unpaid-volunteer	0	0%	2	20%	4	50%	0	0%
Symptoms (any code)	8	100%	10	100%	8	100%	5	100%
Symptoms\Appetite	4	50%	5	50%	2	25%	1	20%
Symptoms\Clumsiness	1	13%	3	30%	1	13%	1	20%
Symptoms\Dizziness	5	63%	3	30%	6	75%	3	60%
Symptoms\Fatigue	5	63%	7	70%	7	88%	4	80%
Symptoms\GI-Nausea	7	88%	9	90%	7	88%	5	100%
Symptoms\GI-Other	3	38%	2	20%	1	13%	0	0%
Symptoms\Mental-Foggy or Clear	8	100%	10	100%	7	88%	5	100%
Symptoms\Mental-Foggy or Clear\Brain fog	6	75%	4	40%	6	75%	5	100%
Symptoms\Mental-Foggy or Clear\Brain not working, migraine brain	2	25%	1	10%	1	13%	2	40%
Symptoms\Mental-Foggy or Clear\Confusion	1	13%	0	0%	0	0%	0	0%
Symptoms\Mental-Foggy or Clear\Feel stupid, less smart	1	13%	3	30%	2	25%	0	0%
Symptoms\Mental-Foggy or Clear\Not as sharp, clear	3	38%	3	30%	2	25%	1	20%
Symptoms\Mental-Foggy or Clear\Slowed, delayed	4	50%	3	30%	4	50%	1	20%
Symptoms\Mental-Foggy or Clear\Spaced out	1	13%	1	10%	0	0%	0	0%
Symptoms\Mood change	3	38%	7	70%	7	88%	1	20%
Symptoms\Pain-head and face	8	100%	10	100%	8	100%	5	100%

Code	4-8 Headache Days (n=8)	Percent of 4-8 Days	9-14 Headache Days (n=10)	Percent of 9-14 Days	15-20 Headache Days (n=8)	Percent of 15-20 Days	21-26 headache days (n=5)	Percent of 21-26 Days
Symptoms\Pain-other	6	75%	8	80%	6	75%	4	80%
Symptoms\Sensitivity	8	100%	10	100%	8	100%	5	100%
Symptoms\Sensitivity\Light	8	100%	9	90%	8	100%	5	100%
Symptoms\Sensitivity\Other	5	63%	3	30%	4	50%	3	60%
Symptoms\Sensitivity\Smell	4	50%	5	50%	3	38%	2	40%
Symptoms\Sensitivity\Sound	7	88%	9	90%	8	100%	5	100%
Symptoms\Sensitivity\Touch	2	25%	4	40%	4	50%	1	20%
Symptoms\Sensory disturbance	7	88%	9	90%	8	100%	5	100%
Symptoms\Sensory disturbance\Eye symptoms	1	13%	0	0%	1	13%	1	20%
Symptoms\Sensory disturbance\Other	1	13%	3	30%	2	25%	0	0%
Symptoms\Sensory disturbance\Skin sensations	2	25%	5	50%	2	25%	1	20%
Symptoms\Sensory disturbance\Taste or smell symptoms	0	0%	2	20%	0	0%	0	0%
Symptoms\Sensory disturbance\Tinnitus, aural disturbances	0	0%	1	10%	2	25%	1	20%
Symptoms\Sensory disturbance\Visual disturbances	7	88%	8	80%	5	63%	4	80%
Symptoms\Sensory disturbance\Yawning	2	25%	0	0%	0	0%	0	0%
Symptoms\Sleep symptoms	2	25%	2	20%	2	25%	2	40%
Symptoms\Symptoms- General	8	100%	10	100%	8	100%	5	100%
Symptoms\Symptoms- General\Relief of symptoms-impacts	3	38%	2	20%	3	38%	3	60%
Symptoms\Tension-Stiffness	3	38%	8	80%	4	50%	2	40%
Symptoms\Weakness	3	38%	3	30%	2	25%	2	40%

Table E- 8. Stratification of Migraine Concepts by Codes Indicating Discussion of Ictal or Interictal Experience

