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Lifting The Burden: The Global Campaign to Reduce the Burden of Headache Worldwide

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Abstract *Lifting The Burden* envisions a future world in which headache disorders are recognized everywhere as real, disabling and deserving of medical care to which all who need it have access without artificial barriers.

Key words Burden of headache • Global public health • Headache related health care

Introduction

Throughout the world, people who are affected by headache disorders and professionals working in the field of headache know that these disorders are real and often lifelong illnesses. They are not only highly prevalent, affecting men, women and children everywhere: they are also disabling. The World Health Organization ranks migraine among the top 20 causes in the world of years of healthy life lost to disability [1]. In USA and Europe, migraine is the cause of an estimated 250 000 000 lost days from work or school every year [2, 3]. Migraine harms family and social relationships and damages quality of life. Migraine, however, is but one headache disorder: all headache disorders together are believed to be responsible for at least double the disability attributable to migraine. If this is correct, headache disorders are in the top ten – and possibly the top five – causes of disability worldwide.

Headache disorders are not complaints of rich countries. Whilst the huge lost-productivity costs resulting from headache disorders focus the attention in high-

income countries, the humanitarian burdens of headache – pain and suffering, lifestyle compromises, damaged relationships and lost opportunities – weigh no less heavily elsewhere. Poverty and its consequences of poor sanitation and infectious diseases may seem to be of overwhelming priority in many low-income countries, but why should headache and the burdens it imposes be any less disagreeable in the presence of hunger and other illness?

It is an irony that effective treatments that could alleviate these burdens are within reach. Research into disease mechanisms and the discoveries of the last 15 years have hugely benefited a few whilst failing to touch most of the world's headache-blighted lives. Yet the reality is that, for the vast majority of those whose quality of life is spoiled by headache, effective treatment requires no expensive equipment, tests or specialists. The essential components of effective medical management are awareness of the problem, correct recognition and diagnosis, avoidance of mismanagement, appropriate lifestyle modifications and informed use of cost-effective pharmaceutical remedies. The principal reason why the burdens attributable to headache persist, and indirect costs remain so

high, is failure of health-care systems to provide these simple measures. Instead, there are artificial barriers throughout the world to access to care.

The key factor underlying this public-health disaster is education failure at every level. Lack of awareness and understanding of headache disorders amongst the general public allows myths to persist that they are not real and not worthy of medical attention. Lack of inclusion of diagnosis and management of headache disorders in the training curricula of health-care providers leaves them unskilled and therefore unwilling to offer health care in this field. Lack of recognition of the humanitarian burden and socioeconomic cost attributable to headache disorders leads health-policy makers grossly to misjudge the priority due to them. Headache disorders in many countries are simply not acknowledged as illnesses requiring health care, and everywhere they have low priority [4].

Table 1 The three stages, summarized, of *Lifting The Burden*

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- *Acquiring knowledge for action* (that is, a clear and objective understanding of the scale and scope of headache-related burden)
 - *Using knowledge to raise awareness*
 - *Exploiting awareness to promote beneficial change*
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Table 2 The eight core values of *Lifting The Burden*

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|--------------------------------------|--|
| Ethical conduct | <i>Lifting The Burden</i> will ensure that all research and other activities conducted on its behalf or in its name respect persons and human rights and otherwise meet universally accepted ethical standards [6] |
| Efficiency coupled with equity | <i>Lifting The Burden</i> will concentrate its activities where they are most needed and where they can best achieve benefit |
| Local needs and local ownership | <i>Lifting The Burden</i> recognizes that local needs are known to and prioritized by local people; their solutions require local determination and must build upon each community's available resources |
| Strength in partnership | <i>Lifting The Burden</i> creates partnerships, coupling the resources of the international headache organizations with WHO's experience, know-how and contacts; <i>Lifting The Burden</i> recognizes that a range of other groups and individuals – academic, professional, lay, governmental and commercial – can through inclusion bring added strength and reach to the Campaign |
| Respect for science | <i>Lifting The Burden</i> recognizes that good health care is based on evidence, and that the origins of evidence lie in science and scientific method |
| Ambition coupled with realism | <i>Lifting The Burden</i> sets itself challenging but achievable targets |
| Openness and accountability | Everyone affected by headache, or working in the headache field, is a stakeholder in <i>Lifting The Burden</i> ; The Global Campaign Committee, with representatives of WHA, IHS, EHF and WHO and which directs the Campaign, is an advisory committee to WHA's Council of Management; <i>Lifting The Burden</i> consults widely in formulating its actions, keeping stakeholders informed of intentions and progress through its website (www.l-t-b.org) |
| Independence from unwanted influence | <i>Lifting The Burden</i> will not be guided or influenced by commercial considerations, and will not seek or accept funding that creates conflicts of interest or from companies dealing in arms, tobacco or alcohol |

Lifting The Burden: responding to need

Recognizing all of this, and in response, the World Headache Alliance (WHA), the International Headache Society (IHS), the European Headache Federation (EHF) and the World Health Organization (WHO) have committed to work together in the Global Campaign to Reduce the Burden of Headache Worldwide, more simply styled as *Lifting The Burden*.

