



THE PRIMARY CARE COMPANION FOR CNS DISORDERS

Supplementary Material

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

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1. [Appendix 1. Codebook](#)

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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 placed 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.