
View and Perspective

Naming Migraine and Those Who Have It

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Medical language has implications for both public perception of and institutional responses to illness. A consensus panel of physicians, academics, advocates, and patients with diverse experiences and knowledge about migraine considered 3 questions: (1) What is migraine: an illness, disease, syndrome, condition, disorder, or susceptibility? (2) What ought we call someone with migraine? (3) What should we not call someone with migraine? Although consensus was not reached, the

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responses were summarized and analyzed quantitatively and qualitatively. Panelists participated in writing and editing the paper. The panelists agreed that “migraine,” not “migraine headache,” was generally preferable, that migraine met the dictionary definition for each candidate moniker, terms with psychiatric valence should be avoided, and “sufferer” should be avoided except in very limited circumstances. Overall, while there was no consensus, “disease” was the preferred term in the most situations, and illness the least preferred. Panelists disagreed strongly whether one ought to use the term “migraineur” at all or if “person with migraine” was preferable. Panelists drew upon a variety of principles when considering language choices, including the extent to which candidate monikers could be defended using biomedical evidence, the cultural meaning of the proposed term, and the context within which the term would be used. Panelists strove to balance the need for terms to describe the best science on migraine, with the desire to choose language that would emphasize the credibility of migraine. The wide range of symptoms of migraine and its diverse effects may require considerable elasticity of language.

Key words: migraine, semantics, terminology, Delphi technique, defining migraine

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The language used to describe and discuss a medical problem can affect public perceptions and institutional responses to the illness and those who have it. Ideally, the language used to discuss migraine should be scientifically accurate, reduce stigma, avoid bias and misperception, and allow persons with migraine to have their headache-related needs addressed properly. The language used in reference to migraine should also help the professionals to communicate with the rest of the medical community and with policy makers. There has been little discussion about what terms should be used or avoided to describe migraine and the people who have it. Is migraine best described as a “disease,” a “condition,” a “syndrome,” an “illness,” or a “susceptibility?” Furthermore, how should we refer to a person with migraine? Is “migraineur” an acceptable term?

“Naming” disease is as much a social process of negotiation among stakeholders as it is a reflection of biomedical evidence.¹ Nowhere is this clearer than in debates about what constitutes a disease. In the past few decades, a great many conditions, such as osteoporosis and erectile dysfunction, have been newly defined as diseases, while only the occasional condition, like homosexuality, has been demedicalized.² Some decry “disease mongering” as a marketing ploy by the pharmaceutical industry.^{3,4}

An ongoing debate about the ontological status of obesity illustrates some of the problems involved in calling a medical condition a disease.^{5,6} One author argues that a disease must have a characteristic group of signs and symptoms, which obesity does not.⁵ Another responds that some disorders that we call

diseases do not have any signs or symptoms and may be derangements of cellular function, as is true of obesity.⁶ He suggests that clinical reality is the over-riding determinant.

Cortelli et al specifically addresses the question of whether or not migraine is a disease. They argue that the migraine attack itself is an adaptive response that serves to alarm the body in an anticipatory fashion for its internal defense: its function is to interrupt the dangerous effect of a migraine trigger upon the brain.⁷ On the other hand, they propose that frequent attacks in predisposed individuals lead to central nervous system remodeling that is maladaptive and may be characterized as a disease. They do not suggest specific criteria for distinguishing between “adaptive” and “pathological” symptoms.

We elected to have an open discussion about whether migraine is a “disease,” an “illness,” a “condition,” a “disorder,” or a “syndrome,” and the language choices used to describe it and those who have it. We endeavored to choose the best term for the person with migraine (“migraineur” or “person with migraine”) and determine if any naming choices are inappropriate. We also attempted to describe the cultural meaning of such choices and, if possible, reach consensus about which choices are most appropriate.

