

# The Romance Of Headache Statistics

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## Abstract

In my office, headache higher math begins with the patient who suffers four headaches a week lasting three days apiece. Even after being out of math for some years, I still recall my lower times tables and recognize these kinds of inconsistencies.

In the literature, it has become fashionable to employ much higher numbers (greater than my number of fingers and toes) in the pursuit of truth. In the NFO study, Migraine in America, they sent out 30,000 questionnaires and interviewed 1184 patients. Dr. James Adelman interviewed 1307 patients in his research. Lipton reviewed 25 large studies in his paper including thousands of headache sufferers.

The total number of migraineurs appears to fluctuate with the tides. There were 21 million in the Migraine in America study, 24 million in Stewart and Lipton's study, 20-25 million in Zeneca data, and 40 million in Taking control of Your Headaches. By any calculation, the population of some European nations.

In all of this work, we begin to develop a global sense of the problem- the social significance and economic burden. That is naturally of great interest to the pharmaceutical industry and to those of us who lecture excessively and need to incorporate some preliminary remarks to knock everybody off their seats. Numbers like millions and billions are always best.

Personal statistics, taking the problem down to the individual, are really more interesting than millions and billions however.

Stang and Osterhaus would say one in ten of us have migraine and that the average migraineur loses 2.2 days a month totally or suffers with some significant headache and loss of productivity 5.8 days a month (5). Thus, at any moment, the probability that any person in America

photographed by a Russian satellite would be suffering some kind of migraine would be  $.10 \times .16 = .016$ . If they could see the 'beds' of America, the probability might be about .008 we would find a migraineur there in agony. ( I thank Mrs. Showalter, my 6th grade teacher for the ability to do this calculation-14) If the satellite could focus in ONLY on midlife women, the probability would be much higher.(7)

Every headache specialist has their favorite statistics, designed to impress their audience.

Now that we've statistically identified the sufferer, we begin to characterize the poor soul. The under-diagnosis and under-treatment of severe headache patients is well recognized. No one disputes the female predominance of three to one in America, another male plot according to one of my feminist colleagues. In the Migraine in America study, just over half had been diagnosed with the migraine label by their doctor. Only one in five was currently seeing their doctor about headache, but 2/3 had seen a doctor for headache sometime in the past.

What's between the lines of those numbers? The patients described above apparently were seen by their doctors and often not diagnosed as migraine by their doctors. On the surface they were misdiagnosed and, therefore, not treated appropriately. In the real world, that means a midlife woman went to a primary care doctor (PCP's see 90% of the headache patients) and had a 10-15 minute visit. She may or may not have emphasized the significance of the problem or she may have tried to slip it in during a revisit for bronchitis, sinus infection or refill of BC pills. Or the migraine complaint could have been what we call a Zinger in our office, the mention of an EXTREMELY important topic as the patient in the hallway is departing. Later on, as the patient is describing her treatment, it all may not come out this way.

The implication to me is NOT that the PCP was necessarily

uninformed or insensitive. The fortunate 2% of headache people who see a headache specialist get a whole hour and aren't allowed to talk about bronchitis. In the headache specialist's office, a headache is not an add-on or a zinger. It's the whole show.

How are our migraineurs being treated? In the Migraine in America study, it is also noted that only one third of migraineurs are given prescription medications with 29% of these prescriptions being triptans. In the 1999 Health Conditions Survey, that latter number was 18% including Imitrex shots (13). To me, what is given out by the doctor depends on numerous variables including how loud the patient complained and exactly what they said. It is not infrequent for a patient to be given a prescription for the year which they will continue to use even if that medication is NOT particularly effective. The patient has to follow-up and say it all over again to get something else. In the real world of patient care, the wheels may turn very slowly. Adelman's study demonstrated that patient satisfaction with the doctor continued to improve with the number of visits. To me, that implies that with more visits, the doctor has had more chances to find the best treatment and spends more time with the patient. I've often asked patients WHY they continued to use a treatment that wasn't particularly effective. Sometimes they will say 'it takes the edge off' the pain or that it might work sometimes and not at other times.

