An Explorative Study of Common Themes of Patient Experiences With Migraine

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ABSTRACT

Objective: To explore important themes in patient experiences with migraine and to understand the relationship of these themes with external factors such as the health care system and societal influences.

Methods: This qualitative study was part of a larger online survey (conducted for a period of 2 months from March 1, 2013, to April 30, 2013) that recruited participants with migraine through nonprobability-based sampling techniques. Respondents were asked an open-ended question to describe their experience with migraine. A codebook was developed based on existing literature and new categories that emerged from the responses. Deductive and inductive content analysis was conducted followed by axial coding of the themes based on the codebook.

Results: The open-ended question resulted in 154 eligible responses. The final codebook contained 28 categories. The categories were combined into 6 distinct themes. The 6 themes included quality of life and health status, disease condition, societal response to disease, health care and medications, support, and patient response to disease. The most frequently occurring categories were pain and quality of life (QoL) (work functioning). The least frequent themes were cognitive symptoms, QoL economic functioning, and caregiver burden. Axial coding of the themes showed that QoL was the central theme. Aspects of the disease condition and negative societal responses were found to substantially affect QoL, leading to caregiver burden and absence/presence of social support.

Conclusions: The findings demonstrate that pain and QoL are central to patient experience with migraine. Attention should be paid to improve the treatment and social support provided to patients and reduce stigma and invalidation.

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Migraine headache is an incapacitating condition. It is defined as an episodic, severe headache generally accompanied by nausea and sensitivity to light, sound, and smell.[1] As per the International Classification of Headache Disorders[2] definition, migraine can be without aura or with aura, which is predominantly characterized by the neurologic symptoms usually preceding or sometimes accompanying the headache. With a 12% global prevalence,[3] migraine is ranked as the seventh most disabling condition worldwide.[4]

Despite being a debilitating condition, migraine headache is often misunderstood, stigmatized, and invalidated.[5,6] People with migraine often have their invisible pain questioned by both society and medical providers. Indeed, this potentially makes many people with migraine forgo medical treatments.[5] Although it is a treatable disorder, migraine is underdiagnosed and undertreated.[7] A study[8] showed that approximately 39% of people with migraine could use prophylactic medication, but only 13% received the treatment. To further elucidate these problems associated with migraine, it is crucial to capture patient experiences. Qualitative methods are useful to show the depth and detail of an experience at a personal level by situating that experience within its context.

Previous qualitative research revealed the importance of understanding patients' experiences with migraine.[9] A focus group conducted in the United States indicated that participants with migraine mentioned 6 main categories when describing how migraine affects their lives: effect on social functioning, effect on family functioning, effect on work, effect on relationship, issues related to physician care, and problems with insurance and drug companies. People with migraine also wanted to understand their disease and gather relevant information about their condition as well as obtain pain relief. Moreover, they were interested in collaborative relationships and wanted a team approach to treatment that engaged both patient and health provider.[10]

The objective of this study was first to explore patients' themes describing their experience with migraine and second to understand the relationships between factors that affect patients' migraine experience. The findings of this qualitative study will potentially inform health care providers about perceptions of migraine patients' experiences and highlight unmet needs of people with migraine and therefore may be useful in optimizing care.

METHODS

This study was part of a larger survey. The online survey was conducted for a period of 2 months from March 1, 2013, to April 30, 2013. Participants were recruited through nonprobability-based

Clinical Points

- People's experience with migraine is multifaceted and complicated.
- Pain was the most frequently expressed concern of people with migraine followed by quality of life and invalidation.
- Clinicians can potentially help individuals with migraine with interventions to decrease pain and invalidation, which will improve their quality of life.

sampling techniques. The survey was advertised by the following organizations on their respective websites: National Fibromyalgia and Chronic Pain Association, Health Central's Chronic Pain, Pro Health, National Headache Foundation, Migraine.com, and social networking websites. Screening questions were incorporated into the survey to allow only respondents with migraine to participate. They were designed to clearly select migraine headache patients and rule out other types of headache. Respondents had to provide consent before proceeding with the survey. As part of the informed consent, they were made aware of the researchers' names, credentials, and affiliations along with the purpose of this research. No personal or identifying information was collected. The study was approved by the Institutional Review Board at the University of Pittsburgh.

