Migraine Diagnosis and Treatment: Results From the American Migraine Study II

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Objective.—A population-based survey was conducted in 1999 to describe the patterns of migraine diagnosis and medication use in a representative sample of the US population and to compare results with a methodologically identical study conducted 10 years earlier.

Methods.—A survey mailed to a panel of 20 000 US households identified 3577 individuals with severe headache meeting a case definition for migraine based on the International Headache Society (IHS) criteria. Those with severe headache answered questions regarding physician diagnosis and use of medications for headache as well as headache-related disability.

Results.—A physician diagnosis of migraine was reported by 48% of survey participants who met IHS criteria for migraine in 1999, compared with 38% in 1989. A total of 41% of IHS-defined migraineurs used prescription drugs for headaches in 1999, compared with 37% in 1989. The proportion of IHS-defined migraineurs using only over-the-counter medications to treat their headaches was 57% in 1999, compared with 59% in 1989. In 1999, 37% of diagnosed and 21% of undiagnosed migraineurs reported 1 to 2 days of activity restriction per episode ($P<.001$); 38% of diagnosed and 24% of undiagnosed migraineurs missed at least 1 day of work or school in the previous 3 months ($P<.001$); 57% of diagnosed and 45% of undiagnosed migraineurs experienced at least a 50% reduction in work/school productivity ($P<.001$).

Conclusions.— Diagnosis of migraine has increased over the past decade. Nonetheless, approximately half of migraineurs remain undiagnosed, and the increased rates of diagnosis of migraine have been accompanied by only a modest increase in the proportion using prescription medicines. Migraine continues to cause significant disability whether or not there has been a physician diagnosis. Given the availability of effective treatments, public health initiatives to improve patterns of care are warranted.

Key words: migraine, headache, diagnosis, American Migraine Study

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Migraine is a common and often debilitating condition that affects 28 million Americans, approximately 18% of women and 6% of men in the United States.[1,2] Migraine is a major cause of absenteeism from and decreased productivity at work and demonstrably reduces health-related quality of life.[3-6] The condition costs American employers approximately $13 billion per year.[7]

Despite its pervasiveness and association with significant disability, migraine has historically been underrecognized and undertreated. In the American Migraine Study conducted in 1989, only 16% of migraineurs identified by questionnaire had consulted a physician for headache in the previous year, and only

38% reported having ever been diagnosed with migraine by a physician.[8-10] Although 96% of migraineurs used medications for their headaches, most (59%) used only over-the-counter rather than prescription medicines (37%).[11] Migraineurs without a physician diagnosis of migraine experienced substantial pain and disability, indicating that they had a significant health problem.[12]

Beginning with sumatriptan in 1993, the introduction of the triptans provided an important opportunity for improved headache management.[13] Educational efforts directed at health care professionals and individuals with headache were started to raise awareness of the clinical manifestations and burden of migraine as well as the availability of effective treatments. In the context of these developments, the patterns of health care use for migraines may have changed since 1989.

We conducted a national survey in the United States to describe the patterns of migraine diagnosis and treatment in 1999, a decade after an identical survey was conducted in the United States. This article describes data on patterns of migraine diagnosis and treatment collected in 1999 in the American Migraine Study II.[2] These results are compared with those of the 1989 American Migraine Study to identify changing patterns of diagnosis and treatment.[1,8-12]

METHODS

The methodology for this study has been previously described.[1,2,11,12] In 1999, a self-administered headache questionnaire was mailed to a stratified random sample of 20000 households. Screening questions were completed by the head of the household, who reported the number of household members and the number of household members suffering from self-defined severe headache. Each household member with severe headache was asked to complete a headache survey.

Sample.—The study targeted 20000 households drawn from a nationwide panel recruited and maintained by National Family Opinion, Inc (NFO; Toledo, Ohio). Each block was constructed to be representative of the US population in terms of regional population density, age of the head of the household, household income, and number of household members. Households were recruited by mailed questionnaires, which elicited household census and demographic information. Additional information about the sample has been published elsewhere.[2]

Survey.—The headache survey contained eight questions on symptoms, frequency, and severity of headaches; headache-related disability; use of medications for headache; diagnosis status; and headache-related health care utilization. The questions were formatted as multiple-choice or fill-in-the-blank.[2]