METHODS

We chose a modified Delphi technique to encourage discussion of these issues among a broad group of interested individuals. The Delphi technique is an iterative process that encourages lively discussion and persuasion, limits the effects of strong personality, and

allows the opportunity to achieve consensus.⁸ For each round, a series of questions was circulated to a group of panelists. Panelists responded either to open-ended or forced-choice questions. Both the complete set of responses and a summary of the responses were then circulated at the next iteration. Participants were then asked a new series of questions, and the process repeated. At the end of 4 iterations, the responses were summarized, analyzed, and a manuscript written. The panel members were invited to review and participate in writing the manuscript.

A purposive sample of 15 panelists was assembled; panel members included physicians, patients, advocates, and academics, all of whom represent various constituencies that have a stake in a discussion about migraine. The panel was selected based largely on areas of expertise, interest in migraine, prominence in their field, or ability to represent various constituencies (see below). The number of panelists was chosen to maximize the number of different constituencies brought to the discussion, while keeping the number of panelists to a manageable level. Many participants fulfilled more than one role – eg, many of the non-patient participants had migraine and some had been migraine patients. To the extent possible, panelists did not know who the other members were. This anonymity was intended to avoid offline discussions in which other panelists could not participate, and limit the influence of reputation and personality on the process. Only the moderator knew the identity of each participant throughout the process.

Panelists were asked to answer a set of questions in 4 rounds of emails. Each round included 3 different kinds of questions. The first question always related to what migraine should be called (“illness,” “disease,” “disorder,” “syndrome,” or “condition,” and, in later iterations, “susceptibility”). The second question focused on what to call the individual with migraine (“migraineur,” “person with migraine”). The third question had to do with what not to call the person with migraine (for the specific wording of the questions, see Appendix S1). The questions were generated by consensus between the 2 lead authors.

For round 2, definitions were abstracted from the Merriam Webster and Oxford English dictionaries (see Appendix S2). In round 3, panelists were asked

to rate 7 terms for acceptability using an ordinal scale. In round 4, panelists were given 12 vignettes with forced-choice preference of a single term and allocation of other terms into “acceptable” and “unacceptable” categories (see Appendix S3).

The text generated from each round of exercise was analyzed using both a limited quantitative analysis and a more extensive qualitative analysis, guided by grounded theory, which identified the principles that participants drew upon to make decisions regarding language. This mixed-methods approach allowed us to see trends in thought about migraine and language and assess the circumstances under which some terms rose in popularity with the panelists.

The project was discussed with the chairman of the institutional review board (IRB) at Thomas Jefferson University and determined not to be research; therefore, the protocol did not require IRB approval.

RESULTS

All panelists but one were native American English speakers. One individual declined participation. Panelists ranged from 25 to 69 years of age and included 8 women, 7 men, 7 physicians, and 8 non-physicians (see Table 1).

The first task for panelists was to determine whether migraine is an illness, disease, condition,

Table 1.—Participant Profile

Coordinator (non-voting moderator, Palatucci advocate, Academy of Neurology, at-large member of the board of the American Headache Society [AHS])
A. AHS Executive Committee member
B. Headache specialist, non-neurologist, National Headache Foundation board member
C. Headache specialist, psychiatry background
D. Epidemiologist
E. Patient advocate
F. Journal editor
G. Professor of sociology
H. Professor of philosophy
I. Professor of rhetoric
J. Neuroscientist
K. Family practitioner, non-expert
L. Member American Academy of Neurology Practice Committee, not practicing headache medicine
M. Patient – chronic migraine
N. Patient – menstrual migraine
O. Patient – episodic migraine

syndrome, disorder, or susceptibility. All panelists responded to this inquiry at least once. “Disease” received strong support throughout the process. “Condition” received moderate support, having less negative connotation than other terms, but some thought that the term “condition” was not perceived as being as serious as “disease.” “Syndrome” received support from only a few panelists; although some participants mentioned comfort with this term, one said it is too vague for general use. “Disorder” originally had more support; however, one panelist was concerned that it “sound[ed] psychiatric.” One panelist suggested “susceptibility,” which was included in subsequent rounds. “Illness” was not originally supported but was brought back into consideration in later rounds, as one panelist felt that its use was appropriate under specific conditions, ie, when an individual wanted to stress his or her own experience of feeling ill.

