

58 *Lifting The Burden: The Global Campaign Against Headache*

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Abstract: Headache disorders are highly prevalent, ubiquitous, often lifelong and disabling. They are largely treatable, but everywhere are under-recognized, underdiagnosed, and undertreated. In many countries, they are simply not acknowledged as illnesses requiring health care, and in all countries they have low priority. The Global Campaign against Headache (GC), launched in collaboration with the World Health Organization, is a response to this public-health disaster.

This chapter briefly describes the origins of the Global Campaign, its vision and purpose, its structure and three stages, and its activities and achievements during the 7 years since its launch.

Introduction

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, they are also disabling.

And they are ubiquitous. Headache disorders are not complaints only of rich countries. While 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 while 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 among 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.

Lifting The Burden: A Response

In September 2003, the World Health Organization (WHO) signed a Memorandum of Understanding that brought into being the Global Campaign against Headache (GC), known as *Lifting The Burden*.

This truly important event for people worldwide affected by headache signaled WHO's recognition of headache disorders as a global public-health priority. It did not come about easily: there are many competing claims upon WHO's limited resources, and WHO accords priority only where it is manifestly due. Headache disorders in fact fulfill all of the criteria against which WHO assesses priority: they are highly prevalent, ubiquitous, disabling, and to a large extent treatable. While we all knew this, WHO required proof of it. This was quite right, and proof was provided, first at a technical consensus meeting on headache disorders hosted at WHO headquarters in Geneva in April 2000 (World Health Organization 2000) and then, crucially, by assimilating the evidence on migraine for WHO's *Global Burden of Disease Survey 2000* (GBD2000) (migraine had not featured in the earlier GBD1990). The outcome was conclusive: Migraine, on its own, was shown to be among the top 20 causes in the world of years of life lost to disability (World Health Organization 2001). Headache disorders came in from the cold.

Initially the GC was a partnership between WHO, International Headache Society (IHS), European Headache Federation (EHF), and World Headache Alliance (WHA), all of whom were cosignatories to the Memorandum of Understanding. It has moved on since. *Lifting The Burden* is now a legal entity in its own right, incorporated and registered as a charity in the United Kingdom, and admitted into Official Relations with WHO, markers of considerable success in its formative years. More broadly based now, the GC is better described as a collaboration between WHO, international nongovernmental organizations, academic institutions, and many willing individuals around the world. Its academic base has moved from Imperial College London to the Norwegian University of Science and Technology (NTNU), where it is better supported; the interests and research priorities of the Department of Clinical Neuroscience at NTNU enthusiastically embrace headache and global public health.

The originally conceived three stages of the GC have been described in detail before (Steiner 2004). In summary, first is to know the nature, scope, and scale of the problem – that is, the burden of headache – everywhere in the world (“knowledge for action”). It is perhaps extraordinary that, in 2003, very little was known of the prevalence or burden of any headache disorder for more than half the people of the world (Stovner et al. 2007): those living in most of the Western Pacific including China, all of South East Asia including India, all of Eastern Europe including Russia, most of Eastern Mediterranean, and most of Africa. Second is to exploit this knowledge, as it is gathered, to persuade governments, health-care providers and the public that, on clear evidence, headache *must* have higher health-care priority (“awareness for action”). Third, and the ultimate purpose of the GC, is to work with local policy makers and principal stakeholders to plan and implement health-care services for headache, ensuring these are appropriate to local systems, resources, and needs (“action for beneficial change”).

Changing the world is a challenging task. Rather than suffer Descartes' paralysis from uncertainty (Descartes 1901), *Lifting The Burden* adopted the indomitable spirit invoked by American poetess, Marianne Moore (► [Box 58.1](#)), and set about the task with an aspirational

vision (► [Box 58.2](#)). It took the three stages of the task apart into multiple steps, all with achievable objectives that, when reassembled at some time in the future, would lead to that vision (*A journey of a thousand miles begins with a single step* (attributed to Confucius)).

Box 58.1: I May, I Might, I Must

If you will tell me why the fen
appears impassable, I then
will tell you why I think that I
can get across it if I try.

Marianne Moore (1887–1972)

Box 58.2: The Global Campaign's Vision

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

The First Seven Years

Filling the very large gaps in knowledge for action has been the first priority. No standard methodology existed for population-based burden-of-headache studies, so *Lifting The Burden* developed its own. The model calls for a representative mix of urban and rural population samples, encountered by door-to-door “cold-calling” at randomly selected households; from each household, one adult, also randomly selected, is interviewed; the structured diagnostic questionnaire, based on ICHD-II, is validated in a pilot study within the population to be surveyed.

