

EDITORIAL

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The Global Campaign against Headache, aged 21: a critical self-appraisal, and plans for phase 2

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The Global Burden of Disease (GBD) study, conducted iteratively over the period 1990 to 2021, shows no diminution in the lost-health burden of the common headache disorders – migraine, tension-type headache and medication-overuse headache [1, 2]. Estimates of years lived with disability (YLDs) attributed to these disorders have kept pace with population expansion.

Absent, therefore, is any evidence of effective intervention to reduce this burden, at population level, throughout these 30 years.

In 1991, sumatriptan was added to the available treatments, the first of a new class of migraine-specific acute medications [3]. It was followed in short order by six other triptans. These efficacious drugs, it was predicted, would revolutionise migraine management. If this happened, the benefits at population level are difficult to perceive.

On 26th March 2004, the Global Campaign against Headache was launched at a meeting in Copenhagen hosted by the European Regional Office of the World Health Organization (WHO) [4]. *Lifting The Burden* (LTB), the UK-registered charitable company created to lead the Campaign in collaboration with WHO, was granted official relations with WHO in 2011 [5]. Over the years, some 400 academic collaborators from 40 countries came on board, supporting a programme of activities expressly intended to reduce the burden of headache [6]. With no evidence of this being achieved, what success can the Campaign claim, as it reaches its 21st anniversary?

The global burden of headache was not known in 2004. There were very few data from low- and lower-middle-income countries, in which were living more than half the world's population [7]. The Global Campaign addressed this by applying new, consensus-based and standardised methodology [8] in 17 population-based studies in Africa, Eastern Mediterranean, Eastern Europe, South America, South East Asia and Western Pacific, and in a programme, starting later and interrupted by the covid-19 pandemic, of schools-based studies of children and

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adolescents [9]. A still-growing database holds >75,000 individual participant records [10]. Informed by these studies, GBD ranks headache disorders third highest cause of YLDs (5.23% of all YLDs) at level 3 (groups of related disorders), and migraine fourth (4.73% of all YLDs) at level 4 (specific disorders) [1]. With a conservatively estimated prevalence of almost 15%, a mean time spent with headache (ictal state) determined from the Campaign's population-based studies of 8.5%, and a disability weight of 44.1% (estimated health loss) attributed by GBD to the ictal state [11], migraine is now believed to account for 5,500 YLDs per million of the population. This is a health loss equivalent to 5,500 people in every million dying one year prematurely each year.

The financial burdens are commensurately high. In 2009, according to the Campaign's estimates, migraine cost the economy of Europe some €50 billion; headache disorders collectively cost €112 billion [12]. More than 90% of these costs were attributable to lost productivity, a blunt but forceful indicator of the extent to which headache is disabling.

The *Atlas of Headache Disorders* was jointly produced by WHO and LTB in 2011, setting out evidence from more than 100 countries [13]. WHO sent it directly to 192 ministries of health, with a stern exhortation: "The facts and figures ... illuminate world-wide neglect of major causes of public ill-health, and the inadequacies of responses to them in countries throughout the world."

But few politicians were listening.

The numbers are the problem. In a highly conservative needs assessment, over 80,000 people (adults, or children and adolescents) among every million are in need of headache care – in the sense that they would be expected to benefit from it [14]. An equally conservative estimate suggests 40 full-time professional health-care providers (HCPs) are required to meet this need [14] – an impossible demand on resources if the perception persists that headache care means specialist care. It does not [15]: >90% of this need can be met in primary care, and not necessarily by doctors: clinical officers, nurses and community pharmacists can, with small amounts of additional training, effectively and safely carry much of the load [14]. Structured headache services, based in primary care but with facilitated upward referral channels for the small minority who need these, are the Campaign's proposed solution, equitable and adaptable to the resources and health-care infrastructures of all countries [14]. Economic evaluation of such services theoretically implemented in Russia, Spain and Luxembourg predicts a cost of less than €2,000 for each healthy life-year they would gain [16] – far below usual cost-effectiveness ceilings.

Because HCPs in primary care are not experts in headache, the Campaign has developed a range of practical

management aids: diagnostic aids based on the international classification of headache disorders (ICHD), a measure (the headache-attributed lost time [HALT] index) for assessing priority, management principles, an outcome measure for all primary headaches (the Headache Under-Response to Treatment [HURT] questionnaire) to guide treatment according to its effectiveness, information leaflets for patients [17], and translation protocols so that these might be rendered into other languages with conceptual equivalence [17, 18]. Because non-expert HCPs require additional basic training, the Campaign conducted a study in Estonia, showing that two days of instruction in headache care improved GPs' care process, avoiding many needless referrals to secondary care [19]. Because quality is of the essence of effective services, the Campaign convened a consensus group to define "quality" in the context of headache care [20], and develop 30 service quality indicators across nine domains: a good service provides accurate diagnosis, individualised management and appropriate referral pathways, educates patients, is convenient and comfortable, satisfies patients, is efficient and equitable, assesses outcomes, and is safe [21]. These indicators have been evaluated in specialist care [22, 23], and in primary care in Germany, Turkey, Portugal and Latvia [24].

All this (Fig. 1) has been reported in more than 150 publications [6], while all materials and products of the Campaign are in the public domain, freely available for non-commercial purposes. It has been done while eschewing support from the pharmaceutical industry, thanks in part to generous donors, but also thanks to the 400 academic collaborators who have contributed without financial reward.

Not every project is finished. The global schools-based programme measuring headache-attributed burden in children and adolescents will continue, making up for the time lost to covid-19, and there is the challenging task of service quality evaluation in pilot implementations of structured headache services. Nonetheless, by characterising and quantifying the global burden of headache, by signalling – loudly, through its partnerships with WHO and GBD – that headache disorders ought to be a high public-health priority, and by proposing an affordable and equitable health-care solution, the Campaign has largely fulfilled the mission and objectives it initially set itself.

But, as GBD shows [1], it has not achieved any measurable reduction in the global burden of headache. For this, political will is needed.

Sadly, with a few exceptions, politicians are still not listening.

So, as the Global Campaign reaches the milestone of its 21st anniversary, LTB is looking to its future, shaping

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