Based upon the responses from round 1, participants were asked to consider a threshold for the use of any particular term, eg, calling migraine a “disease.” “Threshold” meant a severity or frequency of migraine for which a term would apply. There were sharp differences here, but a majority favored the concept of a threshold. One panelist argued passionately that by setting a threshold for use of a term, the number of individuals felt to merit treatment or resource would arbitrarily be reduced. He feels that the gradation of severity could be dealt with using severity indices or modifiers, such as the term “active.”

In round 2, participants were given abstracted definitions of each term from both the Merriam Webster and Oxford English dictionaries (see Appendix S2). They agreed that all the dictionary definitions are met by the word “migraine” in most circumstances, thus preferences were due to the intent of the author and the impact of a word’s use.

For the second question – “What do we call someone with migraine?” – the group remained equally divided regarding the use of *migraineur* or person with migraine. Opinions were strong. Several felt “*migraineur*” is appropriate in an academic context. “*Migraineur*” was thought of as sounding good but unfamiliar to the uninitiated. Some participants thought *migraineur* sounded too sophisticated to be understood by much of the public: “I don’t wish

to be seen as an amateur provocateur, or even saboteur, in our service as accoucheurs for the naming of terms. But I am certainly not willing to be a *claqueur* for the term “*migraineur*.” “Person with migraine” sounded cumbersome, and even ridiculous to some. The supporters of “person with migraine” were emphatic that “*migraineur*” ought not to be used because in the words of one participant, “it conflates the person with the disease.” Several panelists pointed out that “persons with migraine” and similar constructs (“migraine patient”/“person susceptible to migraine”/“patient with migraine disorder”/“person living with migraine”) are the most politically correct. “Migraine sufferer” received little support: one suggested reserving it for special circumstances. One participant suggested “a person susceptible to migraine.”

For the third question (terms to be avoided), participants suggested:

- sufferer;
- migraine victim;
- borderline (psychiatric label);
- migraine personality (same);
- “anything with psychiatric connotation;”
- medication overuser (blames the patient);
- chronic headache patient (“what does ‘chronic’ refer to?”).

The panel also unanimously agreed not to use “migraine headache” unless the pain is specifically singled out from the rest of the migraine symptom complex.

Quantitative Analysis.—In round 3, participants were asked to rate each term listed in Table 2 on how

Table 2.—Terms and How Often They Should Be Used

	Never	Rarely	Sometimes	Usually	Always
Illness	6	1	3	2	0
Disease	2	1	4	2	4
Syndrome	4	1	3	2	2
Condition	2	1	4	2	3
Disorder	5	1	2	3	1
Susceptibility	2	1	6	2	1
Sufferer	3	4	3	1	1

often it should be used (totals do not always equal 15, since not all panelists responded to every question).

“Illness” was the least favored term. Several panelists felt it could be used in special circumstances to describe the experience of the migraineur/person with migraine. A threshold of severity was not favored for this term. “Disease” was the most favored word choice. A strong contingent would limit the use of “syndrome.” However, several commented that its use is appropriate in the absence of the pathophysiology of migraine, and in the absence of a diagnostic test or understanding. “Condition” continued to receive support. Several commented that this term is inoffensive and neutral. “Disorder” was less popular than “condition:” several participants felt that it sounded psychiatric, like the “criteria for the diagnosis of mental disorder.” It was agreed that “susceptibility” may have some use, especially when discussing genetic predisposition and migraine threshold. “Sufferer,” which is a term to describe a person with migraine, not migraine itself, was not favored for frequent use. However, several panelists felt that the person with the migraine may use it to emphasize this feature of his or her own migraines. It may occasionally be used by another with the implicit agreement of the “person with migraine/migraineur.”

