This section will review the epidemiology of headache, with a specific emphasis on migraine. Standard definitions that will appear in this module include:

**Prevalence:** The actual number of existing cases of a disease that appear in a given population at a specific time.

**Incidence:** The number of new cases of a disease that appear in a given population, over a period of time.

**Odds ratio:**

Epidemiology and Impact of Headache

Objectives

- Review the epidemiology of headache, especially migraine
- Discuss the burden of migraine in the United States
- Identify patterns of treatment
- Propose methods for resolving barriers to care
Migraine is common, disabling, and important to physicians.

The burden of migraine is greatest for the most severely affected sufferers.

Despite improvements, migraine remains underdiagnosed and undertreated.

Resolving barriers to care requires several interventions.

Although most migraine patients receive their treatment in the primary care setting, headache nonetheless remains a significant component of the neurologist’s practice. Migraine pain and suffering represents a substantial personal and social burden worldwide, and those individuals with the greatest disability from their migraines incur and create the greatest associated costs.

Although migraine diagnosis and treatment has made substantial gains in the last decade, the disease continues to be underdiagnosed and undertreated.

The issues surrounding this care gap are multifaceted and require improvements in several areas.
There are currently 28 million migraine sufferers age 12+ in the United States

- 21 million female
- 7 million male

Nearly 1 in 4 households has at least 1 migraine sufferer

Migraine prevalence peaks between the ages of 25–55


The American Migraine Study II, a follow-on study of the first American Migraine Study in 1989, was conducted in 1999 with the objective of describing the prevalence, sociodemographic profile, and burden of migraine in the United States and of comparing these results with the first study.

A validated, self-administered questionnaire was sent to 20,000 households to identify IHS criteria-based migraine sufferers 12 years of age or older. Of 43,527 age-eligible individuals, 29,727 responded to the questionnaire, for a 68.3% response rate.

Twenty-three percent of respondent households had at least one member with migraine. The 1-year prevalence of migraine in the United States is 13%. Consistent with other studies, the 1-year prevalence is 18.2% in female patients and 6.5% in male patients. Prevalence is highest in the 25–55 age group.

The study did not find an increase in migraine prevalence or incidence that has been suggested by other studies. The 4 million sufferer increase from the 1989 survey is consistent with population increase. There may be an increase in disease awareness.

This is a population-based study looking at the prevalence of primary and secondary headache disorders with the most common being tension-type headache with a prevalence of 78%. From this study, it is clear that migraine is also very common with a prevalence of 16% of the population surveyed. Among secondary headaches, the most common cause is attributable to fasting. Nasal- and sinus-related headaches, and head trauma are less common. Many fear that headaches are caused by intracranial disease such as tumors, however, this actually occurs in a very small percent of the population (0.5%).

This slide summarizes the 1-year prevalence of some common primary headache disorders. By far, the most common headache disorder in the general population is episodic tension-type headache, which affects 40% of the population. These are the bilateral, pressing or squeezing headaches of everyday life that do not have many accompanying features. Migraine also is a common primary headache disorder, affecting 18% of women and 6% of men.

Chronic daily headaches occur ≥15 days per month and affect 5% of women and 2.8% of men. The two most common headaches are chronic tension-type headache and transformed/chronic migraine, which will be discussed within the context of chronic daily headache.


Headache is clearly an important problem for neurologists. Summary data based on audits of outpatient visits to neurologists in the United States (this is recent data from IMS, an organization that collects health care data in the United States and around the world) indicate that migraine and headache are the leading reasons for outpatient visits to neurologists in the United States. These conditions account for about 20% of all outpatient visits.

Epilepsy and other seizure types come in as a close second at 17%. Migraine and headache are much more common than neurologic problems, such as Alzheimer’s disease and Parkinson’s disease.

IMS Audit, January 1999 [Note: IMS is a market research company that audits physician visits in representative samples to identify reasons for visits and patterns of treatment.]
Migraine is more common than many other chronic, disabling conditions. Its prevalence equals that of asthma and diabetes combined.

- Rheumatoid arthritis affects 2.1 million Americans, mostly women.
- Asthma affects an estimated 14.6 million American adults, has an overall lifetime prevalence of 10.5%, and affects women more than men.
- Diabetes affects 17 million Americans, or 6.2% of the population.
- Osteoarthritis affects 20.7 million Americans and women more than men.
- Severe migraine affects 27.9 million Americans with a female to male ratio of 3 to 1.

http://www.cdc.gov/nedss
http://www.arthritis.org
http://www.census.gov

Although the unique clinical features of cluster headache (CH) have been recognized since the 17th century, the striking periodicity was not articulated until the 1940s. The term “cluster headache” was coined in the 1950s, and since then the International Headache Society (IHS) has identified and classified two major temporal patterns of CH (1). The episodic type (ECH), by far the most common (90%), is characterized by discrete attack and remission phases. The chronic type (CCH) is defined by attacks that occur daily for more than one year without remission or with remission periods lasting less than 14 days.