Applying this model, studies have been completed in Georgia (Kukava et al. 2007; Katsarava et al. 2009a, b) and Moldova (Moldovanu et al. 2007) and have reached the analysis stage in Russia (Ayzenberg et al. 2010), China (Yu et al.), and India; others are underway in Zambia and Pakistan, and more are planned in Saudi Arabia, Ethiopia and, possibly, Morocco, Abu Dhabi, Guatemala, Belize, Serbia, and Brazil. So far, these have revealed an extraordinarily high prevalence of daily headache in countries of Eastern Europe, highly prevalent migraine in Russia and, especially, in India (as represented by Karnataka State), and a prevalence of migraine in China, where it had been thought to be low, that is not very dissimilar from the global average of 11% (Stovner et al. 2007).

Lifting The Burden is a partner in *Eurolight*, a project supported by the European Commission Public Health Executive Agency to survey the impact of headache throughout Europe. This has harvested information from people with headache in Austria, France, Germany, Ireland, Italy, Lithuania, Luxembourg, the Netherlands, Spain, and the United Kingdom (Andrée et al. 2010). All of this will soon be published.

As for awareness, at the International Headache Congress in Kyoto in October 2005, the *Kyoto Declaration on Headache* was drafted with the guidance and signed in the presence not

only of WHO's Regional Director for the Western Pacific Region but also of representatives of the Japanese Ministry of Health, Labour and Welfare. *Lifting The Burden* secured the inclusion of headache disorders in the *Atlas of Neurological Disorders* (World Health Organization, World Federation of Neurology 2004), produced in 2005 jointly by WHO and the World Federation of Neurology (WFN), and as a major chapter in WHO's later publication, *Neurological disorders: public health challenges* (World Health Organization 2007). All of these, not only because they have the imprimatur of WHO but also because their content is compelling, enter the consciousness of politicians, bringing awareness to them of headache as a substantial cause of public ill-health (Martelletti et al. 2007). So, too, does *Lifting The Burden's* joint review with WHO showing the paucity of headache research in low- and middle-income countries (Mateen et al. 2008), and even more so will the joint global survey for WHO's *Atlas of Headache Disorders*, due to be published in 2011. The *Atlas of Headache Disorders*, one in the continuing series of Atlases published by WHO, will include data on headache and headache services gathered from more than 100 countries.

Politically more telling than all of these will be the inclusion of migraine and, for the first time, tension-type headache and medication-overuse headache in the new *Global Burden of Disease Study 2010* (GBD 2010). GBD2010 is a major revision of GBD2000, the importance of which, for the cause of headache, is highlighted above: it is essential for the future that GBD2010 accords due weight to the worldwide burden of headache, and *Lifting The Burden* has put much into assimilating, analyzing, and presenting the evidence on which this depends.

As *Lifting The Burden* considers models of headache service delivery and organization, and endeavors to make evidence-driven recommendations for change (Antonaci et al. 2008; Steiner et al. 2011), one clear principle is that most headache management belongs in primary care. The numbers of people who need it make this so (Steiner et al. 2011), but it is anyway the case that *most* headache management does not benefit from involvement of specialists. Nonexperts in primary care can do it perfectly well, although they do need some training.

Education is a central pillar of beneficial change (Steiner 2004, 2005). Training doctors to be better at managing headache is a huge undertaking on its own, but completely necessary: the current deficiencies in training, themselves engendered by the low priority given to headache, are at the heart (though not the whole cause) of the universal health-care failures for headache. Education is required at all levels, and therefore an undertaking to be shared – with IHS, EHF, and similar organizations, of course, but also with the universities. Within the GC is the Master's Degree in Headache Medicine at Sapienza University, Rome. This annual theoretical and practical course, now in its eighth year, is delivered by an international faculty (Martelletti et al. 2005). It is a training-the-trainers program, directed at specialists but with the hope of reaching primary care, the intended target, as the trainees return as trainers to their home countries.

Management by nonexperts in primary care can be made better also by the provision of practical clinical management supports, upon which *Lifting The Burden* embarked by assembling a writing and review group from all world regions in order to ensure multicultural relevance – a cardinal requirement of everything the GC is engaged in. Already produced, or in development, are diagnostic aids applying the criteria of ICHD-II, but simplified; regional management guidelines developed, where these exist, by harmonizing national guidelines (Steiner et al. 2007); information sheets for patients to aid understanding and promote compliance with treatment (Steiner 2007a); and universally acceptable indices of impact and treatment outcome (Steiner 2007b). The last was developed at a technical consensus meeting on headache outcome measures at WHO headquarters in April 2006, and follow-up validation and evaluation studies are being conducted in six countries.