This article will focus on the responses obtained to an open-ended question asked at the end of the survey wherein respondents were asked to "describe their experience of migraine." Due to the descriptive approach, the question was kept general and broad to capture the wide array of their lived experience of migraine.

Content analysis is widely utilized as a way of interpreting the meaning extracted from transcribed data.[11] It is defined as a systematic coding approach to explore transcriptions or texts to shed light on patterns and frequency of concepts, their structure, and relationships.[12]

Content analysis was conducted by 2 investigators (E.H. and D.R.) on the eligible responses based on a codebook.[13] The codebook, which included potential themes, was initially developed using existing literature. Additionally, it contained themes that people with migraine had already mentioned in previous studies.[14–17]

In addition to the existing categories, new categories were added to the codebook as they emerged from the responses. The responses of those with migraine were thus coded using an iterative process of codebook themes. In the case of any disagreement between the 2 investigators, the response was discussed with the principal investigator (V.G.). Thus, an initial deductive approach was followed by inductive content analysis. The codebook was exhaustive and consisted of mutually exclusive main categories. Some categories such as quality of life (QoL) included subcategories. The codebook (Supplementary Appendix 1) facilitated the coding of the responses and reduced the burden of interpretation on the coders.[11]

Relational or axial coding is a qualitative analysis technique that involves relating data together to construct linkages between categories.[18] This descriptive study was not based on any theoretical model. Thus, we used an axial coding approach to create an initial model describing patient experience with migraine. Categories were first grouped into 6 themes. Relational (axial) coding was then conducted on the developed themes. A central phenomenon was selected from the themes, and the relationships of the other themes with the phenomenon was fit into a basic frame.[18,19]

Axial coding in this study was conducted to provide an understanding of the patient experience. The coding involved examining the relationships between the themes and categories to identify a phenomenon and the subsequent causal relationships or associations, consequences, intervening relationships, and action strategies. Finally, a model describing patient experience based on these identified relationships was formed.[18,19]

RESULTS

Of the total 1,096 survey participants, 176 responded to the open-ended question. It is important to note that the 1,096 survey respondents were mainly female (94%), aged 35–54 years (60%), and married/living with a partner (65%). The majority had at least a college degree (65%). Employment status varied, with 42% employed full-time, 16% employed part-time, 22% unemployed, and 16% on disability. The survey resulted in 154 eligible responses to the open-ended question that was used in this study.

The final codebook had 28 categories (see Supplementary Appendix 1). As the unit of analysis for coding was a few words or phrases, multiple categories were coded for each participant response. This resulted in a total of 398 sum of the frequencies of the codes for the 28 categories. The most frequently occurring category was pain, which showed up 34 times in the responses ($n = 34$, 9.05%). QoL was another common category and was divided into QoL general ($n = 24$, 6.03%) as well as specific subcategories including work functioning ($n = 31$, 7.79%), physical functioning ($n = 27$, 6.78%), family functioning ($n = 9$, 2.26%), social and recreational functioning ($n = 7$, 1.76%), and economic functioning ($n = 3$, 0.75%). Invalidation was the third most frequent category ($n = 29$, 7.29%). Participants experienced invalidation from health care professionals ignoring and dismissing their feelings and experiences related to migraine. They also frequently mentioned the type of migraine they experienced ($n = 26$, 6.53%), with hormonal and hemiplegic migraines being most common. Access to health care ($n = 14$, 3.52%) in the form of gaining access to appropriate providers seemed more frequent than health care costs ($n = 5$, 1.26%), mainly cost of medications. Although pain and psychological symptoms were common, cognitive symptoms were not frequently mentioned ($n = 3$, 0.75%). Categories such as caregiver burden and suicidal ideation were least frequent ($n = 3$, 0.75%).

