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Migraine – the forgotten epidemic: development of the EHF/WHA Rome Declaration on Migraine

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Abstract Despite the availability of effective treatments, many migraine sufferers in Europe still do not receive optimal treatment. A panel of specialists, primary-care physicians and patient-group representatives met in Rome on 10–11 June 2005, under the auspices of the European Headache Federation (EHF), the World Headache Alliance (WHA) and the University of Duisburg-Essen, to review the scientific background, management issues, and physician, patient and government perspectives on migraine. The goal of the meeting was to produce the *EHF/WHA Rome Declaration on Migraine*, a

statement of the actions required to improve migraine care and the quality of life of people with migraine. The key recommendation of the *EHF/WHA Rome Declaration on Migraine* is education of migraine sufferers, health professionals and health-policy makers.

Keywords Migraine • Quality of life • Treatment • Consensus

The Migraine “MetaForum” Meeting

Migraine is a disabling neurological disorder of the brain with potentially serious consequences that, in some patients, extend widely beyond pain itself. Many aspects of a sufferer’s life may be compromised by migraine, including education, employment, personal relationships, family life and social activities.

Despite the availability of effective treatments, many people with migraine in Europe do not receive optimal treatment. As recognition of the disabling effects of migraine increases, a panel of headache specialists, primary care physicians and patient group representatives

from Europe, Canada, Israel, South Africa and the USA gathered in Rome on 10–11 June 2005 for a Migraine MetaForum. The meeting took place under the auspices of the European Headache Federation (EHF), the World Headache Alliance (WHA) and the University of Duisburg-Essen. Its purpose was to review the scientific background, management issues, and physician, patient and government perspectives on migraine. The ultimate goal of the MetaForum was to arrive at a formal consensus, expressed in the *EHF/WHA Rome Declaration on Migraine*, comprising the issues, actions and next steps required to improve migraine care and quality of life among people affected by migraine in Europe.

The MetaForum panel aims to ensure that the findings from the meeting and the *Declaration* are widely publicised through the EHF, WHA and medical press, and used to precipitate constructive change for migraine sufferers.

The continuing achievements of the *Helsingborg Declaration on Stroke Management* [1], developed 10 years ago to improve the care of stroke patients, show that such coordinated efforts are powerful politically. Most goals of the *Helsingborg Declaration* have been achieved, for example, to decrease mortality after stroke and to implement dedicated stroke units.

The burden of migraine on society

Migraine is one of the most common neurological illnesses, with around 12% of the adult population worldwide suffering from migraine [2–11]. The World Health Organization (WHO) has ranked migraine among the top 20 causes of disability, ahead of conditions such as asthma and diabetes [12–14].

The impact of migraine on society includes its cumulative effects on individuals, the direct costs of medical treatment where these are borne by society and the indirect costs of lost workdays and impairment at work, both for people with migraine and for their family members. In European and North American economic surveys, most of the total costs of migraine were found to be attributable to lost work productivity rather than the direct costs of physician visits or medication [15, 16].

Effects of migraine on the affected individual

As well as the financial burden of migraine on health services and employers, it is important not to underestimate the impact of migraine on individuals. The Migraine and its Effects on Life and Treatment (MELT) survey interviewed 1810 women with migraine aged 18–35 years from eight European countries and Israel, all of whom were in full- or part-time work or full-time school or college, and were using headache medication [17, 18]. Participants experienced an average of 23 migraine or other severe headaches per year, which in the previous 6 months had caused an average 2 days of absence and 4 days of reduced function at work or school [17]. As a result, 16% of women reported that migraine had prevented them from achieving their career goals. Approximately two-thirds of participants reported that migraine made them less able to enjoy recreational or leisure activities. Unsurprisingly, most women (86%) believed that their

lives would be better if they did not suffer from migraine. Frustration, anger, depression and fear were commonly reported negative emotions, with 23% afraid to leave the house when anticipating a migraine attack [18].

The MELT study focused on the effects of migraine on young women during a demanding phase of their lives, when they were starting careers and families. Work loss was greatest in the youngest women, in those who were single, divorced, separated or widowed, and for women with more frequent migraine attacks [17].

While 81% of participants had consulted a physician during the previous year, 39% felt that their doctor did not understand how much migraine interfered with their lives [18]. Patients may understate the impact of migraine in consultations with their physicians, especially if they have not had an attack for some time, and should be encouraged to keep a diary recording the longer-term consequences of their attacks as well as the acute symptoms. Physicians should ask not only about the severity of the pain, but also about how migraine affects patients' work or education, family and social activities.

Migraine treatment strategies

Effective treatment requires that individual patients and their physicians work together to develop a treatment plan identifying specific and appropriate short-term goals [19]. Patients should be engaged in their management, for example, by discussing treatment and medication preferences, and treatment should be tailored to each individual's needs, based on frequency and severity of attacks, degree of disability, associated symptoms, comorbid conditions and prior response to medications.

Patients may be uncertain of the best time to take acute migraine medication, delaying treatment until they are sure they are having an attack or because they do not want to use medication unless it becomes severe [20]. There is evidence that acute treatment of migraine attacks with triptans is most effective when taken early in the attack while headache is mild rather than waiting until the pain is more severe [21–25].