Lifting The Burden is a partnership in action planned in three stages (see Table 1). Each of these, and their reduction to seven steps, have been described in detail elsewhere [5]. *Lifting The Burden* aims to work with local agencies worldwide to devise and implement effective and affordable health-care solutions to the headache problem as it occurs locally.

For the reasons set out above, *Lifting The Burden* is founded on the belief that the basis of the health-care solution for headache in most parts of the world is education. Not only can right treatment mitigate these burdens but also, in a world of scarce resources and competing priorities, wrong treatment both *adds* to the burdens *and* wastes resources. In short, *Lifting The Burden* will use knowledge to persuade those with influence over change of two things: that better care and reduction of headache-related burden are a priority demand upon

health systems, and that, through education, these ends are not merely achievable – they can be made cost-effective both by reducing consequential financial costs and through the more efficient use of currently allocated resources.

Lifting The Burden embraces the values of its partners. In particular, the Campaign adopts eight values as core, undeniable and incontrovertible (Table 2).

Project management

Reducing *Lifting The Burden* to its seven steps [5] is an aid towards manageability, but it remains a global project of some magnitude and complexity. Looked at as a whole, *Lifting The Burden* appears vastly ambitious and beyond what can ever be achieved, but this does not mean it is non-viable or misconceived. Strategically, the approach to the Campaign calls upon standard project-management methodology, dividing the world into Regions (those of WHO), countries and localities (localities being larger or smaller than countries) and the task into sub-tasks. As academic and other collaborations and networks are created, these sub-tasks will be distributed amongst working groups. Thus, *Lifting The Burden* is planned on a Global front and simultaneously on Regional fronts and on National and Locality fronts according to priority criteria based on the Campaign's core values. In this way, *Lifting The Burden* is split into bite-sized chunks, each clearly manageable within a timescale and to a budget. There will be a large number of these chunks; project management will, at the right time, reconstitute them. The crucial point of this is that success is not dependent on completion of the entire project: each element of *Lifting The Burden* is a useful end in itself, contributing in some way to better lives of those affected by headache disorders. Each small part achieved of *Lifting The Burden* is a success.

On the Global front, the activities can be classified as *learning, educating, supporting* and *making aware*. To bring together current knowledge of the burden of headache, the Global Burden Working Group is overseeing the establishment of a worldwide observatory of headache. It is undertaking a review of all the epidemiological evidence now in existence of the prevalence and burden of headache disorders, adding to the data on migraine already assimilated into WHO's *World Health Report 2001* [1]. The Group will produce headache maps of the world and then, working with WHO, translate these data into quantified burden using WHO's established methodology. This activity will directly contribute to WHO's *Atlas of Headache Disorders*, a focused derivative

of the *Atlas of Neurological Disorders* which identifies headache as the number one neurological health problem in primary care in all six Regions of the world [7].

This Group will go on to identify the important gaps in our knowledge and consider how to fill them, which will entail moving onto Regional or Locality fronts with new epidemiological studies. The priorities are likely to include China, where the probably underestimated prevalence of migraine significantly affects the global measurement of the burden of headache, and India, where the prevalence of headache disorders may be high but good epidemiological data do not exist. Studies are expected to be required in countries of South America, in Africa and in South East Asia. Epidemiological studies are already planned in Georgia, Azerbaijan, Armenia and European Russia; a methodological pilot in Tbilisi, which may have application in low-income countries elsewhere in the world, has been completed and is undergoing analysis.

Once these new studies and the estimates of burden attributable to headache are complete, *Lifting The Burden* expects to show that headache disorders, taken together, are in the top 10 causes of disability worldwide.

A Working Group for Workplace Studies will provide the crucial missing link in the cost-effectiveness of treatment argument, vital to *Lifting The Burden*. This is clear evidence that effective treatment of headache actually does get people back to work and recover lost productivity.

Since education is the central pillar of *Lifting The Burden*, a number of working groups are needed to propose and develop global educational strategies aimed at various levels. The first, the Working Group for Specialist Education, has responsibility for advanced training which is offered as a Masters Degree course, currently at the University La Sapienza in Rome but with the intention eventually of expanding this activity to other universities. This has priority because this training will educate trainers from around the world. Other modes of advanced training will be explored, not forgetting that the internet is able to reach doctors in most countries of the world at relatively low cost. Working Groups for Primary-Care Education and for General Public Education, yet to be established, will co-operate with the headache organizations, particularly IHS and WHA, and build upon their existing programmes to reach their respective audiences.

Three clinical management-support activities are currently planned. The Working Group for Diagnostic Aids will produce a core cut-down version of *The International Classification of Headache Disorders, 2nd edition* (ICHD-IIR1), selecting only those headache entities that are common or important everywhere. Region-specific variations will then be developed for use around the world especially in primary care. Later this group will formulate diagnostic algorithms based on these key entities as part

of the educational solution upon which *Lifting The Burden* depends. Working Groups for Management Guidelines will probably be Region-based, and seek to harmonize existing guidelines within each Region. An expert consensus panel will be convened to discuss with WHO what drugs for migraine and other headache disorders should be on its essential medicines list. The Working Group on Ensuring Best Outcomes is developing universally acceptable indices of treatment outcome. The focus is on demonstrating that health care for headache in an individual patient has achieved best possible rather than merely good effect. These indices will be needed when *Lifting The Burden* reaches the interventional stages.