Code	Number of Participants with Content Coded as Interictal	Number of Participants with Content Coded as Ictal
Cognitive Function (any code)		
Cognitive\Concentrate-Focus	10	28
Cognitive\Concentrate-Focus\Critical thinking	1	4
Cognitive\Concentrate-Focus\Divided attn	3	17
Cognitive\Concentrate-Focus\Divided attn\Multiple inputs	1	5
Cognitive\Concentrate-Focus\Divided attn\Pain-distraction	0	10
Cognitive\Concentrate-Focus\Divided attn\Sensory-distraction	2	7
Cognitive\Concentrate-Focus\Sustained attn	3	11
Cognitive\Flexibility, multitasking	2	9
Cognitive\Impulse-Behavior	4	5
Cognitive\Info Proc Reasoning	4	17
Cognitive\Language	5	27
Cognitive\Language\Comprehension	1	4
Cognitive\Language\Expression	0	5
Cognitive\Language\Numbers	0	6
Cognitive\Language\Speech	0	20
Cognitive\Language\Speech\Avoiding speaking, not able to speak	0	5
Cognitive\Language\Speech\Jumbled	0	8
Cognitive\Language\Speech\Slowed	0	2
Cognitive\Language\Speech\Slurred, mumbled	0	6
Cognitive\Language\Word finding	2	14
Cognitive\Meds mgmt	0	4
Cognitive\Memory	9	23
Cognitive\Memory\Memory free recall	4	18
Cognitive\Memory\Memory working	7	17

Code	Number of Participants with Content Coded as Interictal	Number of Participants with Content Coded as Ictal
Cognitive\Memory\Recall of attacks	1	6
Cognitive\Money mgmt	0	3
Cognitive\Problem solve	0	2
Cognitive\Read Write	4	18
Cognitive\Read Write\Read	3	14
Cognitive\Read Write\Read\Concentrate	1	9
Cognitive\Read Write\Read\Visual disturbances	0	4
Cognitive\Read Write\Write	2	9
Cognitive\Read Write\Write\Assistive writing	2	3
Cognitive\Read Write\Write\Technology	1	3
Physical Function (any code)	*	*
Physical\Ambulation	11	25
Physical\Ambulation\Head-limb movements	2	5
Physical\Ambulation\Immobility	0	6
Physical\Ambulation\Postural transitions	3	8
Physical\Ambulation\Stand-sit prolonged	3	7
Physical\Ambulation\Walk	4	13
Physical\Basic self-care	3	13
Physical\Basic self-care\Bathing	1	8
Physical\Basic self-care\Dressing	2	1
Physical\Basic self-care\Eat drink	1	3
Physical\Basic self-care\Grooming	0	3
Physical\Basic self-care\Toileting	0	3
Physical\Comms systems	3	8
Physical\Exercise	10	13
Physical\Fine motor	1	7
Physical\General function - Live life	12	16

Code	Number of Participants with Content Coded as Interictal	Number of Participants with Content Coded as Ictal
Physical\Health maintenance	7	6
Physical\Housekeeping	4	16
Physical\Lift carry	1	5
Physical\Meals	8	14
Physical\Mobility Transport	10	24
Physical\Mobility Transport\Driving a car	6	21
Physical\Mobility Transport\Driving a car\Medication prevents driving	1	2
Physical\Mobility Transport\Public transportation	2	3
Physical\Mobility Transport\Travel	2	1
Physical\Shopping errands	5	8
Physical\Sleep impacts	2	9
Psychosocial Function (any code)	*	*
Psychosocial\Accept-adapt	9	14
Psychosocial\Care of others or pets	4	13
Psychosocial\Coping	21	28
Psychosocial\Coping\Cocooning	14	27
Psychosocial\Coping\Cocooning\Voluntary avoidance	9	13
Psychosocial\Coping\Lifestyle changes-adjmts	7	4
Psychosocial\Coping\Maintaining	0	5
Psychosocial\Coping\Non-pharmaceutical therapies	3	10
Psychosocial\Coping\Sensory control	6	7
Psychosocial\Direct costs	5	7
Psychosocial\Emotion States	0	0
Psychosocial\Emotion States\Anger-Frustration	7	19
Psychosocial\Emotion States\Anxiety	14	18
Psychosocial\Emotion States\Depression	9	13
Psychosocial\Emotion States\Embarrassment	4	4

