Barriers to headache care in India and efforts to improve the situation

K Ravishankar

With the recent launch of the joint Global Campaign to reduce the burden of headache by the World Headache Alliance (WHA), the International Headache Society (IHS), the European Headache Federation (EHF), and WHO, a welcome focus on the management of migraine is expected. Migraine management is influenced by numerous factors that are regionally different around the world. Through a discussion of the "barriers to care" of migraine in India, I attempt to appraise the academic headache community of the need for region-specific guidelines derived from the standard guidelines. Some of these barriers are within the control of the patient, some are within the control of the treating physician, and many are beyond the control of both. The efforts needed to remedy the situation are also discussed. Hopefully this article will serve to emphasise again the well-known maxim that treatment of migraine is much more than just a prescription!

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March 26, 2004, was a major landmark in the lives of people with chronic headache. On this day, three major international headache organisations—the World Headache Alliance (WHA), the International Headache Society (IHS), and the European Headache Federation (EHF)—in collaboration with WHO, launched a global campaign to reduce the burden of headache. Tim Steiner outlined this seven-step campaign, appropriately titled "Lifting the burden", in an excellent commentary.[1] Steiner rightly commented that, in many regions of the world, headache disorders are neglected and that there are large gaps in the way headache is managed. WHA will lead the campaign partners and will try to establish a worldwide observatory of headache to develop an understanding of region-based problems and to direct efforts accordingly.

Migraine is the main cause of headache burden worldwide. With no major focus on migraine management and a lack of awareness of the recent advances in research and treatment, migraine is underdiagnosed and undertreated in all countries. Unlike most other neurological disorders—for which the prevalence, diagnosis, management, and outcome are not regionally different—migraine is a complex neurological problem, the end-result of which can differ depending on many location-specific variables. In contrast to what prevails in developed countries, there are many additional barriers to care in developing countries that make migraine management much more difficult. Even though the clinical features may be the same in patients the world over, the final treatment outcome may vary depending on differences in genes, geography, and environment. In addition, when you take into account other factors—such as the attitude to headaches in general and migraine in particular, the level of awareness among both the lay and medical communities, the non-availability of the latest drugs, and the lack of managed care—it is not difficult to realise that the burden of headache differs among populations.

With a focus on India, this article aims to highlight some of the additional barriers to care in a developing country and thereby to drive home the message to policy-developers and decision-makers that guidelines for management of migraine need to be region-specific and cannot be globally standardised. Although the Indian scenario has been highlighted, the same may be true for many other parts of the world. The global campaign committee should therefore take stock of barriers to care on a regional basis.

Barriers to care in India

There are still no reliable epidemiological studies to indicate the prevalence of migraine in India. On the basis of a survey of migraine patients who attended the headache and migraine clinics at Jaslok and Lilavati Hospitals (Mumbai, India), all factors that were possible barriers to care were analysed. This was the topic of a platform presentation at the 11th International Headache Congress (2003) held in Rome, Italy.[2] Patients with migraine who fulfilled the International Headache Society criteria for migraine were assessed by use of a questionnaire. Besides details of the headache, the questionnaire asked for information regarding the patient's perceptions about his or her headache, their personal data, fears, expectations, experience from previous consultations, and possible reasons for poor compliance and outcome. These factors were categorised into three groups: patient-related barriers, physician-related barriers, and regional barriers.

Patient-related barriers

Myths and misconceptions about headaches, patients' own presumptive diagnoses, and delays in seeking treatment are all barriers to care (panel 1). Financial constraints

KR is at The Headache and Migraine Clinic, Jaslok Hospital and Research Centre and Lilavati Hospital and Research Centre, Mumbai, India.

Correspondence: Dr K Ravishankar, The Headache and Migraine Clinic, Jaslok Hospital and Research Centre, 15 G Deshmukh Marg, Mumbai 400 026, India. Tel + 91 22 2407 4257; fax +91 22 2407 1523; email dr_k_ravishankar@vsnl.com

Panel 1. Patient-related barriers

Myths and misconceptions
Headaches are caused by a defect in visual acuity
Headaches are caused by emotional upset
No permanent cure, so you might as well live with it
All headaches are caused by sinusitis
Headaches are caused by acidity or constipation

Delays in the seeking of treatment
Self medication
Fear of side-effects of allopathic drugs
Trial with alternative treatment options