This *Handbook of Headache*, written by authors from all over the world, is also aimed at nonspecialists. It is a supplement to these aids, providing detail when this is required.

Because good translation is crucial to multicultural relevance, *Lifting The Burden* has developed translation standards and protocols for GC materials (Peters 2007).

Lifting The Burden is working with, and supporting, the Cochrane collaboration, fostering systematic reviews of treatments for headache. One of the purposes is to be able to advise WHO on revisions to its essential medicines list, which, in time, will encourage availability worldwide of the drugs most needed to treat headache effectively.

As for actual intervention, *Lifting The Burden* has developed a headache-service model, to be tested soon in Georgia and later, if plans go forward, in Serbia, Bulgaria, and Abu Dhabi. The model is adaptable, but involves first assessing local need, together with willingness to pay, upon which sustainability will depend. The next steps in Georgia are to establish three clinics, provide free care and drugs to geographically defined populations and show the benefits of treatment to people and of the service to population health. Only once these benefits are apparent, the service will charge according to willingness to pay in order to become self-sustaining.

Ultimately, *Lifting The Burden* must evaluate what it helps to create, and amend it, in an iterative process if necessary, to achieve what is best possible. This raises a fundamental question: What is a good headache service? Surprisingly, or perhaps not, “quality” in the context of headache services has no accepted definition. Indeed it is not easily defined, although in part it must lie in the attainment of good outcomes, which can be measured. In preparing its proposals for headache-service quality evaluation, soon to be published, *Lifting The Burden* has undertaken a worldwide consultation.

Conclusion

This is a summary of what has happened. Not everything has been included. We believe *Lifting The Burden* can be pleased with and proud of its first 7 years. The activities represent many more than a single step (*A journey of a thousand miles begins with a single step* (attributed to Confucius)); more importantly, the steps are all in one and the right direction – each part of a cohesive, managed project directed toward a clear purpose. They involve actions in 28 countries, a seventh of the world’s total.

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University, Guangzhou, and the First Hospital of Jilin University, Changchun; in Denmark: the Danish Headache Centre, Glostrup, and the University of Copenhagen; in Ethiopia: the University of Addis Ababa; in France: Hôpital Pasteur, Nice, and Hôpital Lariboisière, Paris; in Georgia: Tbilisi Medical University; in Germany: the University of Essen and the Institute for Health and Rehabilitation Sciences, Ludwig Maximilians University, Munich; in India: the National Institute for Mental Health and Neurosciences, Bangalore; in Italy: the National Neurological Institute C Mondino, Pavia, Sapienza University, Rome, Department of Neurology Policlinic of Monza, the University of Turin and the Neurological Institute Carlo Besta, Milan; in Japan: the Ministry of Health, Labour and Welfare and the International Headache Center, Kawasaki, Kanagawa; in Luxembourg: Centre de Recherche Public de la Santé; in Moldova: Chisinau State Medical and Pharmaceutical University; in the Netherlands: Medisch Centrum Boerhaave, Amsterdam; in Norway: the Norwegian National Headache Centre and the Norwegian University of Science and Technology, Trondheim; in Pakistan: DOW University of Health Sciences, Karachi; in Portugal: Hospital da Luz, Lisbon; in Russia: Setchenov Moscow Medical Academy and the Institute of Sociology, Russian Academy of Sciences, Moscow; in Saudi Arabia: King Abdullah International Medical Research Center, Riyadh, and the Saudi Arabia National Guard; in Serbia: the Ministry of Health and the Institute of Neurology and School of Medicine, Belgrade; in Spain: University Clinic Hospital, Valencia University; in Sri Lanka: the University of Colombo; in United Arab Emirates: the Health Authority – Abu Dhabi (HAAD); in the United Kingdom: Imperial College London, the City of London Migraine Clinic, the University of Oxford, and Isis Medical Media Ltd, Tonbridge; in the United States of America: Albert Einstein College of Medicine, Bronx NY, Brigham and Women's Hospital, Boston MA, Duke University, Durham NC, Geisinger Clinic, Center for Health Research, Danville PA, Michigan State University, East Lansing MI, the New England Center for Headache, Stamford CT, Park Nicollet Headache Clinic & Research Center, Minneapolis MN, Roosevelt Hospital, New York NY, Uniformed Services University, Bethesda MD, and the University of North Carolina, Chapel Hill NC; in Zambia: Chainama Hills College Hospital, Lusaka. And at individual level, they include many people, far too numerous to list.

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