Headache Clinics: Organization, Patients and Treatment

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6 Organization of a headache centre: an Indian perspective

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Objectives

It is an established fact that in headache centres, primary headaches are more common than secondary headaches; however, unlike secondary headaches, the final outcome of primary headaches and migraine in particular can differ depending on region-specific variables.

In contrast to what prevails in developed countries, in many regions of the world there are additional limiting factors such as resource limitations and other health priorities that can have a bearing on the organization of a headache centre.[1] Citing the Indian headache scenario, this study attempts to appraise the international headache community of factors that are barriers to the organization of a headache centre. Suggestions for adaptations to deliver optimal headache care in this setting are also detailed.

Background and methods

The author has trained in 'headache medicine' at model headache centres in the West and since 1995 is in charge of headache and migraine clinics at two tertiary care hospitals in Mumbai, India.

This study addresses the question, 'Why are there not as many headache centres in India and other Asian countries as in the West?' and tries to find answers to 'How and what needs to be done to remedy the situation?' The impressions and conclusions included herein are based on the analysis of more than 7000 patients who attended headache clinics in Mumbai over the last decade.

Results

'Barriers' to the organization of headache centres in India

1. *Overpopulation and resource limitations.* With India's population exceeding 1 billion, there is a significant strain on the healthcare system. At all levels, headache is perceived as a trivial problem that does not warrant a waste of resources.

   There are still many people living in the lower-income category; so with all their wants not being fulfilled, it is difficult to expect them to attend specialized centres for the treatment of their headache problem.
2. *Other pressing health priorities.* Our health priorities keep changing and so long as there are other major health problems—such as tuberculosis, malaria, HIV—one cannot expect governmental focus or funding to organize headache centres.
3. *Lack of awareness of the 'headache centre' concept.* As in many other countries, the true misery of 'headache' is not known to lay people and primary care physicians are not aware of the benefits of care through 'headache centres'. Unless physicians are aware of the advantages of specialized care, headache centres cannot succeed.

   The national literacy level is only 59.5 per cent (men 70.2 per cent and women 48.3 per cent). This has a direct bearing on a patient's understanding of primary headaches, the impact, the expectations through treatment plans, and also the need for attending a headache centre.
4. *Patient myths and misunderstandings.* India is a land of a multitude of cultural and social diversities. There are 28 states, more than 24 languages and 10 different religions, and with this diversity, there are many different traditions, customs, habits, and beliefs that nurture many myths and misunderstandings (74 per cent). Treatment of primary headache is perceived as an unnecessary waste of money by patients and their families for a recurrent disorder with no permanent cure and they prefer to self-medicate (62 per cent) rather than attend special clinics.
5. *Inadequacies of the healthcare system.* The healthcare system in India is represented by three sectors. At public hospitals (the state-managed free service) due to overcrowding, there is no scope for organizing model headache centres. The private sector (self-paid care) is where headache centres can ideally be organized, but because of costs, less than 5 per cent of the population seek private care. Insurance agencies in India do not perceive primary headache as a biological problem warranting specific treatment. Expenses incurred at headache centres are therefore not reimbursed.
6. *Easy availability of alternative therapies.* Misplaced expectations of magical relief force patients to rely on alternative therapies such as homoeopathy (32 per cent), ayurveda (25 per cent), and unani, which are easily available. Patients prefer to self-medicate.
7. *Non-availability of the right staff.* It is difficult to bring together at the same venue a headache specialist with the right attitude, interest, and training to co-ordinate with a team of overlap specialists with correct headache knowledge, and organize a model multidisciplinary headache centre. Trained nursing staff educated and experienced in the care of chronic headache patients are difficult to come by.

Table 6.1 'Barriers' to the organization of headache centre

- Overpopulation and resource limitations
- Inadequacies of the healthcare system
- Other pressing health priorities
- Easy availability of alternative therapies
- ↓ awareness of the 'headache centre' concept
- Non-availability of the right staff
- Patient myths and misunderstandings
- Absence of follow-up care

8. *Absence of follow-up care for headache disorders.* In India we do not have a uniform pattern of referral that is GP-oriented; so it is difficult to maintain continuity of care and assure proper compliance and follow-up.

'Adaptations' that are needed in the organization of headache centres in India

1. *Create 'service-oriented' rather than 'academic' headache centres.* Keeping in mind the constraints of different regions of the world, we need to vary the level of services offered at headache centres. In certain regions 'service-oriented' headache centres that are primarily geared only to correctly diagnose and treat would serve a better purpose than 'academic' headache centres that are also inclined towards research and training.
2. *All headache centres should preferably be hospital-based.* Hospital-based headache centres have many advantages over stand-alone centres. When starting out with a new concept, it gives the headache centre quicker recognition and credibility; it reduces the operational expenses and helps in providing outpatient as well as inpatient care at reasonable cost. Hospital-based headache centres enhance awareness among overlap specialists and colleagues and increases referrals to the clinic. All necessary equipments and investigational facilities are available under one roof and the occasional acute emergency headache can also be managed.[2]
3. *Choose the headache specialist with the right training and experience.* Besides medical knowledge and skills in multidisciplinary settings, he/she should be able to oversee contracts, make administrative decisions, and have marketing skills.[3] Because the frequency and severity of migraine is largely influenced by trigger factors, they should know the country they practise in, the people, their habits and customs, their attitudes and expectations, and any peculiar socio-economic problems.
4. *Ensure a proper referral system.* A multidisciplinary headache centre that encourages referral through primary care physicians is always more effective in ensuring compliance, better follow-up and interim management.
5. *Share common infrastructure between neurological subspecialty clinics.* Costs can be reduced by having floor space and other infrastructural costs shared between the headache centre and other neurological subspecialties.

Table 6.2 'Adaptations' that we need in the organization of headache centres

• Create 'service-oriented' headache centre
• Shared infrastructure—between neurological subspecialties
• Hospital-based headache centre
• Avoid walk-in consultation
• Choose the right headache specialist
• ↓ consultation cost and ↑ follow-up care
• Ensure proper referral system
• ↑ awareness among the lay and primary care physicians

6. *Avoid walk-in consultations.* When patients walk in without an appointment, the headache specialist is not able to give time to the patient and this affects the maintenance of records and communication with referring primary care physicians.
7. *Limit consultation costs and expense.* Costs of consultation and long-term medications for a temporarily disabling disorder are perceived as an unnecessary waste of money by the patient and his family. The chronicity of headaches needs to be emphasized and thus while establishing the headache centre, you need to limit consultation cost based on an overview of start-up costs, fixed costs, variable costs, the marketing plan, and the role and number of personnel.

Conclusions

In some countries around the world headache centres need to be organized differently. This study proposes that where an ideal state of the art headache centre cannot be organized, adequate specialized headache care can be rendered even through headache centres with suboptimal facilities but with a knowledgeable headache specialist.

In India and many other countries in Asia, it is important that we adapt and create more such simplistic 'service-oriented' headache centres. It is necessary for all to understand these barriers peculiar to different geographic settings in order to provide optimal headache care globally.[4]

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