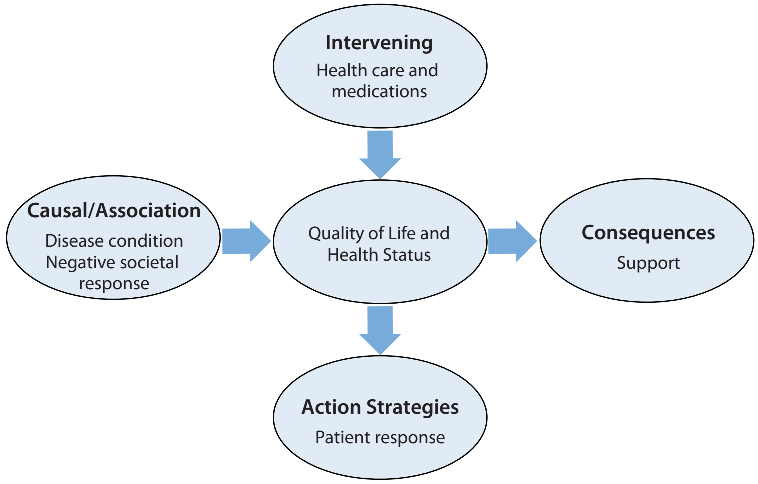
Grouping of these 28 categories resulted in the 6 themes as follows: QoL and health status, disease condition, societal response to disease, health care and medications, support,

Table 1. Frequencies of Categories and Their Corresponding Themes

Category	Frequency, n (%)	Theme
Pain	36 (9.05)	Disease condition
QoL work functioning	31 (7.79)	QoL and health status
Invalidation	29 (7.29)	Societal response (negative)
QoL physical	27 (6.78)	QoL and health status
Typology of migraine	26 (6.53)	Disease condition
QoL general	24 (6.03)	QoL and health status
Quality of care: insufficient	24 (6.03)	Health care and medications
Medications	22 (5.53)	Health care and medications
Coping strategies	22 (5.53)	Patient response (positive)
Psychological symptoms	19 (4.77)	Disease condition
Frequency of attacks	19 (4.77)	Disease condition
Access	14 (3.52)	Health care and medications
Expectations of care and provider	13 (3.27)	Health care and medications
Stigma	13 (3.27)	Societal response (negative)
General comorbidity	12 (3.02)	Disease condition
Quality of care (good)	10 (2.51)	Health care and medications
QoL: family functioning	9 (2.26)	QoL and health status
QoL: social and recreational functioning	7 (1.76)	QoL and health status
Lack of social support	6 (1.51)	Support
Presence of social support	5 (1.26)	Support
Positive perceptions of health status	5 (1.26)	QoL and health status
Side effects of medications	5 (1.26)	Health care and medications
Health care costs	5 (1.26)	Health care and medications
Negative perceptions of health status	4 (1.01)	QoL and health status
QoL: economic functioning	3 (0.75)	QoL and health status
Cognitive symptoms	3 (0.75)	Disease condition
Caregiver burden	3 (0.75)	Support
Suicidal ideation	2 (0.50)	Patient response (negative)
Total	398 (100)	

Abbreviation: QoL = quality of life.

Figure 1. Model of Themes Describing Patient Experience With Migraine



and patient response to disease (Table 1). Axial coding of the 6 themes as well as the individual categories resulted in a model (Figure 1) encapsulating the patients' experience of migraine. QoL emerged as the central theme in the model, providing a link between all the other themes. It was thus categorized as a central phenomenon in the model. Themes such as disease condition (including pain, psychological and cognitive symptoms, typology and frequency, and comorbidity) and negative societal response (stigma and invalidation) were accompanied with a decrease in QoL. Support, a theme combining the categories of presence or lack of social support and caregiver burden, was needed due to this reduced QoL. It was therefore categorized as a consequence of poor QoL. Health care and medications (access, cost, side effects, provider expectations, quality of care) acted as intervening variables on QoL with patients' positive experiences leading to improved QoL and negative experiences leading to decreased QoL. Finally, action strategies were themes involving both positive and negative patient responses to their decreased QoL.