Multiple triptan studies have found that severe migraine headache is more difficult to treat, which may not be surprising. However, advising patients to treat early in the attack has the potential disadvantage of encouraging overuse of migraine medication and the associated risks of inducing medication-overuse headache. Indeed, an important goal of migraine management is to prevent episodic migraine from transforming into chronic headache. It is vital to educate patients to avoid triggers and treat headaches appropriately, reduc-

ing the risk of a chronic headache disorder. Patient education includes understanding that acute medications should not be used too frequently: triptans used regularly on more than 10 days per month or simple analgesics on more than 15 days per month can result in medication overuse headache.

Evaluating the success of migraine treatments

The endpoints currently used in clinical trials may not be ideal for assessing migraine treatment in clinical practice. Questionnaires such as the Migraine Disability Assessment (MIDAS), Headache Impact Test (HIT) and Migraine Therapy Assessment Questionnaire (MTAQ) are reliable and valid tools that provide valuable data in clinical studies. However, such questionnaires may be too complicated for patients and physicians to complete within limited consultation time in primary care. Simple, patient-friendly evaluation instruments are more practical for use in primary care, both for initial assessment and as a treatment outcome measure.

The most frequently used tools for the assessment of migraine treatment success in clinical practice are headache diaries or calendars. Patients should be instructed to record the date, duration, intensity and any triggering factors of each attack, and the medications used to treat it. The physician can then use the diary to assess migraine severity and impact on daily life, and success of current treatment, and plan future follow-up.

In everyday clinical practice, reappraisal of treatment success should be routine and repeated from time to time, as migraine characteristics and patients' treatment needs can evolve.

Consensus of the MetaForum: the EHF/WHA Rome Declaration on Migraine

With the great diversity and depth of experience and knowledge among the participants, the MetaForum panel has drawn together a unique view of the key issues and developed goals and action points for the *EHF/WHA Rome Declaration on Migraine* that will improve outcomes for patients with migraine. The key recommendation to come out of the meeting was education of people affected by migraine, health professionals who treat migraine and health-policy makers. The MetaForum panel was unanimous in its hope that the *EHF/WHA Rome Declaration on Migraine* will improve quality of life greatly for migraine sufferers.

The EHF/WHA Rome Declaration on Migraine: Migraine "The Forgotten Epidemic": A European Perspective

Consensus statements

- Migraine is a neurovascular disorder of the brain.
- The WHO recognises that migraine is the 12th highest cause of disability in women and the 19th highest cause of disability amongst both sexes:
 - it affects approximately 50 million people in Europe;
 - every day nearly 2 million Europeans have a migraine attack;
 - it costs the European economy well over 10 billion every year.
- A range of effective treatments exist. Acute therapy reduces disability during the attack and preventative therapy can reduce the frequency and severity on a long-term basis.
- Failure of healthcare systems to provide effective treatments to those who need them is the most important reason why this socio-economic burden persists.
- We call upon the governments and health policy makers of Europe to:
 - match our commitment to people affected by migraine;
 - recognise the priority that migraine deserves;
 - provide the resources that these initiatives require.
- We would like to emphasise that the cost of these resources will be offset by recovered work productivity.

Consensus actions

- Over the next 5 years, these are the targets we wish to achieve in Europe:
 - the percentage of migraine patients in the care of a physician should increase from the current level of 30% to 50%;
 - the number of patients receiving effective therapy for acute migraine attacks should increase from the current level of 40% to 70%;
 - at least 50% of patients requiring migraine prevention therapy should be receiving this treatment.
- We will work with the WHO on their public-health report, which will publish the trends and burden of migraine including:
 - collation of national data on risk factors, incidence and prevalence;
 - a clear definition of the burden of migraine (both direct and indirect costs) and a definitive report on the associated health economics;

- the need to screen for conditions co-morbid with migraine and to help patients' understanding that migraine can lead to co-morbid states.
- By working together, the professional and patient organisations active in Europe will:
 - set up awareness initiatives for the general public in order to create recognition of the need for treatment of migraine;
 - set up educational programmes for healthcare providers in order to improve their ability to diagnose and treat migraine;
 - produce and disseminate diagnostic aids, management guidelines and instruments for outcome evaluation.
- To achieve this, we will:
 - publish a literature review on current knowledge, perception and attitude of physicians and patients as a first step in awareness and improving the treatment of migraine across Europe;
 - develop active communication between patient organisations, healthcare providers and governments on migraine, its disabling effects, its public-health importance and its management;
 - promote use of tools that increase the knowledge of physicians, support them and sustain their compliance with nationally established guidelines;
 - challenge governments and health-policy makers to promote programmes to diminish the social and economic burdens of migraine;
 - urge physicians to encourage their patients to communicate freely their personal concerns and experiences in order to understand the true impact of the disorder;
 - apply measures of outcome to optimise acute and preventive migraine therapy.
- We will monitor the effects of these initiatives to demonstrate beneficial change.

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