The Global front includes an important public relations front. Public relations are managed by the Global Campaign Committee. Explanatory printed materials for various audiences – the stakeholders in *Lifting The Burden*, sponsors and potential sponsors and the media – include WHO's *Fact sheet on headache disorders* [8] and the "blue book" [9]. These materials will, when resources allow, be produced in the Campaign's priority languages: Arabic, Bengali, English, French, German, Hindi/Urdu, Italian, Japanese, Mandarin, Portuguese, Russian and Spanish. Awareness initiatives also include the *Lifting The Burden* website (www.l-t-b.org), where all materials will be posted.

The first formal national initiative was launched in Spain in July 2004, with government recognition. The aim of *Lifting The Burden* on Regional, National and Locality fronts is to follow data acquisition in each geographical area (knowledge for action) with interventional programmes supported by educational and awareness campaigns directed at the public, health-care providers and health-policy makers. In particular, through education, *Lifting The Burden* will aim to overcome the barriers to care that maintain burden: firstly by increasing the reporting rate by people with headache; secondly by improving doctors' understanding of the need for medical care and by promoting better diagnosis and care; and thirdly by making health-policy makers aware of the socioeconomic benefits of good headache care supported by adequate resources. These activities can be classified as *acquiring knowledge for action, obtaining commitment, making change happen and evaluating the effects of change*.

Wherever knowledge of the scale and scope of the local burden attributable to headache is insufficient, epidemiological studies will be undertaken to fill that gap. Unless the problem is known and understood, effective solutions to it cannot be proposed.

Declarations on Headache, from each of the six WHO Regions that between them encompass the world, signed by representatives of the Ministries of Health in each participating country in the Region, signal governmental acknowledgement of the problem in their Region and

commitment to seeking solutions. A priority of *Lifting The Burden* is to obtain these. Each *Declaration* will be drafted by a local editorial board and presented at a WHO-hosted two-day meeting in the Region. On the first day, the problem of headache in the Region will be presented by experts from the Region. On day two, the *Declaration* will be discussed in detail, finalized and adopted.

Interventional programmes will follow. In demonstrational projects, *Lifting The Burden* will, country by country, adapt the solution to the problem as it exists locally. The solution will always have education at its centre, and it will call upon the clinical management supports being developed by *Lifting The Burden* on the Global front. But it will also require health service delivery and organization that will, generally, depend upon local government to put in place. That is why government commitment is needed. *Lifting The Burden* will work with local governments and other country policy-makers, as well as with WHO's Regional Offices, to plan and implement each of these solutions, and make them achievable with locally available resources and within a defined term.

Finally, and perhaps the most difficult activity, *Lifting The Burden* will measure the effect of these local solutions in terms of reductions in the burden attributable to headache in the local population. The methodology for doing this still has largely to be developed: the process is likely to involve a number of academic centres working in headache, in health policy and in health economics.

In summary, in each locality *Lifting The Burden* will measure the headache burden, raise awareness of it amongst those who can cause change, work with people and agencies locally and put in place, and test, locally-appropriate health-care solutions. To achieve these objectives, *Lifting The Burden* will exploit whatever opportunities are presented, and create others in order to observe the Campaign's priorities. However, needs in highly-developed countries including USA and those of Western Europe [4] will not be overlooked.

Resource realization

Even though many of its direct contributors will give their time as part of their academic commitment, and benefiting from association and a stream of publications, *Lifting The Burden* will inevitably be costly. It is impossible to set out an overall budget: the cost of the Campaign depends wholly upon what activities are undertaken within it.

The source of funds so far has been the pharmaceutical industry, who have been generous in underwriting the costs of the early planning phase. Pharmaceutical companies who share and may therefore wish to support many of

the objectives of *Lifting The Burden* are welcomed as partners in the Campaign. The industry are seen as helpful collaborators but not necessarily as the principal long-term sponsors of *Lifting The Burden*, and the Campaign will seek to create new income sources. There are two good reasons why the non-pharmaceutical industrial sector might support *Lifting The Burden* in strategic alliances: the first is that employers bear most of the cost of headache; the second is corporate social responsibility, which can be tapped as awareness is raised of the social damage wrought by headache.

In addition there is the Millennium Fund, raised for the purpose as the proceeds of *Headache World 2000* by a combined effort of the British Association for the Study of Headache, the Migraine Trust, IHS, EHF and WHA. This fund, held by WHA, can for several years cover most of the cost of the human resources that *Lifting The Burden* must have at its disposal in order to operate.

The Working Group for Resource Realization has the tasks of identifying likely sources of, and building and implementing a strategy for raising, the financial and logistic support that will make *Lifting The Burden* possible.

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