

Lifting the burden: the global campaign against headache

On March 26, 2004—after 7 years of planning and discussions—WHO's European Office in Copenhagen will host the launch of a global enterprise unique in the specialty of headache disorders.

Headache disorders are ubiquitous. Their lifetime prevalence is over 90% in those populations that have been studied. Pain, suffering, and disability caused by headache disorders impose substantial burdens, at both personal

and societal levels. Effective health care can alleviate much of the symptomatic burden of most headache disorders, and thereby mitigate both the humanitarian and the financial costs. But this depends not only on the existence of effective treatments but also on due allocation of health-care resources so that these treatments are made available to all who need them. There is good evidence that these needs are met only partially, if at all. A consensus conference in 1998⁴

treatments made available. Yet we know that the discoveries of the last 15 years—so exciting in the developed world—do not touch on most of the world's headache-blighted lives.

In recognition of this, and the scale of the global problem, three major international headache non-governmental organisations, in collaboration with WHO, have committed to work together for an initial period of 5 years. The World Headache Alliance (WHA), the International Headache Society (IHS), and the European Headache Federation (EHF) believe that, through a formal collaboration with WHO, they can open doors, address problems, and propose and test potential solutions in parts of the world that could not otherwise be reached.

Joint action by these four groups will take the form of a global seven-step campaign formally entitled *Reducing the burden of headache world-wide*, which has been branded more simply as *Lifting the burden*.

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The seven steps

Ultimately the campaign entails setting priorities and finding—on a region by region basis—effective and affordable solutions that are achievable with locally available resources and within a defined timeframe. The campaign's central tenet is that the health-care solution for headache in most areas of the world is education. By educating, we can raise awareness that a problem exists and inform about correct recognition and diagnosis of common headache disorders, how to avoid mismanagement, appropriate lifestyle modifications, and use of cost-effective pharmaceutical treatments.

WHO has clearly identified ways in which countries can “enhance capacity to reduce the burden of mental disorders”⁵, which, in WHO terms, includes all neurological disorders. Building on these, the campaign will proceed in seven steps.

The first of these is to acknowledge the problem—ie, that headache disorders are burdensome, that the burdens can be reduced by effective treatment, and that gaps exist

The burden of headache

and societal levels. According to WHO, migraine is 19th in the list of causes of years of life lived with disability.¹ There are huge consequential financial costs. A recent US study reported indirect costs in a managed-care population of over US\$4500 per patient per year.² In the UK, costs of migraine due to loss of productivity are partly the result of absenteeism during acute attacks, which is estimated to account for 25 million days of missed work or school each year.³

These studies have focused our attention on the developed world where money is persuasive, but this does not mean that the humanitarian burden of headache is less in resource-poor countries.

concluded that migraine is underdiagnosed and undertreated worldwide. In many countries, headache disorders are not recognised as diseases but only as self-limiting—and therefore unimportant—symptoms, that do not warrant allocation of resources that are already scarce. Thus, large gaps exist between the need for care and access to it.

Partnership in action

For those of us who specialise in headache disorders, the time has come to ask where our responsibilities lie and what our priorities should be. Research into disease mechanisms is unquestionably important if they are to be understood and new, more effective

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worldwide between the need for health care for headache and its provision.

The second is to build networks and collaborations as tools for this task, bringing together WHA, IHS, and EHF and also involving WHO for its global influence on public health.

Step three is to gather "information for better decisions".⁵ This will be done by the establishment of an international observatory of headache and by putting headache into WHO's *Project Atlas*, which maps mental-health resources in the world. This means bringing out all existing evidence of the burden of headache worldwide, translating prevalence and incidence data into disability data. It requires the gathering of information, by region and country, on the allocation of health-care resources to headache disorders, not only highlighting the gaps between need and delivery but also uncovering the underlying causes. The large holes in the evidence base will be identified so that studies can be set up to fill them.

Hence, the fourth step: "enhancing the research capacity in developing countries".⁵ In order that proposed solutions reflect the needs of patients in these countries, and not only the needs perceived by the developed world, direct support must be provided for studies that aim to understand headache burden and health-care gaps in these countries. This is where priorities must be set; not simply highlighting the countries with greatest need but identifying where action can best achieve results. This is reflected in one of the campaign's core values: efficiency coupled with equity.

Step five is to persuade others of the problem and its priority through the humanitarian and socioeconomic arguments for change. Sound evidence will be presented to governments and other health-service policymakers that headache disorders should be high among the priorities for health care. The campaign is based on the beliefs not only that individual and societal burdens are heavy, but also that correct treatment can mitigate these burdens, whereas incorrect treatment both adds to these burdens and wastes resources. Therefore, the campaign must

convince those who can influence change that, through education, better care and reduction of these burdens not only are achievable but also can be cost effective, either through the more efficient use of currently allocated resources or by reduction of consequential financial costs.

Step six will tackle these problems in each community through "integrated policy and service development".⁵ The aim will be to bridge the gaps between health-care need and delivery while removing, or at least alleviating, their causes. Programmes of education, key to effective solutions, will exploit those that have already been put in place by IHS, EHF, and their member national societies for health-care providers and by WHA for the general public and those people directly affected by headache disorders. These programmes will use acquired data to "advocate against stigma and discrimination",⁵ which exist against those who complain of headache.

Finally and crucially, it will be necessary to prove the need for these measures. Region-based demonstrational projects will be established in collaboration with WHO's Regional Offices. The purpose of these projects is to convene policy-makers and other key stakeholders to plan and set up headache-related health-care services appropriate to local systems and local needs. These projects will recognise that "training is an absolute prerequisite for the effective conceptualisation and implementation of mental health policies and services",⁵ and will assess outcomes in terms of measurable reductions in the population burden attributable to headache disorders.

The campaign has begun

Although these seven steps need not be taken in order and may proceed in parallel, the first two have already been taken. Towards step three, WHO has gathered all of the worldwide evidence of the burden attributable to migraine that existed in 2001. This information was assimilated in the *World Health Report 2001*.¹

WHA will lead the campaign partners; its accepted responsibilities

The Global Campaign committee

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Ms V South (IHS)
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include promotion and support of the discussion between the collaborators in detailed planning, production of materials to be the "face" of the campaign, and the generation of financial support for it. The Global Campaign Committee, which will direct the campaign, is a subcommittee of the WHA Council. WHA has appointed representatives to this committee who have been nominated by WHO, WHA, IHS, and EHF (panel).

A working group is being appointed to oversee the establishment of the world-wide observatory of headache (step three) and to advise on the studies required, in developing countries and elsewhere, to fill the knowledge gaps (step four).

WHA will consult widely to formulate effective joint action (steps five to seven) with the campaign partners. The existing website (<http://www.liftingtheburden.org>) will be developed for this purpose.

There is a huge task ahead. It challenges all of us who recognise headache as a global public-health problem. Let us, together, be equal to it.

TJ Steiner, on behalf of World Headache Alliance

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