Poor compliance
Financial constraints
Normal CT-scan results lead to the misapprehension that all is well

Inability to understand migraine
Frequent change of doctors
Poor control of triggers
Wrong levels of expectation

commonly lead to failure to comply with follow-up consultation and long-term prophylactic treatment. Treatment of a primary headache is perceived as an unnecessary waste of money by many patients and their families for a recurrent disorder with no permanent cure. Cheap and easy access to CT scans can be detrimental. Walk-in CT scans are obtained and all further treatment is given up once they are told that the scan is normal. Low literacy levels lead to an inability to understand migraine and the reasons for recurrent head pain. Many patients change doctors frequently, consult different specialists, do not recognise the importance of trigger-control measures, and lapse from care if they are not assured of a permanent cure.

Physician-related barriers

In India, as in most countries, all doctors treating headaches are not aware of the recent advances in migraine management and do not have the right attitude towards headache (panel 2). Most physicians do not appreciate the true misery caused by headache, and the medical curriculum does not adequately train in the treatment of headache disorders. Overcrowded clinics with no regulated system of consultation by prior appointment make it more difficult for the general neurologist who also has to treat epilepsy and stroke, to devote much time to patients with headache.

Panel 2. Physician-related barriers

Wrong diagnosis
Low emphasis of headache in medical curriculum

Wrong treatment
Faulty drug choice
Suboptimum dose
Inadequate duration of prophylaxis

Wrong referral

Lack of effort to educate patients

Under-use of non-pharmacological strategies

Assessment of burden with the migraine disability assessment (MIDAS) score[3] is difficult in India because of the lack of records about days of work lost due to headache, and, therefore, care is not stratified. Patients and family practitioners do not readily accept in-patient management for chronic recurrent headaches, even for status migrainosus. Drug rebound headaches go unrecognised, alternative routes for drugs are unknown, and the latest treatment options are not used.

Regional barriers

These barriers (panel 3) are beyond the control of both patient and physician, vary widely, and may have a direct bearing on the prevalence, the frequency, the severity, and the intractability of headaches. The barriers peculiar to each geographic setting must be understood if we are to make a joint effort to decrease the burden of headache worldwide. Eight major region-specific factors have an effect on the management of migraine in India.

Overpopulation

With a population of more than 1 billion, India is the second most populous country in the world, second only to China. India has 16% of the world population and with an annual population growth rate of 19·5%, India's population is expected to reach 1·2 billion by the year 2011.[4] This population growth also puts significant strain on the health-care system. Our health priorities also keep changing and so long as other major health problems—such as tuberculosis, malaria, HIV, etc—are not brought under control, we cannot expect focus on an invisible misery like headache (figure 1).

Low literacy

Low literacy has a direct bearing on the way patients perceive primary headaches and the way they set their expectations and understand treatment plans. Our national literacy level is 59·5% (men 70·2% and women 48·3%).[5] Because migraine is more prevalent in women than in men, and owing to the high level of illiteracy in women, quality-of-life on the basis of work-related functional disability is not easily assessed, hence the estimation of the true burden of migraine is difficult.

Low income

Despite the fact that India has an emerging middle class of more than 250 million, there are still 350–400 million people living in lower-middle class conditions. So, with basic wants not being fulfilled, it is difficult for patients to seek treatment for their headaches.

Panel 3. Regional barriers

Overpopulation
Low literacy
Low income
Growing urbanisation
Cultural and social diversity
Triggers peculiar to India
Inadequacies of the health-care system
Alternative therapies

Figure 1. Headache is overlooked because of other problems.

Growing urbanisation

Unlike many other countries with a high degree of urbanisation, 25% of India's population live in cities and 75% live in rural villages, where proper infrastructural facilities are lacking. Rural areas also have no access to specialised care of headache. As India has become more urban, more doctors have moved into cities, and now 70% of physicians paradoxically are based in urban areas.

Cultural and social diversity

India has to deal with major cultural and social differences. There are 24 major languages, with many different traditions, customs, habits, beliefs, all of which have a bearing on the attitude to the seeking of care for headaches. This also makes it difficult for migraine to be perceived and treated in the same way all over the country.