Case Definition.—Survey data on migraine symptoms were used to determine whether respondents met diagnostic criteria for migraine. Migraine criteria based on those of the International Headache Society (IHS)[14] were considered met if a respondent reported at least one severe headache in the previous 12 months with unilateral or pulsatile pain and either nausea, vomiting, or phonophobia with photophobia; or visual or sensory aura before the headache with headache-free intervals (daily headache excluded). As discussed elsewhere,[1,2] these criteria differ slightly from those of the IHS, which specifies an attack duration (4 to 72 hours for an untreated attack) and a lifetime number of attacks (at least 5),[14] but have demonstrated sensitivity (100%) and specificity (82.3%) in a validation study among a population sample of clinically diagnosed migraineurs (n = 112) and controls with tension-type and other types of headache (n = 62) (R.B.L., data on file). Respondents with daily severe headache were not categorized as migraine because migraine is an episodic disorder.

Self-reported Physician Diagnosis.—In addition to IHS-defined migraine status, self-reported physician diagnosis was ascertained. Participants were considered to have received a physician diagnosis of migraine if they responded affirmatively to the question, "Have you ever been diagnosed by a physician as suffering from migraine?" The same question was asked regarding physician diagnosis of tension-type headache, sinus headache, cluster headache, and "sick" headache. Individuals were assigned to self-reported categories of physician diagnosis based solely on their reported diagnosis and whether or not they met IHS criteria. Respondents who met IHS criteria for migraine but who did not report a physician diagnosis

Demographic and Headache Characteristics by Self-reported Physician Diagnosis of Migraine*

Characteristic	Physician Diagnosis of Migraine (n = 1750)†	No Physician Diagnosis of Migraine (n = 1878)†	P‡
Sex			
Female	79.4	71.7	<.001
Male	20.6	28.3	
Age, y			
12-17	4.4	5.4	<.05
18-29	12.8	19.8	
30-39	25	26.8	
40-49	28	25.4	
50-59	19	14.3	
≥60	10.8	8.2	
Household Income			
<$15000	18.9	19.8	<.001
$15000-$29999	15.9	22.3	
$30000-$49999	23.3	22.9	
$50000-$74999	22	18.6	
≥$75000	20	16.4	
Symptoms			
Nausea	80.6	67.7	<.001
Vomiting	40.7	18.8	<.001
Unilateral pain	66	57	<.001
Pulsatile pain	88.4	88.5	NS
Photophobia	89.4	72.3	<.001
Phonophobia	82.2	71.8	<.001
Blurred vision	54.8	32.7	<.001
Aura	44.6	24.1	<.001
Neurological signs	14.2	7.1	<.001
Severity of head pain			
Extremely severe	45.9	21.8	<.001
Severe	43.8	50.3	
Moderately severe	9.7	26.1	
Mild	0.6	1.7	
Frequency of severe headache			
Daily	0	0	NS
2-6 per week	14.9	13.9	
1 per week	10.6	11	
1-3 per month	35	38.3	
1-12 per year	39.4	36.8	
Highest level of impact			
Function normally	4.3	11.8	<.001
Some impairment	30.4	45.2	
Severe impairment	14.3	12.3	
Bed rest	50.4	28	
Duration of activity restriction, d			
0	10.5	26.8	<.001
<1	47.2	50	
1-2	37.2	21	
3-5	4.1	1.6	
≥6	1	0.5	
Missed at least 1 day in the previous 3 months			
Work or school	38.2	24.4	<.001
Household work	80.1	71.3	<.001
Family or social activity	64.9	53	<.001
Productivity reduced by at least 50%			
Work or school	57.6	45.1	<.001
Household work	71.7	62.4	<.001

*Values are percentage of respondents.
†Symptom data were used to identify International Headache Society-defined migraine cases to yield a sample of 3738. Of these subjects, 1750 reported a physician diagnosis of migraine, 1878 reported no diagnosis, and 110 had missing data.
‡By *t* test or χ^2.

were defined as having undiagnosed migraine. To estimate the time to diagnosis among those with a diagnosis of migraine, respondents were asked to provide the age at which they began having severe headaches and the age at which they were first diagnosed with migraine. The strengths and limitations of using self-reported physician diagnosis as a measure of physician diagnosis are explored in the "Comments" section.

Medication Use.—Medication use practices were determined by the response to the question, "Which best describes the way you usually treat very severe headaches?" Options included: (1) nonprescription medications, (2) prescription medications, (3) both prescription and nonprescription medications, and (4) no medications. Those responding affirmatively to options 2 or 3 were classified as using prescription medicines, those responding affirmatively to option 1 were classified as using over-the-counter medicines only, and those responding affirmatively to option 4 were classified as using no medication.