James Adelman's recent study in Headache quarterly was particularly enlightening because it dissected into that population of undiagnosed and under-treated migraineurs further, getting beyond the cold statistics to the individual. In his study of 801 patients identified and interviewed out of a general database, he reached some interesting conclusions. He described patients as consulters (now seeing a doctor for the headache), lapsed patients (people who had seen a doctor but in the past one year have not done so) and non-consulters, people who had never seen a doctor for their headache. Their numbers were surprising: 45% were consulters; 32% were lapsed consulters; 23% were non-consulters. The implication of this being that only 23% had NEVER seen a doctor for their headache.

The 'lapsed' group is a particularly interesting one: people who have quit seeing or given up on their 'headache' doctor for whatever reason. In the Glaxo data (1999) it was noted that it takes an average of 3.5 years to find an effective treatment and the average sufferer has tried nearly 5 medications before finding an effective option. Most have gone to multiple doctors without success and only 50 % are

satisfied with their current doctor.

I must conclude these patients, trying ineffective drugs and trying different doctors, are part of that lapsed group. They are being counted in the middle of their pursuit of a better life. They are a cross section of misery. Adelman noted further that the lapsed group had only half the headaches of the current consulters, so that one of the reasons they finally said goodbye to their doctor and lapsed was that they 'weren't all that bad'. The ones who remained in the current treatment group were just too miserable to move on or give up.

With regard to the patient's impression of their diagnosis, in the current consulter group, 79% had identified their headache as migraine; in the lapsed consulters 80% identified their headache as migraine and in the non-consulters, 60% still called themselves migraine. In total, in Adelman's group of 801, 75% called themselves migraine. Where did the non-consulters get their diagnosis? Off the internet? From relatives? From Books? There's no way to know, but it is of interest that thinking of themselves in that light might lead them to pick up the phone and consult a headache specialist next week after that horrible menstrual headache. Those who imagine themselves as sinus headache patients would not do so.

Eventually, the statistics run out until the next set of 30,000 questionnaires are sent out bulk rate. Now we have to reach our own conclusions about our own populations.

Given all these latter facts, one might consider some other migraine subgroups based on their current status out there in the REAL World. Some of the variables (among many) which would identify these groups would be:

1. Currently diagnosed as migraine. Yes or no.
2. Currently being treated and followed for migraine. Yes or no or lapsed.
3. Currently self diagnosed as migraine? Yes or No. (if the patient doesn't buy the doctor's diagnosis, it makes no difference what she or he is called.)
4. Currently receiving any kind of effective treatment whether for the correct diagnosis or not. Yes or No (Some treatments work for more than one kind of headache. An occasional Percocet might help just about any kind of pain)
5. Currently in a circumstance or having an attitude

which will allow any kind of treatment. Yes or no.

6. Seriously impacted by other health issues which might influence or prevent treatment efforts. Yes or No.

The permutations of these variables are many. Create a few theoretical patients.

- A 32 year woman with a lifetime history of headaches she's always called sinus headaches. A single neurologist who she didn't particularly like called her a migraine person, which she didn't buy. She continued to see her PCP who gave her Vioxx and Vicodin which helped her 'sinus headaches, some of the time. The ENT doctor is trying to talk her into antral windows
- A 23 year old woman has had the diagnosis of migraine for her PCP for 5 years. Her naturopath feels she has food allergies and has her on an extensive food elimination diet. She is opposed to taking medications of any type except herbs. She is now having 6 headaches a month lasting 1-2 days apiece. The Naturopath has referred her to a biofeedback therapist who works in her office one day a week.
- A 41 year old female has a ten year history of headaches in conjunction with diabetes and coronary artery disease. One of her doctors called her a migraineur and the other one says it's her blood pressure. She's on 8 medications including vicodin which she uses for headache on a daily basis.

Many variables effect the fact of headache treatment and success. Just as in the above cases, it certainly isn't as simple as 'patient diagnosed or not', and certainly nobody would accuse Richard Lipton of missing that point. There are multiple patient and doctor variables. In totality, those variables are known as Clinical Judgement and Experience.

How do you know that Feverfew will not relieve a level ten headache? It just wont. And will a blood pressure of 140/90 cause a terrible incapacitating migraine? No never.

The romance of statistics gets our attention and makes a good first page on your next textbook of headache . Basic understanding of the science of headache medicine carries on the battle and it is finally won by experience and clinical expertise.

And incidentally, if all of America's Migraineurs were laid end to end they WOULD stretch right around the Earth with some to spare.(14). Could you imagine all those suffering headache people hanging on over the Himalayas?

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