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## Migraine and disability: WHO's work to measure functioning, disability and health and the Global Burden of Diseases Study

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**Abstract** This paper briefly describes some of the work developed by the World Health Organization in the field of health, disability and burden of diseases and how this work has relevant implications for migraine and, in general, for headache disorders. It presents some of the basic principles of the Global Burden of Diseases (GBD) study, its goals and some of its outcomes as related to neurological and psychiatric disorders as well as the implications for neuropsychiatric disorders to move from mortality towards disability indicators. It also presents some of the World Health Report 2001's data, where migraine

has been reported as a leading cause of years lived with disability. A brief presentation of the basic principles of the WHO Classification of Functioning Disability and Health (ICF) is provided as well as the reasons why ICF answers the pressing need for new measures for health. This WHO's instrument will be useful for the classification of functioning and disability in the field of headache disorders.

**Key words** World Health Report • Disability • Burden of disease • DALYs • YLD • Classification of functioning • Disability and health • Burden of migraine

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### Introduction

Mental and neurological disorders are common, affecting more than 25% of all people at some time during their lives. They are also universal, affecting people of all countries and societies, individuals at all ages, women and men, the rich and the poor, from urban and rural environments. They have an economic impact on societies and on the quality of life of individuals and families. Mental and neurological disorders are present at any point in time in about 10% of the adult population. Around 20% of all patients seen by primary health care professionals have one or more mental or neurological disorders. They cause a great burden to patients, families and societies. Common disorders, which usually cause severe disability, include depressive disor-

ders, substance-use disorders, schizophrenia, epilepsy, Alzheimer's disease, Parkinson's disease, migraine, multiple sclerosis, mental retardation, and disorders of childhood and adolescence.

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### The World Health Report 2001 and the burden of migraine

In 2001, the World Health Organization (WHO) published the annual World Health Report *Mental Health: New Understanding, New Hope* [1]. The Report focused on how neurological and psychiatric disorders represent a burden on a population's health and how this has been highlighted, moving from a mortality to a disability per-

**Table 1** Leading causes of years of life lived with a disability (YLDs) (From [1] with permission)

Females, all ages	Rank, % of total YLDs
1. Unipolar depressive disorders	14.0
2. Iron-deficiency anemia	4.9
3. Hearing loss, adult onset	4.2
4. Osteoarthritis	3.5
5. Chronic obstructive pulmonary disease	2.9
6. Schizophrenia	2.7
7. Bipolar affective disorder	2.4
8. Falls	2.3
9. Alzheimer's and other dementias	2.2
10. Obstructed labor	2.1
11. Cataracts	2.0
12. Migraine	2.0
13. Congenital abnormalities	1.9
14. Asthma	1.8
15. Perinatal conditions	1.8
16. Chlamydia infection	1.8
17. Cerebrovascular disease	1.8
18. Protein-energy malnutrition	1.6
19. Abortion	1.6
20. Panic disorder	1.6
Both sexes, all ages	Rank, % of total YLDs
1. Unipolar depressive disorders	11.9
2. Hearing loss, adult onset	4.6
3. Iron-deficiency anemia	4.5
4. Chronic obstructive pulmonary disease	3.3
5. Alcohol-use disorders	3.1
6. Osteoarthritis	3.0
7. Schizophrenia	2.8
8. Falls	2.8
9. Bipolar affective disorder	2.5
10. Asthma	2.1
11. Congenital abnormalities	2.1
12. Perinatal conditions	2.0
13. Alzheimer's and other dementias	2.0
14. Cataracts	1.9
15. Road traffic accidents	1.8
16. Protein-energy malnutrition	1.7
17. Cerebrovascular disease	1.7
18. HIV/AIDS	1.5
19. Migraine	1.4
20. Diabetes mellitus	1.4

*HIV/AIDS*, Infection with human immunodeficiency virus, or acquired immunodeficiency syndrome

spective, using then the methodology of the Global Burden of Disease (GBD) study. In the Report, WHO identified migraine among the world's top 20 leading causes of years lived with disability, with an impact that extends far past the suffering individual, to the family and community. The landmark report established the burden of migraine for the very first time after collecting information on migraine from around the world. The result is

anticipated to have long-reaching impact: on individual sufferers, their caregivers, family and colleagues, and on society itself.

The Report places migraine among all leading causes of years lived with disability (YLDs) in the world. Migraine is estimated to account for 2.0% of years of life lived with disability in women of all ages. In both sexes of all ages, migraine is responsible for 1.4% of total years of life lived with a disability (Table 1). These data arise from the results of the GBD study's methodology.