In round 4, panelists were asked to choose their single preferences to describe migraine for each of 12 vignettes (see Appendix S3) covering discussions about migraine in a variety of clinical and non-clinical situations, ranging from the extremes of severity and disability and encompassing a variety of clinical and

social situations (see Fig. 1). Subjects were also asked to indicate whether each term was acceptable or unacceptable for each vignette. Selections varied according to the clinical situation.

Across a broad range of situations, “disease” was the most favored term. “Condition” was the second common choice. “Syndrome” and “illness” were favored in the fewest cases. Panelists found that certain terms were unacceptable for use in various situations (Fig. 2). “Condition” was the least likely term to be unacceptable, and “susceptibility” was the most unacceptable across the 12 scenarios.

Qualitative Analysis.—Panelists were asked to provide explanations for their language choices. Although the panel was not able to arrive at a definitive consensus about which word or words should be used to describe migraine, there was consistency regarding the rationale used to choose terminology. Panelists drew upon 3 principles in their decision making: first, did *biomedical evidence* support their choice of terminology? Second, did their terminology choice communicate an appropriate *cultural meaning*? And third, would the terminology choice make sense in the *context* in which it was to be used? We describe these principles below.

Biomedical Evidence.—The first task for panelists was to determine whether migraine is an “illness,” “disease,” “condition,” “syndrome,” “disorder,” or “susceptibility.” This question elicited 2 related debates. The first debate invoked *validity*, and centered on the question of whether enough biomedical evidence exists to call migraine a “disease.” The second

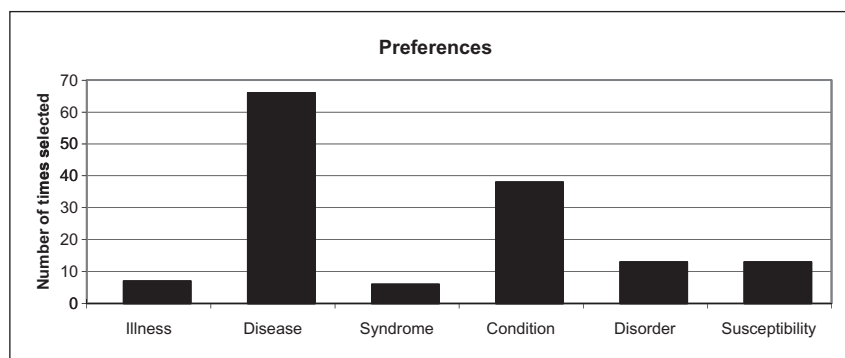


Fig 1.—Preferences of 13 respondents among terms to describe migraine in 12 vignettes encompassing a variety of social and clinical situations. Participants needed to choose 1 single preference for each vignette. Overall, disease was the most preferred term, and syndrome the least.

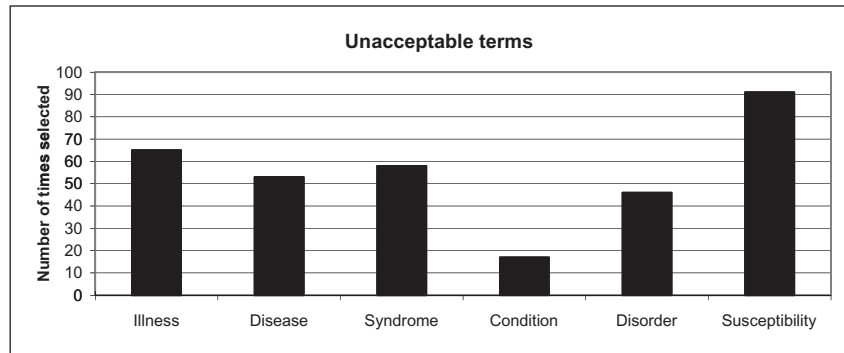


Fig 2.—Tabulation of unacceptable word choices for 13 respondents characterizing terms to describe migraine in 12 vignettes relating to a variety of social and clinical situations. Condition was found to be unacceptable in the fewest circumstances, and susceptibility the most.

debate invoked *variability*, as panelists wondered whether any single term could accurately describe the varied manifestations of head pain that fall under the International Classification of Headache Disorders criteria. While these debates featured prominently in physicians' deliberations, patients, advocates, and non-medically trained academics on the panel tended to remain uncommitted on this question.