Cluster headache is rare (about 0.4% of the general population), and it predominates in males, although recent studies indicate that the rate in females is rising (2). Onset can occur at any age but usually begins between 30 and 50 years of age (3).

In contrast to migraine headache, genetics in cluster headache is not thought to be important, although recent studies have shown a positive family history in about 7% of patients with cluster headache. When compared with prevalence of CH in the general population, first-degree relatives have about a 14-fold increased risk of developing CH. Furthermore, in one study, five sets of monozygotic twins were 100% concordant for CH (4).

A number of related short-lasting headaches, referred to as “cluster variants,” may be confused with cluster headache. These less common variants include chronic and episodic paroxysmal hemicranias and short-lasting unilateral neuralgiform with conjunctival injection and tearing (or SUNCT). Cluster variants have a number of distinguishing features that have therapeutic implications and are important to recognize. These related syndromes will be reviewed later in this presentation.

This study was designed to evaluate the validity and reliability of a short, self-administered migraine screening questionnaire in patients with headache complaints who seek medical care for their headaches in a primary care setting. Overall, 563 patients attending primary care offices for routine appointments and who also reported headaches in the past 3 months completed a self-administered migraine screener. All patients were referred for a second evaluation to a headache expert, where they received a specific migraine diagnosis. Four-hundred and fifty one (80%) participants completed the full evaluation.

In this study, migraine was significantly more common in primary care offices that what was previously reported in the general population. This study suggests that patients with tension-type headache do not seek medical treatment for their headaches, whereas, migraine patients do.

Although the prevalence of tension-type headache appears to vary across different countries, the prevalence of migraine appears relatively consistent ranging between 3 and 11%. Methodological issues make across-study comparisons difficult as the prevalence of migraine changes with age, and therefore, these rates are all dependent upon the age of the child and the gender.

<table>
<thead>
<tr>
<th>Author</th>
<th>Sample size</th>
<th>Age (years)</th>
<th>Headache Prevalence</th>
<th>Migraine Prevalence</th>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Males</td>
<td>Females</td>
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<tr>
<td><strong>Bille Sweden/1962</strong></td>
<td>8,993</td>
<td>5-15</td>
<td>10.6</td>
<td></td>
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<tr>
<td><strong>Linet USA/1984</strong></td>
<td>10,132</td>
<td>12-29</td>
<td>90</td>
<td>95</td>
</tr>
<tr>
<td><strong>Mortimer UK/1992</strong></td>
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<td>3-11</td>
<td>40.6</td>
<td>36.9</td>
</tr>
<tr>
<td><strong>Raieli Italy/1995</strong></td>
<td>1,445</td>
<td>11-14</td>
<td>19.9</td>
<td>28.0</td>
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<td><strong>Sillanpaa Finland/1976-83</strong></td>
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<td>3</td>
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<tr>
<td></td>
<td>3,784</td>
<td>7</td>
<td>79.8</td>
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</table>

In both males and females, the prevalence distribution of migraine is an inverted U-shaped curve. Prevalence rises through early adult life and then falls after midlife. The second important point to emphasize is that, at all postpubertal ages, migraine is substantially more common in women than in men.

The prevalence of migraine varies as a function of age. Migraine is a disorder that is most prevalent between the ages of 25 and 55. Part of the reason the condition has such a big impact in the workplace is that it affects people during their peak productive years.

At prepubertal ages, the rate of onset for migraine is actually a little bit higher in boys than in girls, but at all postpubertal ages, the incidence is higher in girls than in boys. The incidence of migraines without aura peaks around age 12 in boys and age 15 in girls. Although half of all migraine onsets begin before the age of 20, migraine can begin at age 1.


When contemplating the burden of migraine, it is useful to distinguish individual burden and societal burden. Individual burden is determined by symptoms during attacks, by anticipation of symptoms between attacks, by the reduced quality of life in people who suffer with migraine compared with the general population, and in lost economic opportunity. The evidence shows that migraine reduces family, social, and recreational activities.