The themes have all been individually described in Table 2 along with corresponding illustrative quotes from

Table 2. Themes Describing Patient Experiences of Migraine With Illustrative Quotes

Theme	Description	Relationship With Central Theme	Illustrative Quotes
QoL and health status	• Specific (physical, work, social, family, or economic functioning) and overall poor QoL • Work life most affected	Central theme	"My migraines are so severe that I have been hospitalized [in] the past 3 years, and I am unable to work." "Had to cancel plans and had to change everything. Have to be careful with everything and leave events early because of the pain." "These migraines, and the doctor's lack of cooperation, have made mine and my daughter's lives very hard financially, as well. My child does not deserve this."
Disease condition	• Commonly mentioned pain • Accompanied by psychological symptoms such as depression and hopelessness • Typology and frequency often described • Comorbidities such as cluster headaches, diabetes, asthma, increased disease severity	• Directly led to decreased QoL, especially family, social, and work life	"When I am in pain, my ability to function is decreased between 80% and 100%." "I plan my life around my pain, and I hate it." "My migraines are also triggered by scents such as perfume and chemicals and smoke. I can [no] longer enjoy the company of mixed crowds or go to church. When I am in public, I have to stay away from people with perfume on. It has affected my life tremendously." "Because my diabetes is not well-controlled (and sometimes this is because I am stuck hiding under the blanket and the light makes it hurt worse, as does moving … and I do not get out to take care of [diabetes] what feels like the more minor problem at the time)"
Negative societal response	• Invalidation most frequent (by the general society as well as health care professionals) • Stigma was often perceived	• Directly affected work, social, and physical QoL • Indirectly led to poor overall QoL and health status	"My biggest frustration is at work where my supervisor has absolutely no clue about migraines and does not understand why I have to stay home 'because of a headache. Therefore, unless I am vomiting or have impaired vision, I will come to work with a migraine, but I cannot say that I am very productive on those days." "I am turned away at emergency rooms because "the ER is not pain management," and I was told to never return with a headache again and to take Tylenol and wait until I can see a family doctor. I'm embarrassed; doctors treat me like a drug seeker and a pain."
Health care and medications	• Most experienced poor quality of care, but some mentioned good quality of health care • Medications described as insufficient, and side effects were a common concern	• Intervened on QoL both positively and negatively, depending on quality of care • Access and cost issues affected economic and family functioning	"Until my most recent switch to [yet another] primary care doctor, none took my complaints, symptoms, or questions seriously enough to suggest I see a neurologist for the interference with my life migraines have had. (At their worst, 6 to 7 times a week, at their best [now] about 3 times a week)." "All the preventative meds have not helped me, and the side effects are horrible with brain function." "Migraines have changed me; I suffer greatly. The medicine to treat a migraine onset is very expensive; Medicaid will not cover it. So, my whole family is suffering because of it."
Support	• Caregiver support needed but resulted in caregiver burden • Many perceived lack of social support, while some received it (including financial and emotional support) • Lack of support often related to stigma and invalidation	• Support needed as result of poor QoL including physical, economic, work functioning	"I feel like a burden to my future husband. I hope one day there will be a better understanding of what we go through. I have chronic migraines and suffer almost daily." "I am currently on FMLA, and my coworkers have donated their own ETO time to make sure my insurance is covered." "I went many years without their [family] support. Including during my childhood and teenage years when they thought I was making up my symptoms and dismissed headaches as no big deal."
Patient response	• Response included positive coping strategies (yoga, alternative medicines, spending time with pets, diets, massages, and exercise) and negative responses such as suicidal ideation	• To deal with poor QoL, patients took action	"Not many meds work for me due to chemical sensitivity so [I] work to manage pain through both alternative medicine and Western [medicine], along with diet." "I try things to help … nothing works, but it is not considered a disability … some days I wish I had a gun to end it all."

Abbreviations: ETO = earned time off, FMLA = Family and Medical Leave Act, QoL = quality of life.

participants. The central theme of most responses was QoL and health status. Relationships of the other 5 themes with QoL are also explained in Table 2.

