

**The Burden of Headache Disorders
and
Planning Best Practice in Headache Services**

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INTRODUCTION

Recognition of headache disorders as a major public health problem calls for fundamental change in society's approach to these burdensome disorders. These common neurological complaints significantly impair health, whilst 80% of migraine sufferers and many of those with tension-type headache experience disability and reductions in social activities and working ability. Despite this, both the public and the majority of health-care professionals everywhere still tend to perceive headache disorders as minor or trivial complaints. In some regions they are not recognized as medical conditions at all. As a result, the physical, emotional, social and economic burdens of headaches are poorly acknowledged.

It is right to consider the impact of headache disorders on public health from the humanistic perspective of suffering rather than limit the discussion to one focused on financial cost (Martelletti and Leonardi, 2003). The World Health Organization (WHO, 2000) held a consensus conference on the public health impact of headache where several recommendations were produced. Between them they underlined the need to evaluate, in a broad sense, the **burden** attributable to these disorders.

Epidemiology is essential in assessing the burden of a disease. The epidemiology of headache disorders is only partly documented; for example, migraine is the most extensively studied headache disorder whilst the more common tension-type headache and the more disabling cluster headache and subtypes of chronic daily headache have been less well investigated (eg, Rasmussen, 1991; Osterhaus *et al*, 1992; Stewart *et al*, 1996; Schwartz *et al*, 1997). In addition, because of the high cost of conducting large-scale studies, because of obstacles in the way of access to the general population and because headache is accorded low priority in regions where communicable diseases may pose a greater threat to public health, definitive epidemiological data for most developing countries is lacking across all headache types (Leonardi, 2003). These data deficiencies need to be made good if burden is to be adequately understood.

The contemporary appearance at international level of the concept of "sustainable medicine", in terms of allocation of the available health resources, challenges the headache community. Everywhere in the world, allocation is not fairly matched to the high levels of headache-related health-care needs, whilst demands for a larger share of resources meet resistance from those whose counter-claims are accorded higher priority. This has led headache research groups to involve and work closely with health economists, public-health administrators and lay organizations, co-operating to develop ideas for best practice in meeting these needs.

This publication is composed of a trilogy of papers. The first sets out the aspirations and objectives of the *Strengthening Patient Organizations Globally* (SPOG) project of the World Headache Alliance (WHA), which seeks to promote best practice in health-care provision for headache disorders. WHA's goal is to reduce the burden of headache worldwide. WHA believes that lay organizations play an important role in raising awareness. Armed with the scientific evidence, they are particularly well-placed to transfer the core message to their members, communities and governments that headache disorders are real, ubiquitous, common, burdensome and treatable. Regionally based, WHA's member organizations understand first-hand the cultural mix in their communities of support for and barriers against effective delivery of health care and access to it, and the context created by local government systems, societal attitudes to disability and perceived public stigmas.

The second paper reports part of the work of WHO on *Global Burden of Disease* reported in the *World Health Report 2001*. This key WHO publication discusses and endeavours to quantify the burdens attributable to more than 135 health conditions. Amongst these are the most disabling mental and neurological disorders: dementias, epilepsy, Parkinson's disease, multiple sclerosis and migraine. The Report uses a summary measure of population health, the Disability-Adjusted Life Year (DALY), which adds disability to mortality. The great importance of including disability is that it properly increases the relative weight given to non-communicable diseases, which cause much more disability than mortality and were invisible in traditional estimates of burden that used mortality based measures alone. The Report shows that mental and neurological conditions account for 30.8 per cent of all years lived with disability (YLDs) in the world; **migraine** is in the top 20 causes of YLDs, representing almost 0.5% of the total burden expressed in DALYs.

Migraine is only one of several common and burdensome headache disorders. An overview of epidemiological information on migraine and tension-type headache helps to identify the size of the problem of headache and highlight the need for further epidemiological studies in many parts of the world.

The third paper is a case study. Its purpose is to illustrate, in a country-specific context, how the case for improved health care for headache towards best practice might be mounted in order to persuade policy-makers of the need for change.

Whilst the arguments in the case take their strength from the verifiable evidence of high burden attributable to headache, and of unmet need, this alone is not persuasive. There are many other competing claims for health-care resources that are limited everywhere. All improvements in provision in one area are likely to be at opportunity cost to others. The case therefore acknowledges the inevitable counter-arguments that will resist change and, crucially, takes careful account of the political context and priorities in which proposals for change are made. Unless this is done, the case will not be made.

It is appreciated that many aspects of the case are unique to the UK and will not have obvious relevance to other countries. This would be true of any country case. It is hoped that the approach, and the general issues raised and dealt with, will be useful as an example to groups elsewhere who are seeking to plan and implement best practice in headache care.

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