Migraine Impact.—Measures of headache impact included headache symptoms, severity, and frequency; impact on functioning; duration of activity restriction; missed days of school, work, or household work because of headaches; and 50% or greater reduction in work/school or household productivity because of headaches. Response categories for these variables are listed in the Table.

Analysis.—Subjects younger than 12 years were excluded because of concerns regarding their ability to interpret and reliably respond to questions. Symptom data were used to identify migraineurs using the IHS-based definition described above. These subjects were divided into those who reported and those who denied having received a physician diagnosis of migraine.

Linear regression analysis was used to model gender-based prevalence estimates and to adjust diagnosis data for age, race, income, geographic region, and urbanization.[1,2]

Diagnosis rate and medication usage patterns were examined for 1989 versus 1999. Percentage distributions and cross-tabulations were examined for differences between migraineurs who were physician-diagnosed and those who were not.

RESULTS

Response Rate.—Of the 20000 households administered the survey, 34009 individuals in 13869 households responded to the questionnaire, for a 69.3% household return rate. Response rates did not differ by sex, region, regional population density, or household income but were inversely related to household size (from 59.2% for households of 5 or more members to 75.9% for one-member households), higher in whites (69.6%) than in blacks (59.2%), and higher in individuals at least aged 60 years (77.2%) than younger individuals (from 65.9% in 12- to 17-year-olds to 71.9% in 50- to 59-year-olds).

There were 29727 individuals 12 years and older in responding households; individuals with severe headache comprised 20.9% (n = 6211; 1940 males and 4271 females). There were 3738 individuals with headache (12.6%) who met the symptom-based IHS case definition for migraine (920 males and 2818 females).

Diagnosis of Migraine and Demographic Characteristics.—Approximately half (48%) of IHS-defined migraineurs (41% of males and 51% of females) reported a physician diagnosis of migraine (Figure 1). These proportions are higher than those estimated in the 1989 survey in which 38% of IHS-defined migraineurs (29% of males and 41% of females) reported a physician diagnosis[9,12] (Figure 1). Rates of diagnosis varied with certain sociodemographic characteristics (Table). Diagnosed migraineurs were more likely to be females than undiagnosed migraineurs (79.4% versus 71.7%, *P*<.001). Diagnosis was also associated with age (*P*<.05); older age groups were more likely to be diagnosed. Moreover, household income was associated with diagnosis (*P*<.001); those with incomes more than $50000 per year were more likely to be diagnosed.

Regardless of whether they had received a physician diagnosis of migraine, many migraineurs reported a physician diagnosis for other headache types. The proportions of physician-diagnosed and undiagnosed migraineurs reporting other headache types were 44% and 32.3% for tension-type headache, 43.1% and 42% for sinus headache, 17.9% and 6.5% for cluster headache, and 13.1% and 7.8% for "sick" headache, respectively.
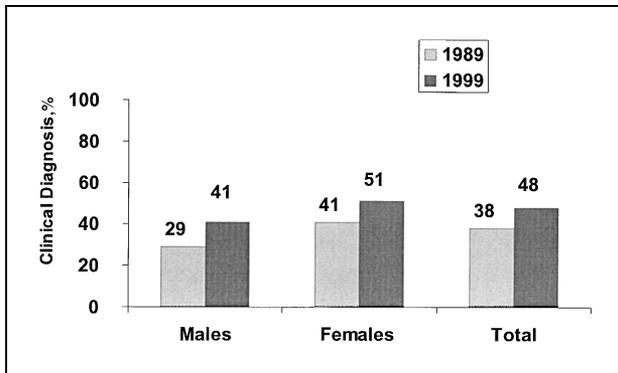
Fig 1.—Self-reported physician diagnosis of migraine among International Headache Society-defined migraineurs: 1989 and 1999.

Fig 2.—Patterns of medication use among International Headache Society-defined migraineurs from the 1989 and 1999 American Migraine Studies.

Medication Use.—A total of 41% of IHS-defined migraineurs used prescription drugs for headaches, a finding similar to that observed in the American Migraine Study in which 37% reported use of prescription drugs for headaches[11] (Figure 2). The proportion of IHS-defined migraineurs using only over-the-counter medications to treat their headaches was 57% in 1999, compared with 59% in 1989 (Figure 2). A very small subgroup used no medication at all.