DISCUSSION

This study explored patients' experience and issues with migraine. QoL emerged as the central theme in participants' experience of migraine. Quantitative studies[20,21] comparing health-related QoL of people with migraine and other chronic illnesses such as chronic musculoskeletal pain, epilepsy, and asthma found that people with migraine reported worse physical, mental, and social functioning. One study[20] also reported that people with less frequent migraine attacks had better QoL, which is similar to our finding that the disease condition was directly related with QoL. Our study also found that negative societal behavior and attitudes including stigma and invalidation are associated with poorer QoL for those with migraine. Another study[22] found that chronic migraine patients received higher stigma scores than episodic migraine and epilepsy patients on the Stigma Scale for Chronic Illness, which measured both internalized (perception of self: eg, shame) and enacted stigma (eg, actual discrimination). That study[22] also found that stigma had the most impact on work functioning and mental health. Although illness invalidation has not been extensively studied in migraine, a qualitative study[23] of college students with migraine found that the students perceived invalidation of their pain experience. Greater invalidation was associated with impaired QoL, lower satisfaction, higher stigma, self-reported depression, and increased pain perception.[23] Decreasing stigma and validating patients' experience of migraine would greatly benefit their QoL.

The results of this study regarding the impact of migraine on patients' work and family are consistent with a qualitative study[24] conducted in Spain on women with migraine. The study[24] indicated that patients with migraine reported a lack of understanding at work that led them to hide the symptoms and diagnoses to avoid being discredited or eventually losing their jobs. In our study, these themes emerged as well. For instance, "I have horrible migraines and keep getting fired from work" or "I was forced to resign my full-time job due to my health" or "I'd like to mention that within that time I lost my job because of absences due to migraines." Although most respondents in the Spanish study[24] found more support in their family than at work, they reported a certain degree of disbelief even among family members. Moreover, some patients were concerned that they might have passed migraine on genetically to their children. Some patients in our study also expressed such concerns: "I often feel sad that the tendency to have migraine headaches has been passed on to my family. My daughter and 3 granddaughters have headaches." In addition to our study, a narrative review[25] on the burden of migraine demonstrated that the impact of migraine on work or family activities was among the most frequent themes in all studies evaluated.

Another study[26] using qualitative analysis assessed the impact of migraine for evaluating outcomes of preventive treatments. In that study,[26] patients most often reported impacts on physical functioning from migraine symptoms. They indicated a vast series of problems from needing to rest or lie down to difficulty with moving one's head or body and walking. In addition, 78% of the subjects reported that migraine affected their ability to do daily activities, for instance missing school or work, being unable to tolerate loud noises or bright lights, and decreased performance in work/school activities.[26] These findings do appear to correlate with trends in our study in which pain and work and physical functioning were among the most frequent concerns our participants expressed. In addition, the subjects in our study mentioned having to avoid triggers of migraine as a barrier to their activities: "My migraines are also triggered by scents such as perfume and chemicals and smoke. I can longer enjoy the company of mixed crowds or go to church. When I am in public I have to stay away from people with perfume on." "I don't have a social life, and shopping is a nightmare with the lighting."

Although our participants mostly reported medications to be ineffective, research suggests that some people with migraine overuse medications for acute migraine attacks, resulting in progression of the disease to chronic migraine and development of tolerance.[27–29] This research indicates the need for effective medication counseling by health care professionals that explains the effect of medication overuse while validating their painful experience of migraine. As improved health care impacts the QoL of patients, effective use of medications could also potentially reduce the occurrence of tolerance and help improve their QoL by reducing pain. In our study, while medications assisted with pain in some cases, they were not reported merely sufficient within themselves to increase QoL. The side effects of the medication added additional burdens. QoL appeared to be significantly enhanced by improving the quality of the relationship with the provider. Reduction of stigma and invalidation were important aspects of the quality of health care in addition to having a caring practitioner. This in turn increased QoL for the respondents.

Participants in our study reported both presence and absence of social support. Lack of social support—including caregiver burden—was more common than presence of social support. A study[30] conducted in Australia found that even though there were no significant differences in the measures of life event stress and coping among participants with and without migraine, there was a significant difference in the amount of social support received. Participants with migraine reported receiving significantly less social support than those without. In addition, quality of family life was affected by a family member with chronic migraine headaches. Social support appeared to moderate QoL, with some respondents having more social support at home and at work than others.[30]

The conceptualized model for this descriptive study is similar to the Wilson and Cleary model, which is the most widely used conceptual framework of health-related QoL[31] and indicates 5 correlated domains: biological and physiologic factors, symptom status, functioning, general health perceptions, and overall QoL.[32] Our model adds migraine-specific constructs such as negative societal response and social support. The model can be used as an initial framework for future studies that utilize theoretical approaches and in-depth interviews to further refine the model.