Traditionally, assessment of societal burden is expressed in economic terms by distinguishing between direct costs and indirect costs. Direct costs refer primarily to the cost of medical care. Indirect costs refer primarily to the impact the illness has on work and on function in other domains. For work, it is useful to distinguish absenteeism from reduced effectiveness.

With regard to indirect costs, which are the primary costs of migraine, individuals with migraine from the general population required on average 3.8 days of bed rest for men and 5.6 days of bed rest for women per year. Projecting to the US population, migraine causes a total of 112 million bedridden days per year. Migraine costs American employers about $13 billion per year because of missed work and also reduced function while at work. Patients between the ages of 30 and 49 inurred the greatest indirect costs relative to younger and older workers, which is not surprising given the epidemiologic profile of the disease.

It is important to recognize that the distribution of the burden of migraine is not uniform across the population of migraine sufferers. Individuals who miss the equivalent of 6 or more days of work per year account for most of the reported work lost due to migraine. Fifty-one percent of women miss the equivalent of 6 or more days of work per year due to migraine, which accounts for 93% of all work lost due to migraine. Thirty-eight percent of men lose that same amount of time (6 days), accounting for 85% of work loss because of migraine.

There is a compression of disability where the most disabled segments of migraine sufferers account for most of the work loss. These most disabled individuals are good targets for intervention because, by effectively and aggressively treating these individuals, one is likely to reduce the burden of migraine at work.


For many patients, migraine has a significant adverse impact on patient’s daily lives. This can be measured using time missed from routine activities including work,

Lack of consultation for headache is a major contributing factor to underdiagnosis.

_Never consulters_ have never seen a doctor specifically for headache. In 1989 and in 1999, this group accounted for about one third of migraine sufferers. 

_Lapsed consulters_ have seen a doctor for headache at some point in the past but not within the last year. The lapsed consulter group has decreased from 50% to 21% of all migraine sufferers.

_Current consulters_ have seen a doctor for headache in the last year. By 1999, the proportion had tripled to 47%.

These changes in consultation patterns are not fully reflected in patterns of diagnosis and treatment. These data are very much the sort that can be looked at from the perspective of, “Is the glass half empty or is the glass half full?” Clearly, the increase in the number of migraine sufferers who are currently seeking care (47% in 1999) is encouraging. On the other hand, more than half of migraine sufferers are not seeking care (21% of the lapsed and 32% of the never consulters), and not everyone who does consult his or her doctor gets a specific diagnosis of migraine or receives specific therapy.


Of the migraine sufferers who consult a doctor, about two thirds consult primary care physicians, which includes general practitioners, family practitioners, internists, and pediatricians; 16% consult neurologists or headache specialists.

Each iceberg represents the migraine sufferers in the US—23 million people in 1989 and 28 million in 1999. Those above the water line represent the medically diagnosed migraine sufferers. Those below the water line represent the migraine sufferers who never receive a diagnosis. In 1989, only 38% of IHS migraine sufferers, who were identified by direct questionnaires, had received a medical diagnosis. In 1999, the good news is that the migraine iceberg has risen. The proportion of medically diagnosed migraine sufferers has increased to 48%. The bad news is that the majority of migraine sufferers remain below the water line without a diagnosis (1,2).

Many people who suffer with severe headache continue to receive care on an episodic basis in emergency departments. In 1999, there were 102.7 million emergency department visits. Of these, 2.8 million of them were for headache, representing nearly 3% of all emergency department visits for the period (3). Despite the availability of cost-effective migraine-specific agents like DHE and the triptans, most headache sufferers diagnosed with migraine in the emergency department received IV opioids and an antiemetic as their only treatment (4).

In another survey, migraine sufferers in the United States were asked how satisfied they were with the usual acute treatment. Only 29% of migraine sufferers in 1998 said that they were very satisfied with their usual acute treatments. When asked why they were less than completely satisfied, they said the following:

- Pain relief takes too long
- Pain relief is incomplete
- The pain does not go away completely
- The medication doesn’t always work (meaning that it works for one attack, but not others)
- The pain goes away and comes back (a phenomenon called headache recurrence)
- Medications produce too many side effects

It is interesting to note that dissatisfaction with efficacy was much more important than dissatisfaction with side effects for the majority of migraine sufferers.

In considering the group of migraine sufferers in need of medical care, the first question is: Are they consulting a physician, and are they seeking medical care for their headaches? If not, patients need to be motivated to seek medical care specifically for their headaches.

If they are consulting, the next question is: Did the patient receive a specific medical diagnosis? If there has been no diagnosis, the need is to improve medical diagnosis.