Code	Number of Participants with Content Coded as Interictal	Number of Participants with Content Coded as Ictal
Psychosocial\Emotion States\Energy and drive	9	7
Psychosocial\Emotion States\Grief	2	2
Psychosocial\Emotion States\Guilt	6	9
Psychosocial\Emotion States\Happy-Euphoria	3	6
Psychosocial\Emotion States\Irritable	7	13
Psychosocial\Emotion States\Other negative thoughts	4	4
Psychosocial\Emotion States\Other positive thoughts	2	1
Psychosocial\Emotion States\Relief-invigorated	6	10
Psychosocial\Emotion States\Skepticism	5	4
Psychosocial\Family relations	13	20
Psychosocial\Feeling heard	17	22
Psychosocial\Feeling heard\Friends-family	8	6
Psychosocial\Feeling heard\Healthcare providers	2	4
Psychosocial\Feeling heard\Work-school-society	6	5
Psychosocial\Identity	18	18
Psychosocial\Interpersonal relations	21	17
Psychosocial\Intimate relations	12	6
Psychosocial\Life satisfaction and meaning	16	4
Psychosocial\Predictability-control	22	27
Psychosocial\Pushing through	10	23
Psychosocial\Pushing through\Care for others	1	5
Psychosocial\Pushing through\Desire to live life	2	4
Psychosocial\Pushing through\Maintain self-image	1	3
Psychosocial\Pushing through\No choice-no other alt.	1	9
Psychosocial\Pushing through\Scheduled plans-obligations	3	2
Psychosocial\Recreation-leisure	20	18
Psychosocial\School	3	3

Code	Number of Participants with Content Coded as Interictal	Number of Participants with Content Coded as Ictal
Psychosocial\Self-sufficiency	9	14
Psychosocial\Soc Comm Civic roles	20	20
Psychosocial\Soc Comm Civic roles\Civic roles-events	11	5
Psychosocial\Soc Comm Civic roles\Community life	7	2
Psychosocial\Soc Comm Civic roles\Friends-family social	11	10
Psychosocial\Social support-isolation	15	11
Psychosocial\Spiritual	3	1
Psychosocial\Stigma	11	4
Psychosocial\Well-being	19	21
Psychosocial\Well-being\Enjoy life	12	6
Psychosocial\Well-being\Missing out on life	4	5
Psychosocial\Well-being\Needs-wants to do ability	12	16
Psychosocial\Work	24	27
Psychosocial\Work\Work for pay	21	25
Psychosocial\Work\Work for pay\Accom.-adjmts	9	6
Psychosocial\Work\Work for pay\Job-career loss	6	3
Psychosocial\Work\Work for pay\Missed work-leave	6	11
Psychosocial\Work\Work for pay\Productivity-performance at work	4	16
Psychosocial\Work\Work for pay\Working through attacks	2	10
Psychosocial\Work\Work for pay\Work-stress, tasks, workload	4	7
Psychosocial\Work\Work unpaid-volunteer	5	3
Symptoms (any code)	*	*
Symptoms\Appetite	3	8
Symptoms\Clumsiness	2	6
Symptoms\Dizziness	3	17
Symptoms\Fatigue	11	17
Symptoms\GI-Nausea	9	26

Code	Number of Participants with Content Coded as Interictal	Number of Participants with Content Coded as Ictal
Symptoms\GI-Other	2	4
Symptoms\Mental-Foggy or Clear	12	29
Symptoms\Mental-Foggy or Clear\Brain fog	6	19
Symptoms\Mental-Foggy or Clear\Brain not working, migraine brain	0	6
Symptoms\Mental-Foggy or Clear\Confusion	0	1
Symptoms\Mental-Foggy or Clear\Feel stupid, less smart	4	3
Symptoms\Mental-Foggy or Clear\Not as sharp, clear	3	6
Symptoms\Mental-Foggy or Clear\Slowed, delayed	3	10
Symptoms\Mental-Foggy or Clear\Spaced out	0	2
Symptoms\Mood change	6	16
Symptoms\Pain-head and face	15	31
Symptoms\Pain-other	8	23
Symptoms\Sensitivity	24	31
Symptoms\Sensitivity\Light	19	29
Symptoms\Sensitivity\Other	7	11
Symptoms\Sensitivity\Smell	7	12
Symptoms\Sensitivity\Sound	15	28
Symptoms\Sensitivity\Touch	1	9
Symptoms\Sensory disturbance	5	29
Symptoms\Sensory disturbance\Eye symptoms	0	2
Symptoms\Sensory disturbance\Other	0	5
Symptoms\Sensory disturbance\Skin sensations	1	10
Symptoms\Sensory disturbance\Taste or smell symptoms	0	2
Symptoms\Sensory disturbance\Tinnitus, aural disturbances	1	4
Symptoms\Sensory disturbance\Visual disturbances	3	23
Symptoms\Sensory disturbance\Yawning	0	2
Symptoms\Sleep symptoms	3	4

Code	Number of Participants with Content Coded as Interictal	Number of Participants with Content Coded as Ictal
Symptoms\Symptoms- General	16	25
Symptoms\Symptoms- General\Relief of symptoms-impacts	7	5
Symptoms\Tension-Stiffness	3	15
Symptoms\Weakness	1	8