Symptom Profile, Pain Intensity and Frequency, and Headache-Related Disability.—Migraineurs with a physician diagnosis of migraine were more likely than undiagnosed migraineurs to report symptoms of nausea (80.6% versus 67.7%), vomiting (40.7% versus 18.8%), unilateral pain (66% versus 57%), blurred vision (54.8% versus 32.7%), aura (44.6% versus 24.1%), and neurological signs (14.2% versus 7.1%; $P<.001$ for all symptoms). Photophobia (89.4% versus 72.3%, $P<.001$) and phonophobia (82.2% versus 71.8%, $P<.001$) were also more frequent in the physician-diagnosed group than in the undiagnosed group. Pulsatile pain occurred with equal frequency in the diagnosed group (88.4%) and the undiagnosed group (88.5%; NS).

Physician-diagnosed migraineurs were more likely to report extremely severe head pain (45.9% of diagnosed migraineurs; 21.8% of undiagnosed migraineurs; $P<.001$) and the need for bed rest during headaches (50.4% of diagnosed migraineurs; 28.0% of undiagnosed migraineurs) (Figure 3). Nonetheless, headaches were severe in both diagnosed and undiagnosed migraineurs. In the undiagnosed group, 72.1%
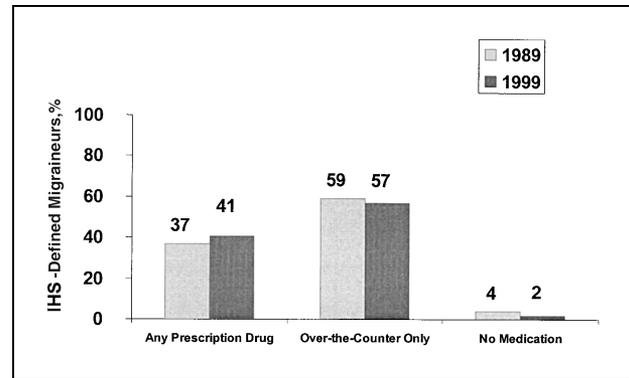
had severe or extremely severe pain and 85.5% experienced at least some activity limitations. The percentage of diagnosed migraineurs with 1 or more days of activity restriction per migraine was 42.3% versus 23.1% for undiagnosed migraineurs ($P<.001$). The corresponding numbers for missing at least 1 day of work or school in the previous 3 months were 38.2% and 24.4% ($P<.001$), and for at least a 50% reduction in work or school productivity, 57.6% and 45.1% ($P<.001$), respectively.

COMMENTS

The proportion of migraineurs who reported a physician diagnosis of migraine in the United States has increased over the last decade—from 38% of all individuals with migraine in 1989[9,12] to 48% in the present report. This increase in diagnosis reflects an improvement in migraine management in the United States. Nonetheless, more than half of the migraineurs meeting modified IHS criteria in this population-based sample reported that they had never received a diagnosis of migraine. This underrecognition of migraine constitutes a significant public health problem given the substantial disability migraine causes.[3-7]

A number of factors may explain why individuals with symptoms of migraine do not report a physician diagnosis. Migraineurs may not seek medical care for migraine; they may seek care but not receive a diagnosis; or they may be diagnosed but fail to remember a diagnosis. Lack of consultation for headache is a major contributing factor to underdiagnosis. A recent
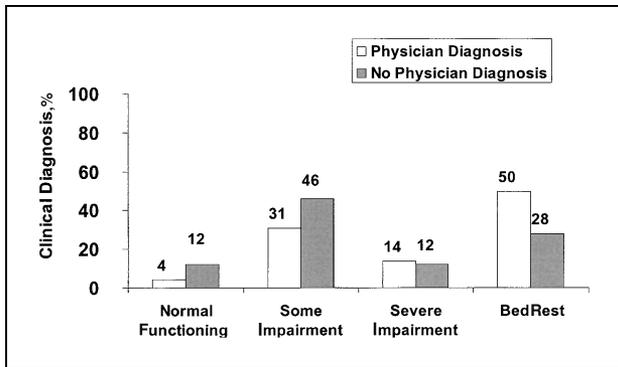
Fig 3.—Functional impact of migraine by self-reported physician diagnosis of migraine.

study found that current consultation rates for migraine have tripled from 16% in 1984 to 47% in 1999.[8,15] Thus, although consultation rates have risen, the majority of migraineurs have not seen a physician for headache preceding the study.