### The Global Burden of Diseases Study

Estimation of needs for health services, their costs and effectiveness requires indicators that go beyond measures of death rates or diagnosis alone, and include the "functioning" of people. Policy-makers, their public health partners and consumers alike seek rational guides to set priorities for health, to evaluate the outcomes of interventions and health care reforms, and to monitor changes over time at local, national, regional, or global levels. To respond to this need, the Global Burden of Diseases (GBD) study was carried out by the World Bank in collaboration with the World Health Organization (WHO) and the Harvard School of Public Health [2, 3]. The GBD study was designed to address three main goals:

- Provide information on non-fatal health outcomes for debates on international health policy which had until then focused on mortality
- Develop unbiased epidemiological assessments for major disorders, and
- Quantify the burden of disease with a measure that could also be used for cost-effectiveness analysis.

One specific variety of burdens is the *health* burden. This has traditionally been measured in national and international health statistics only in terms of incidence, prevalence and mortality. While these indicators are well suited to acute diseases that either cause death or result in full recovery, their use for chronic and disabling diseases poses serious limitations. This is particularly true for mental and neurological disorders, which more often cause disability than premature death. One way to account for the chronicity of disorders and the disability caused by them is the Global Burden of Diseases (GBD) methodology.

The Global Burden of Diseases (GBD) study has attracted the attention of policy makers and public health experts alike because it provides a common measure for evaluating and prioritizing across a wide range of health problems. This measure, the disability adjusted life year (DALY), has added "disability" to "mortality" in the evaluation of the burden of disease. The addition of disability has increased the relative

importance of non-communicable diseases, which cause much more disability than mortality. These conditions were invisible in traditional estimates of burden that used mortality-based measures alone. DALYs is a health gap measure that combines information on the impact of premature death and of disability with other non-fatal health outcomes. Being based on a universal measure of time, i.e. life years, DALYs provide a trans-professional currency to determine priorities for health and human services and to evaluate their effectiveness [2, 3].

The appeal of the DALY measure is that it provides a potentially useful tool for health policy purposes: the transformation of epidemiological data to informed decisions about resource allocation for health care. The results of the 1990 GBD study were based on epidemiological and demographic indicators, such as prevalence and incidence rates, life expectancy, probabilities of death in different age groups, disability-adjusted life expectancy, years of life lost because of premature death (YLLs) and years of life lived with disability (YLDs). In summary, one DALY is one lost year of healthy life:  $DALY = YLLs + YLDs$  (Burden = Mortality + Disability)

As this approach clearly shows, DALYs take into account not just mortality but also disability to reflect the total burden, which is a more sound approach to setting health priorities. This applications focus mainly on estimations of the “disability” component of the DALYs. DALYs are an aid to decision-making; they are not a complete procedure for making decisions because they cannot incorporate all the values relevant to the decisions. The use of DALYs in decision-making should be studied in a collaborative effort by decision makers and consumers to improve its usefulness. Therefore, calculation of time lived with disability strongly requires replication and further empirical study of the construct if DALYs are to be used for resource allocation and outcome evaluation [2, 3]. The World Health Organization has undertaken a new assessment of the global burden of diseases, GBD 2000, with the specific objectives to quantify the burden for 135 major causes or group of causes and to develop various projection scenarios of the burden of diseases over the next 30 years.

In the original estimates developed for 1990, mental and neurological disorders accounted for 10.5% of the total DALYs lost due to all diseases and injuries. This figure demonstrated for the first time the high burden due to these disorders. The estimate for 2000 is 12.3%. By 2020, from an analysis of trends, it is projected that the burden of these disorders will increase to 15% [3].

Taking the *disability* component of burden alone, GBD 2000 estimates show that mental and neurological conditions account for 30.8% of all years lived with disability (YLDs). Indeed, depression causes the largest amount of disability, accounting for almost 12% of all disability. Six

neuropsychiatric conditions figured in the top 20 causes of disability (YLDs) in the world: unipolar depressive disorders, alcohol-use disorders, schizophrenia, bipolar affective disorder, Alzheimer’s and other dementias, and migraine. Migraine, which represents almost 0.5% of the total burden, contributes with an important percentage of years lived with disability, YLDs [1].

However, due to lack of broad epidemiological studies, there are varying degrees of uncertainty in GBD 2000 estimates of DALYs and YLDs for mental and neurological disorders, reflecting uncertainty in the prevalence of the various conditions in different regions of the world, and uncertainty in the variation of their severity distributions. In particular, there is considerable uncertainty in the estimates of prevalence of neuropsychiatric disorders in many regions, reflecting the limitations of self-report instruments for classifying symptoms in a comparable way across populations, limitations in the generalizability of surveys in subpopulations to broader population groups, and limitations in the information available to classify the severity of disabling symptoms of these conditions.