Panelists who worried about the validity of their chosen term tended to prefer ambiguous language, like “condition” or “disorder,” to “disease.” Panelist D, a researcher, explained, “The one term I don’t like, after more reflection, is “disease,” since that term implies more understanding of migraine than we currently have.” Other panelists argued that none of these terms truly describe the biological underpinning of migraine. For example, panelist B, a physician, argued that migraine is best understood as “. . . a genetically unique nervous system configuration . . . I think migraine is a genetic susceptibility with the potential to develop into a chronic disease.”

This notion of “susceptibility” prevented many panelists from endorsing the wholesale adoption of the disease moniker. First, they were challenged to find a term that described the variability of symptoms across the population of people diagnosed with migraine. For example, panelist A favored “condition,” “because it seems to encompass the variability among people with migraine.” Panelist I, an academic, agreed that “condition” was most descriptive since:

Migraine is not a single thing, so . . . there may be no single term that will be suitable in every case.

Discrete episodes of migraine, one or two a month or a year, might constitute a disease with flares or attacks (on the model of epilepsy). Very frequent migraines, including migraines now referred to as chronic daily headache, are . . . more like a migraine “condition” . . . One might, for that reason, want, with a range of names, to suggest the different ways in which migraine may, for example, interfere with work.

Others resisted calling migraine a “disease” because of new arguments that a migrainous nervous system may convey evolutionary advantages. If that were the case, use of the term “disease” seemed to risk pathologizing an otherwise advantageous phenotype. Most panelists thought that these problems might be surmounted if migraine symptoms were made to pass a threshold of severity before they could be known as a “disease.” However, panelists also resoundingly agreed that it would be impractical, as well as politically unwise, to recommend (or endorse?) such a threshold on language use. The final majority opinion seemed to be that the term “condition” best captured the biological underpinnings of migraine in all of its manifestations.

Cultural Meaning.—Panelists were eager to choose language that might elevate the status of migraine, while avoiding any terms that might undermine this goal or, worse, further stigmatize those who have migraine. When considering the cultural meaning of migraine, panelists almost always preferred to describe migraine as a “disease,” a choice that they argued was essential to building the *credibility* of

migraine. Many argued, as did panelist O (a patient), that “classification of a problem as a ‘disease’ is likely to be beneficial in calling attention to the problem, drawing spokespersons to serve as educators of the general public, and generating funds for research and treatment.”

At the same time, one panelist worried that it might undermine credibility to call migraine a “disease” if there was insufficient biomedical evidence to support such a claim. “I am trying to imagine, though, if [the term ‘disease’] can be used without having to give a long-winded and nuanced answer: a lawyer or senate committee directly asking the question – is this a ‘disease’, yes or no?” (participant F, editor).

Panelists also worried about the *connotation* of their language choices, and thought it was important not to choose language that could further stigmatize those who have migraine. The term “sufferer” was uniformly rejected, since suffering is a subjective state, analytically separable from symptoms, and because “sufferer” may suggest victimhood or submission. In addition, panelists agreed that any language used to describe migraine should not have psychiatric connotations. For example, panelists roundly rejected terms like “medication overuser” to describe a person with medication overuse headache, as it implied a moral culpability on the part of the patient with this diagnosis.

Context.—Panelists thought that context mattered in all of their language choices. Language might vary, they argued, depending on who the *speaker* and who the *audience* would be. For example, a medical doctor might describe migraine as a “susceptibility” when talking to a room full of peers, but choose something more accessible, like “condition,” when describing the same thing to a patient. A patient, on the other hand, might describe him- or herself as a “sufferer,” since this is a word that describes an emotional state, whereas “sufferer” was thought not to be appropriate for a medical journal.