The most notable limitation of the present study is the possibility of selection bias because the participants who filled out the open-ended question in the survey could be different from those who did not. Another limitation is the unclear response rate; since this was an online survey that was advertised on websites and social media, we had no way of knowing how many people were contacted. In these situations, response rates cannot be calculated with any certainty. Due to the nature of sampling, clinically different types of migraine could not be identified even though type of migraine might be influential on the patients' experiences and perceptions. Also, age and sex of the 154 participants with eligible responses to the open-ended question could not be determined. In addition, the influence of interrater reliability was difficult to determine. This was a slight concern because English was not the native language of the coders. Thus, both coders explored the data simultaneously. Hence, coding together under supervision of the third researcher helped increase reliability of the coding. The findings of this study can be viewed as a snapshot of the patients' experience with migraine.

Despite its limitations, this study provides insight into migraine experience from the patients' perspective with a relatively large sample. The study results can be used to provide better treatment and health care services and eventually improve health care for people with migraine.

CONCLUSION

Overall, this study describes the experiences and relationships between the themes of pain, invalidation, comorbidities, poor QoL, and unsatisfactory health care in the lives of people with migraine. The results identify the areas that need improvement so that migraine patients' QoL can be increased.

The relationships between pain, decreased QoL, invalidation, stigma, and social support formed the context for understanding migraine experiences. The findings from this study demonstrate that along with prescribing the appropriate medications, practitioners need to focus on the nature of their relationship, ensuring a strong therapeutic relationship with patients by reducing any potential stigma, validating patient responses, and listening empathically to the needs of their patients. Also, spending time on assessing and counseling people with migraine, especially regarding medications, can reduce the medication burden for patients. While economic barriers were mentioned in the study, this issue must be addressed in the larger issue of availability of cost-efficient medications and health care. For people with chronic migraine, brief interventional sessions with family members educating them on the nature of the disease may be useful in facilitating social support. Further, enlisting support from family members could significantly increase QoL for patients. While this research was a qualitative study with a limited sample, these findings based on experiences with migraine can assist practitioners in improving QoL for people with migraine.

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THE PRIMARY CARE COMPANION
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Supplementary Material

Article Title: An Explorative Study of Common Themes of Patient Experiences With Migraine

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List of Supplementary Material for the article

1. Appendix 1. Codebook

Disclaimer

Appendix 1. Codebook

1. Stigma:

Brief Definition: Preconceived beliefs and attitude about the disease or patient with the disease.

Full Definition Disapproving based on negative preconceived beliefs and attitudes of disease or patients with disease.

When to use: Code when respondents refer to being labeled or negatively perceived because of their illness or expression of symptoms regarding their illness.

When not to use: Do not use this code for invalidation which is a reference to lack of understanding the patient's experience by a health care professional or other person.

2. Invalidation:

Brief Definition: Dismissal, rejection or ignoring feelings, attitudes and experiences.

Full Definition: Rejecting, ignoring or judging another's feelings, thoughts, attitudes or experiences.

When to use: Code when misinterpreting, not understanding, judging or discounting of respondent's experience.

When not to use: Do not code when person is places in a stereotypical, preconceived label more appropriate to stigma.

3. Cognitive Symptoms:

Brief Definition: Symptoms affecting thought process.

Full definition: Symptoms affecting process of thinking related to migraine that alters thinking and perception.

When to use: Code when the process of thinking such as attention, recognition, concentration, focus and ability to interpret experience is affected by migraine.

When not to use: Do not code for physical/ psychological symptoms.

4. Psychological symptoms:

Brief Definition: Symptoms affecting mental/emotional health.

Full definition: Symptoms that affect respondent functioning that are the result of anxiety, depression and other emotional states.