Despite this variability and uncertainty in epidemiological data, it has been clearly shown that disability caused by mental and neurological disorders is high in all regions of the world. As a proportion of the total, however, it is comparatively less in the developing countries, mainly because of the large burden of communicable, maternal, perinatal and nutritional conditions in those regions. Even so, neuropsychiatric disorders cause 17.6% of all YLDs in Africa. These disorders are not the exclusive preserve of any special group; they are truly universal. Mental and neurological disorders are found in people of all regions, all countries and all societies. They are present in women and men at all stages of the life course. They are present among the rich and poor, and among people living in urban and rural areas. The notion that these disorders are problems of industrialized and relatively richer parts of the world is simply wrong. The belief that rural communities, relatively unaffected by the fast pace of modern life, do not have these disorders is also incorrect.

This has been brought to clear attention when evaluating the epidemiology of migraine; wherever in developing countries studies have been conducted, it has been shown that migraine is affecting large part of the population but it is a disorder that is well underestimated by health professionals and by the community.

The socioeconomic impact of migraine as well as of many neuropsychiatric disorders is wide ranging, long lasting and huge. These disorders impose a range of costs on individuals, families and communities as a whole. Part of this economic burden is obvious and measurable, while part is almost impossible to measure. Among the measurable components of the economic burden are health and social

service needs, lost employment, reduced productivity, impact on families and caregivers, levels of crime and public safety, and the negative impact of premature mortality. Indirect costs arising from productivity loss account for a larger proportion of overall costs than direct costs. WHO defines the “burden” of migraine to include the economic and emotional difficulties that a family experiences as a result of migraine, as well as the lost opportunities - the adjustments and compromises that prevent other family members from achieving their full potential in work, social relationships, leisure and so on [4]. All these estimates of economic evaluations are most certainly underestimates, since lost opportunity costs to individuals and families are not taken into account, but are nevertheless vital to fully understanding the implications of the disorder.

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### **ICF, the International Classification of Functioning Disability and Health, and its application to headache disorders**

The knowledge about prevalence, incidence and prognosis of many diseases, as mentioned before, is still limited because of methodological weakness of many studies. Epidemiological data on migraine, as well as of almost all neuropsychiatric conditions, are still scarce in many parts of the world and are inconsistent because of the sampling frames and how prevalence rates are defined (e.g. the lifetime or point prevalence) and of inconsistency between incidence and prevalence estimates. There is an urgent need to implement epidemiological studies and to demonstrate possible effects of changes in epidemiology of the disorder.

Uncertainty about the prevalence distribution, as well as in the variation of severity of many neurological conditions, reflects the limitation of instruments for classifying neuropsychiatric conditions in a comparable manner across populations and the limitation in the information available to classify the severity and the disability for the disorders. In recognition of the limitation of using a disease-centered approach to health, the WHO developed in 1980 the International Classification of Impairments, Disabilities and Handicaps (ICIDH). This classification provided a new framework for examining the consequences of health conditions. It was developed for field trials only. The key issues were in defining disability including various domains of activities, measuring duration and severity of disability, mapping diseases through to their sequelae, which may all be condensed in determining the disability weights. After many years of use and through an extensive revision process of the ICIDH, involving researchers in more than 65 countries, the WHO published in 2001 a new tool and the standard to measure health and disability: the ICF, International

Classification of Functioning Disability and Health [5]. This classification represents an important instrument for all those who need a tool to measure health and health-related issues, particularly for all those who deal with conditions with low mortality and high disability.

Traditionally, scientists have measured the *outcomes* of health conditions by relying on mortality data. More recently, as discussed above, the international concern about health care outcomes has shifted to the assessment of functioning and disability at the level of the whole human being, in day-to-day life. The need is for universally applicable classification and assessment tools, both for activity levels and for overall levels of participation, by the individual in the basic areas and roles of social life. This is what the new International Classification of Functioning, Disability, and Health (ICF), approved by the World Health Assembly in May 2001, provides and makes possible.

Studies have shown that in the health services sector, diagnosis alone does not predict service needs, length of hospitalization, level of care or outcomes. We also know that a medical condition is not an accurate predictor of receipt of disability benefits, work performance, return to work potential, or the likelihood of social integration. So, a purely medical classification of diagnoses does not provide us with the information we require for planning and management purposes. However, when data on functioning are taken into account, the predictive power and understanding of needs and outcomes are increased [6]. It is true then that migraine could benefit from a *functional* measurement, and ICF could be the instrument to help researchers in the headache field by providing an internationally recognized tool and a common language.