Among those who specifically consult for headache, poor patient-physician communication about migraine is most frequently cited as a barrier to appropriate care.[16-18] Diagnosis is complicated by the fact that physicians almost never see patients during a migraine and must rely on patients' retrospective descriptions of their prior symptoms. Furthermore, consultation lengths (which ranged from 5.7 minutes to 8.5 minutes in a recent study[19] of general practitioners) provide little opportunity for patients to communicate the information most important to physicians in diagnosing migraine and initiating appropriate treatment.[19] Additionally, in primary care settings the patient may have multiple complaints that the clinician must prioritize.

Sociodemographic characteristics were associated with self-reported physician diagnosis of migraine in this study: low income ($15 000 to $29 999), young age (18 to 29 years), and male gender were associated with a lower probability of being diagnosed. These trends, also observed in the 1989 American Migraine Study,[12] may reflect demographic differences in health care-seeking behavior (eg, higher income groups have better access to health care than lower income groups); in physician beliefs about the seriousness of disease (eg, diseases in older patients may be taken more seriously than those in younger

patients); and in likelihood of patient recall of a migraine diagnosis (eg, if older patients are more concerned about their health than younger patients they may be more likely to recall a migraine diagnosis than younger patients).

Clinical characteristics including severe disability as well as symptoms such as nausea, vomiting, and aura were also associated with physician diagnosis. Perhaps these features increase the probability of consultation. In addition, physicians may be more likely to diagnose migraine in patients with specific migraine features such as aura.

Substantial proportions of physician-diagnosed and undiagnosed migraineurs had also been diagnosed with other headache types, especially tension-type headache (44% of physician-diagnosed and 32.3% of undiagnosed migraineurs) and sinus headache (43.1% of physician-diagnosed and 42% of undiagnosed migraineurs). Many patients may suffer more than one headache type; migraine and tension-type headache frequently occur together. The prevalence of self-reported diagnosis of sinus headache was far greater in this study than in epidemiologic studies based on in-person medical assessment to assess its prevalence.[20] These high rates may reflect errors of overdiagnosis of sinus headache.

Patterns of prescription versus over-the-counter medication use for migraine have remained relatively stable over the last decade: 57% of migraineurs in 1999 used only over-the-counter medications, compared with 59% in 1989[11]; 37% and 41% of migraineurs in 1989[11] and 1999, respectively, used prescription medicines. Given the increase in consultation rate and the introduction of triptans during the 1990s, the changes in the rates of prescription medication use are surprisingly small. Of course, choice of prescription medications among those who receive them has changed dramatically.

According to the United States Headache Consortium, prescription medication is warranted for migraineurs with moderate or severe migraine.[21] Sixty-four percent of physician-diagnosed migraineurs and 41% of undiagnosed migraineurs reported experiencing severe impairment or needing bed rest during their most recent headaches. Productivity at work or school was reduced by at least 50% during a head-

ache in 57.6% of physician-diagnosed and 45.1% of undiagnosed migraineurs. Many migraineurs in both the diagnosed and undiagnosed group have unmet treatment needs; and many continue to experience substantial disability, which should be a target for effective treatment.[21] Diagnosis of those with moderate to severe disability so that these impaired patients can receive appropriate treatment is a benchmark of improvement in migraine management from a public health perspective.

The data from this study should be considered in the context of its limitations. First, individuals not suffering from migraine may have been incorrectly assigned a diagnosis of migraine based on the application of diagnostic criteria to questionnaire responses. If migraine overdiagnosis was substantial, migraine prevalence estimates as well as age, sex, and disability profiles of this study population would be expected to differ from those from other studies using more rigorous methods. The similarity of American Migraine Study II results to those of other studies using different methods[22] suggests that overdiagnosis is unlikely to be a major factor.

Second, selection bias, whereby individuals with a physician diagnosis of migraine may have been more likely than undiagnosed migraineurs to respond to the survey, might have led to an overestimation of the values for some study parameters (such as the proportion of migraineurs who have ever consulted physicians). The degree to which such selection bias operated was explored in the American Migraine Study.[8] Selection bias was found not to have led to overestimations of study parameter values or to have affected relationships among values in that study.

In summary, the results of the American Migraine Study II demonstrate that diagnosis of migraine has increased over the past decade. Despite this increase, approximately half of migraineurs in the United States remain undiagnosed. Furthermore, the increases in consultation and diagnosis of migraine have not been accompanied by increased use of prescription medicines for migraine management. Migraine continues to cause significant debilitation in sufferers, whether or not they are diagnosed by a physician. As in 1989, migraine in 1999 remains an underdiagnosed condition that produces substantial disability. These data underscore the need for health care professionals to renew their commitment to recognizing and effectively managing this important health problem.

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