When to use: Code when patient indicates emotional experiences due to migraine that do not indicate a mental illness diagnosis

When not to use: Do not code if respondent indicates a mental health diagnosis.

5. Suicidal Ideation:

Brief Definition: Suicidal thoughts

Full definition: Expression of need or want or desire for ending life.

When to use: Any expression of hopelessness or other negative emotions regarding life which indicates a tendency to end life.

When not to use: General feelings of hopelessness without indication of lack of desire to live.

6. Mental Co-morbidity:

Brief Definition: Mental Health Diagnosis

Full Definition: Respondent mentions a co-occurring mental health diagnosis.

When to use: Code when respondent states that they have been diagnosed with or assigned a mental health diagnosis by a health professional.

When not to use: Do not code when respondent psychological symptoms or believes they have a diagnosis without stating they have been diagnosed by a professional.

7. Physical Co-morbidity:

Brief Definition: Physical Health Diagnosis

Full Definition: Respondent mentions a co-occurring physiological health diagnosis.

When to use: Code when respondent endorses a physiological health diagnosis like diabetes, cardiac disorders, etc.

When not to use: Do not code when respondent physical or physiological symptoms.

8. Pain:

Brief Definition: Description of pain affecting ability to function.

Full definition: Any description of pain that impairs activities of daily functioning

When to use: Code when respondent specifically indicates pain related to migraine.

When not to use: Do not code when their physical symptoms do not primarily contain pain.

9. Quality of Life (QoL): Physical

Brief definition: Being able to function and perform routine activities of daily living

Full Definition: Condition leading to decreased or complete cessation of physical ability to engage in daily tasks due to physical symptoms like nausea, fatigue or changes in sensory functions.

When to use: Respondent mentions decreased or cessation of ability to function in daily living due to migraine and its symptoms.

When not to use: Do not code when patients mention work or social functioning or pain.

10. QoL: Work functioning

Brief Definition: Patient’s ability to work at employment

Full Definition: Condition leading to decreased performance at work including presentism and absenteeism.

When to use: Respondent mentions decreased or cessation of ability to function at work due to migraine

When not to use: Do not code when patients mention physical or social functioning or pain or inability to perform personal work not employment related.

11. QoL: Social functioning

Brief Definition: Patient’s social activities.

Full Definition: Condition leading to decreased ability to engage in social activities.

When to use: Respondent mentions decreased or cessation of ability to engage in social activities outside family role due to migraine

When not to use: Do not code when patients mention work or family functioning or pain.

12. QoL: Family functioning

Brief Definition: Patient’s relationships in the family

Full Definition: Condition leading to affected inter-personal relationships and decreased ability to fulfill family role.

When to use: Respondent mentions decreased or cessation of ability to fulfill family role and problems in interpersonal relationships with others in family due to migraine

When not to use: Do not code when patients mention work or social functioning or pain.

13. QoL: Economic Functioning

Brief Definition: Patient’s economic stability.

Full Definition: Condition leading to decreased economic stability.

When to use: Code when patient mentions decreased or cessation of ability to be financially viable due to migraine

When not to use: Do not code when patient’s express inability to afford healthcare.

14. Healthcare costs:

Brief Definition: Expressions related to medical costs.

Full definition: Any direct or indirect medical costs that are accrued because of their migraine.

When to use: Code when patient indicates any out of pocket costs due to migraine.

When not to use: Do not code when access is limited because of lack of coverage.

15. Access:

Brief Definition: Difficulty in accessing services because of lack of coverage.

Full Definition: Lack or inadequate insurance to meet the patient’s medical needs.

When to use: Code when the patient expresses difficulty in accessing medical services due to lack of medical coverage.

When no to use: Do not code when patient mentions direct medical costs.

16. Medications

Brief Definition: Name of prescribed medication

Full Definition:

When to use: Code when patient mentions the name of a prescription medication.

When not to use: Do not code when patient mentions any non-pharmacological treatment more suited to a coping strategy.

17. Coping strategies:

Brief Definition: Individual techniques to manage or adapt to migraine.

Full Definition: Non-pharmacological techniques that the patient practices to manage or adapt to symptoms of migraine.