If the patient is consulting and has been diagnosed, the next question is: Are they being appropriately treated? If not, therapy will need to be improved.

If patients are being appropriately treated, the next question is: Are they receiving regular assessment of headache control to ensure their needs are being met? If not, routine follow-up and assessment need to be established.

If ongoing assessment occurs, this can be defined as a “good headache outcome”—a patient in need of medical care who has consulted, been diagnosed, received appropriate treatment, and receives ongoing monitoring to make sure that the treatment benefits continue. “Good outcome” is defined during a dialogue between the doctor and patient. In general, good outcomes includes: a good feeling of illness control; management of attacks with effective acute treatments that rapidly relieves pain and restores ability to function; reduction or stabilization of frequency— which should be ≤10 per month in order to minimize the risk of medication overuse; and achieve good tolerability with medications and overall treatment.

Headache progression in migraine is not common, but occurs in a small subgroup of patients. Epidemiological studies suggest that there are specific factors that might lead to progression in selected patients. Understanding the natural history of migraine progression as a clinical phenomenon will help better understand how to prevent it.
In a recent study by Scher and colleagues assessed factors that predicted CDH onset or remission in an adult population. Overall, there were 1134 potential cases who reported having 180+ headaches per year and 798 controls who reported 2 to 104 headaches per year. Patients were interviewed twice during an average of 11 months of follow-up.

The incidence of chronic daily headache and associated risk factors for chronic daily headache were evaluated in the control population, who had a headache frequency increase to 180+ per year (over the 2 to 104 headaches per year) during follow-up. At follow-up, 3% of the controls developed CDH and reported 180 or more headaches per year. This agrees with epidemiologic studies in the general population, whether in Spain or Greece or Taiwan or United States showing that about 3 to 5% of the patients go on to develop chronic daily headache.

Six percent went on to develop intermediate (105 to 179 headache days per year) CDH. The authors suggest that this is is a sign of progression. Ninety-one percent were stable and maintained a headache frequency between 2 to 104 headache days per year. So the vast majority of control patients remained stable and did not develop chronic daily headache, but clearly there was a significant number who did.

The results from this study report that CDH was more common in women, in whites, and in patients with less education. Other predictors included:

- obese
- previously married (divorced, widowed, separated),
- diagnosis of diabetes or arthritis

The found that body mass index was highly predictive for development of chronic daily headache as illustrated with an adjusted odds ratio of 5.28. Patients who were obese, with a body mass index of 30 or higher, were at least five times more likely to go on to develop chronic daily headache.

This curve illustrates the control patients who went on to develop intermediate headache and those controls who went on to develop chronic daily headache.

Patients who had more than 52 attacks per year, the incidence of chronic daily headache or intermediate headache went up significantly. In other words, for those patients who have one attack per week, that is predictive of those patients who are going to go on and develop chronic daily headache.

This is actually the first data to show that baseline headache frequency is an actual risk factor for CDH development. Frequency is a highly significant predictor of those patients who were destined to develop chronic daily headache.

The conclusions from this frequent headache epidemiology study is that the incidence of chronic daily headache is 3 per 100 person-years, meaning 3% of the general population will develop chronic daily headache over the next year.

Case control and cohort analyses have identified risk factors for CDH. There are risk factors that are not readily modifiable and there are risk factors that are readily modifiable.

We cannot modify inherited genetic predisposition for migraine, or being female, or education or social economic status, or a history of head injury.

But what we may be able to intervene on and modify is attack frequency, obesity, and medication overuse. We hope to find a way to modify response to stressful life events. Snoring is an interesting factor that needs further exploration.

As physicians these are factors that we ought to be looking for in our patients with chronic daily headache because modifying them may prevent development of chronic daily headache. They also may be risk factors that, if modified, may increase the remission rate of CDH, reverting to episodic headache.

OVERALL CONCLUSIONS

Migraine is:
- common
- disabling
- underdiagnosed and undertreated

Improvements needed in:
- consultation
- treatment
- follow-up
- diagnosis
- outcomes


In summary, migraine is a highly disabling disease that affects roughly 18% of women and 6% of men in the US. Prevalence is highest during the peak productivity years between the ages of 25 and 55. It represents a large part of the neurologist’s practice.

Progress has occurred over the last decade in the proportion of migraine sufferers who seek care and in the proportion of migraine sufferers who have received a diagnosis and have been treated with prescription drugs. The majority of individuals suffering from migraine still do not receive a physician diagnosis nor receive migraine-specific agents. The bottom line remains that better diagnosis and treatment are needed.