Unusual triggers

India is located to the north of the equator in the eastern hemisphere and the heat and humidity are conducive to increased frequency and severity of migraine. Some parts of the country can have temperatures of up to 38°C for more than 8 months of the year. The hot and humid weather for most of the year, the increased light and noise levels, the different food triggers, the fasting habits in different communities, the application of henna, stressful school education, and the stress of travel in crowded conditions (figure 2) can all contribute to more frequent headaches that may not respond to medical treatment.

Inadequacies of the health-care system

In India, the health-care system is represented by three sectors. The public-health sector is the state managed free service in which doctors have no scope for ideal headache management particularly in the face of so many other pressing medical problems.

The private sector or self-paid care is where patients can expect to get proper treatment for their headaches; however, because of the costs, less than 5% of people in India seek private care. As a result only the higher strata of society can get their headaches treated correctly.

In insurance-funded or managed health care, insurance agencies do not perceive primary headaches as a biological problem needing specific treatment (and sometimes hospitalisation). This view not only prevents effective treatment but also wrongly indicates to the community that headache is not a disorder that needs to be taken seriously.

Easy availability of alternative therapies

Most of the rural population try alternative methods of treatment, such as homoeopathy, ayurveda, and unani. There are also unqualified practitioners and local chemists who treat patients unsuccessfully. Failed attempts at treatment only serve to reaffirm the idea that headache is difficult to treat.

Efforts to improve the situation

Special efforts are needed to tackle the barriers to care of headache in India. In the light of all the new understanding of migraine and after the launch of the triptans, it is essential to promote awareness that migraine is a treatable disorder. Awareness can be raised by use of the press and television under the guidance of a global organisation such as the WHA. Emphasis needs to be placed on the identification and control of triggers specific to our country instead of efforts only to implement advanced pharmacotherapy. Like elsewhere in the world, the medical community needs to be updated on the management of a common problem like headache and migraine, and the undergraduate and the postgraduate curricula must be expanded to include more teaching on headache by dedicated specialists. The IHS can

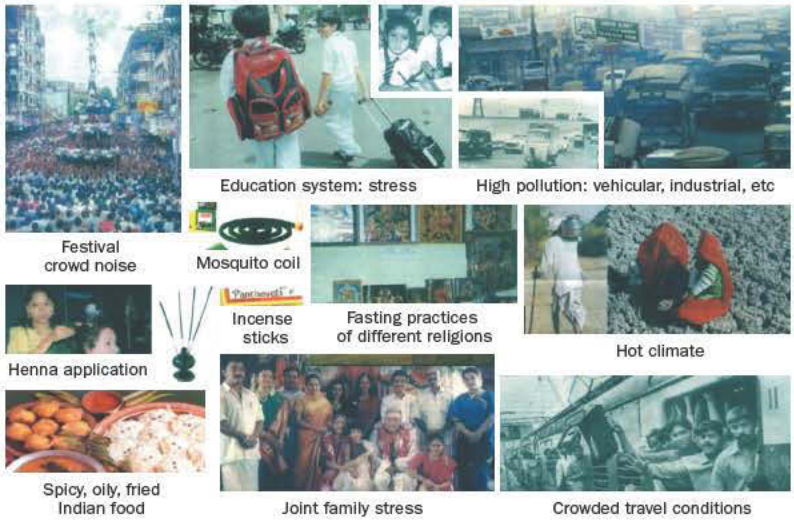

Figure 2. Possible headache triggers peculiar to India.

play a major part in supporting this effort. Health care needs to be modified taking into account the fact that migraine is a biological rather than just a psychological disorder. Insurance must reimburse claims for migraine to encourage timely investigation of headache management on a long-term basis. The setting up of more tertiary clinics exclusively devoted to headache management will increase the focus on this neglected subject. A non-medical support group will help to promote awareness and to create interest in simple treatment measures for mild to moderate migraines.

Conclusion

To alleviate the burden of headache worldwide, in addition to the application of standard guidelines, we need to focus regionally, to change the attitude to headache of both patients and physicians, to educate doctors about recent advances, to influence insurance agencies, and to improve health-care systems.

In India there are many other important health problems and so headache is still low on the priority list. But if we address these additional barriers to care, headache burden can be reduced substantially and headache relief can get the priority it deserves. The Global Campaign recently launched jointly by the WHA, IHS, EHF, and WHO to reduce the burden of headache augurs well for patients with headache. If all goes well, in the future, we can look at reducing the misery caused by headache worldwide.

Conflict of interest

I have no conflicts of interest.

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