When to use: Code when patient refers to practicing non-pharmacological techniques such as yoga, meditation or cognitive behavioral techniques.

When not to use: Do not code when they refer to otc, prescription or herbal treatments.

18. Caregiver burden:

Brief Definition: Stress perceived by the person who takes care of the patient as referred to by the respondent.

Full definition: The physical, psychological, emotional, social and financial stresses that the patient perceives the person who takes care of them is experiencing.

When to use: Code when the respondent refers to stress they perceive their caretaker experiences.

When not to use: Do not code when the patient refers to their own quality of life.

19. Expectation of care and healthcare provider: (Future)

Brief Definition: Anticipation or hope related to future health care or healthcare provider.

Full definition: Expression of patients' hope and anticipations for future health services.

When to use: Code when patient refers to anticipated improvements in treatment with respect to coordinated services, collaborative care or support group in the future or any added health care intervention.

When not to use: Do not code when the patient refers to the quality of care provided.

20. Quality of care: (Current)

Brief Definition: Perceived value or comprehensiveness of care.

Full Definition: Perceived value or comprehensiveness of care that refers to the process of the treatment or relationship with the health care providers.

When to use: Code when the patient refers to process of treatment delivery, positive or negative outcomes

When not to use: Do not code when patient refers to expectations of care or improvement in condition.

21. Clinical Outcome of care (Positive)

Brief Definition: Patient's perception of improvement in the condition.

Full definition: The patient’s perception of positive clinical status of the condition based upon the current treatment.

When to use: Code when the patient refers to the attainment of any symptom relief or improved clinical outcomes.

When not to use: Do not code when patient refers to the process of care.

22. Clinical Outcome of care (Negative)

Brief Definition: Patient’s perception of worsening health condition.

Full definition: The patient’s perception of negative clinical status of the condition based upon the current treatment.

When to use: Code when the patient refers to the symptom worsening or poor clinical outcomes.

When not to use: Do not code when patient refers to quality of care.

23. Presence of Social support:

Brief Definition: Assistance provided by others in relation to the disease or treatment.

Full definition: The perceived or actual social, economic, and/ or emotional support, care or assistance currently received from others and/ or inclusion in a supportive group.

When to use: Code when the patient refers to receiving emotional, physical or economic support from the society to help with the disease or treatment.

When not to use: Do not code when the patient refers to caregiver burden or when patient refers to expectation of future support.

24. Lack of Social support:

Brief Definition: Lack of assistance provided by others in relation to the disease or treatment.

Full definition: The lack of social, economic, and/ or emotional support, care or assistance currently received from others and/ or inclusion in a supportive group.

When to use: Code when the patient refers to not receiving emotional, physical or economic support from the society to help with the disease or treatment.

When not to use: Do not code when the patient refers to caregiver burden or when patient refers to expectation of future support.

25. Side effects:

Brief Definition: A record each side effect of medications mentioned by the patient.

Full Definition: All side-effects or unintended consequences of taking migraine medications as described by the patients.

When to use: Use when symptoms occurring directly as a result of the medication are described

When not to use: Do not code symptoms of disease or if side-effects are a result of medications not used for migraine (medications for co-morbidities).

26. Frequency of migraine attacks: a) Low or b) High

Brief Definition: Code each time patient mentions the frequency of migraine attacks.

Full Definition: Frequency is number of attacks occurring per day/month/ year/longer period or a general description of frequency.

When to use: Use when patients describe a particular number as frequency rate or they describe decreasing or increasing rates in general.

When not to use: Do not code when patients mention type of migraine

27. Quality of Life (General):

Brief Definition: Patient’s overall life quality/ well-being.

Full Definition: Condition leading to decreased quality of life overall or a sense of decreased well-being of the patient.

When to use: Code each time patient describes an impact on overall quality of life.

When not to use: Do not code when patient describes a specific aspect of life being affected such as physical, social or any categories above.

28. Typology of Migraine:

Brief Definition: Patient’s description of type of migraine.

Full Definition: Standard forms of migraines as well as description of condition in layman terms are considered as the type of migraine.

When to use: Code each time patient mentions the type of the disease

When not to use: Do not code when patient mentions symptoms of disease.