Context became particularly important when thinking about issues of credibility and migraine, but this sometimes seemed like a difficult balance. For example, panelist A (physician) said, “When talking to medical audiences and trying to convince them of the

seriousness of migraine, I may use the word ‘disease,’ since that gives a problem credibility in doctors’ eyes.” But the same panelist thought ‘disease’ might sound too serious in a clinical setting: “I thought the doctor should refrain from using the term ‘disease’ in mild or early cases of migraine, since it might convey an overly negative or pessimistic view.”

DISCUSSION

Panelists represented varied constituencies from a range of pertinent disciplines in order to find common ground. The 3 patients represented various degrees of severity of illness, from severe chronic migraine to non-disabling episodic migraine, and were selected for their intellect and verbal skills. The panel was not designed to proportionally represent the interests of any constituencies or to speak for patients in particular. It would be of interest to obtain the opinions of a larger cross section of persons with migraine.

Although panelists were not able to agree on a single answer to the 2 principal questions raised, agreement was reached on several issues. “Migraine,” not migraine headache, is the preferred term unless the symptom of head pain is specifically singled out for discussion. There was general agreement that terms with psychiatric valence should be avoided, and the term “sufferer” should only be used in very limited circumstances, by the person who has the migraine, or with his or her tacit agreement.

We were able to identify both the terms preferred by the group and their principles for choosing language. “Disease” and “condition” were panel favorites, and their preference depended on validity, variability, credibility, connotation, speaker, and audience. In general, panelists preferred “disease” when concerned about credibility, and “condition” when concerned about validity and variability.

In the end, panelists agreed that the great variability in the symptoms and impact of migraine required some elasticity in language. Having a broad vocabulary to describe migraine is useful for a condition so variable in its symptoms and with such multidimensional effects. Thus, no panelists favored censoring any language choices, and sometimes actually resurrected

unpopular terms because they could always see the potential for that term to be useful in some context.

Throughout the process, the group remained passionately and approximately equally divided on the choice between “migraineur” and “person with migraine.” “Migraineur” was considered by many to confuse the identity of the individual with the disease, and to be confusing or unfamiliar to many audiences. On the other hand, the phrase “person with migraine” seemed neutral and appropriate to some but cumbersome and too politically correct to others.

Language exercises can lead to thoughtful changes in the way we use language in addition to describing the reasons we make certain word choices now. These discussions can inform us about how others may interpret our use of a particular word. This exercise could lead to substantial changes in the words we choose to describe migraine.

Our discussion might seem to be an exercise in political correctness. We believe, however, that decisions about how a condition is named should be made after open academic discussion, rather than directed only by unseen economically interested parties without input from diverse points of view. The choice of panelists may be arbitrary but it did represent a varied group of individuals with a stake in the discussion’s outcome, most of whom had extraordinary personal or professional familiarity with migraine and all of whom were judged capable of representing a constituency with eloquence. The English language usually changes on an informal, community-wide basis; take for example the evolution of word choice from Negro to African American. Occasionally, word choices are directed by interested parties with financial or other stakes, such as the pharmaceutical industry in its promotion of the term erectile dysfunction. We believe that language choices matter and that open, thoughtful discussion by concerned persons is the best way to help individuals make better word choices.

We hope that interested parties will continue the discussion we have begun. Professional groups, advocacy organizations, and journal editors may wish to consider more deliberately the language they use to describe migraine.

As migraine can be so variable in its symptoms and impact, the most appropriate term can vary

based upon the audience and the purpose of the speaker. For this reason, we suggest that future researchers use detailed, specific vignettes to appropriately focus their discussions.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Appendix S1.—The “specific asks” for each iteration.

Appendix S2.—Dictionary definitions used in round 2.

Appendix S3.—Ratings of terms in vignettes.

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