The International Headache Society (IHS) has a long experience in classification and its collaboration with WHO on ICD-10 and ICD-10-NA (Neurological Adaptation) has led to the publication of the IHS classification of headache disorders [7]. Although this classification has been shown to be useful, in any case it classifies diseases by the diagnosis (etiological classification), not considering the functioning and disability (functional classification) due to headache disorders. Disability is a multi-dimensional construct, which covers different aspects at body, individual and society levels. These may range from self-care to work, from moving around to being able to travel and from participating in sporting events or household activities to voting. ICF provides the basic framework to operationalize the disability constructs that should be employed in developing measures for disability.

It is quite difficult to measure all the dimensions causing disability of a disease like migraine, but ICF allows to highlight all of them, including the environment and how this plays a key role on migraine sufferers. According to ICF's construct, any health condition, in a unfavorable environ-

ment, can cause disability. Environment as a barrier for migraine sufferers could be, for example, lack of health care facilities, lack of accurate diagnosis, lack of care or availability of drugs, but also difficulty in being taken seriously, and so on. In this sense the use of ICF in the headache sector would allow, beyond data comparability (which “per se” would be a success), the evaluation of the role of the environment as a cause of disability on headache sufferers.

Headache disorders are common, in many cases lifelong conditions that are associated with recognizable burdens including personal suffering, disability and impaired quality of life. With the publication of data on the burden of migraine in the 2001 World Health Report, WHO recognised headache disorders as a high-priority public health problem. As such they should deserve higher attention, but low priority is given to them in the queue for health care. ICF makes it possible to classify migraine and other headache disorders, highlighting the burden.

There is an increased recognition among social planners and service agencies that reducing the incidence and severity of disability in a population involves modifying the social and physical environment as well as enhancing the level of functioning of the person. Designed to meet these growing needs, the ICF has potential uses in many different sectors such as health services, insurance, social security, pensions, employment, human rights, research, planning and policy formulation, economics, human development, education and training. Thus, the ICF, in addition to providing a scientific model for the study of functioning and disability, meets the urgent need for a common, international language for globalized data collection, research, health care resource allocation and management, and social welfare programming.

Why is there a need for a classification of functioning and disability and how could this be useful in the field of headache?

- To better define the *need for health services* and related interventions;
- To define *health outcomes* in terms of body, person and social functioning;
- To provide a *common framework* for research, clinical work, and social policy;

- To ensure the *cost-effective* provision and management of health care and related services;
- To characterize *physical, mental, social, economic or environmental interventions* that will improve the lives and levels of human functioning.

The ICF provides a model of human functioning and disability, as well as a classification system that is useful at all levels of service provision and policy development, scientific research, intervention strategies and economic analyses [5, 8]. It is hoped that further collaboration with scientific and lay non-governmental organizations (NGOs) such as, World Headache Alliance (WHA), and IHS, will implement the use of such an useful instrument.

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## Conclusions

This paper summarizes the work done by the WHO to measure functioning, disability and health through the publication of the International Classification of Functioning Disability and Health (ICF), and to define disability with the development of the Global Burden of Disease study. These tools are useful to identify the burden of migraine as reported in the WHO World Health Report 2001. The WHO’s recognition of migraine as a major global disorder, therefore, is a major step toward relieving the burden of headache around the world. The next step will be to develop global and regional educational programs that will increase public awareness of the burden of headache disorders, and to increase research for the development of effective therapies for headache disorders.

It is hoped that further epidemiological studies, developed within the framework of the World Headache Alliance’s projects and of scientific societies, will provide further information that can help to identify strategies and interventions that may not only reduce the burden of migraine but furthermore try to prevent the development of migraine itself.

**Note** The opinions expressed in this paper are solely of the author and do not represent those of the WHO.

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## References

1. WHO (2001) The World Health Report 2001: mental health, new understanding, new hope. World Health Organization, Geneva (<http://www.who.int/whr/2001/main/en/overview/outline.htm>)
2. World Bank (1993) World Development Report: investing in health. Oxford University, New York
3. Murray CJL, Lopez AD (eds) (1996) The global burden of diseases: a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020. Harvard University, Cambridge (Global Burden of Disease and Injury series, Vol. II)

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4. Gallagher SK, Mechanic D (1996) Living with the mentally ill: effects on the health and functioning of other members. *Social Sci Med* 42(12):1691–1701
  5. WHO (2001) International classification of functioning disability and health: ICF. World Health Organization, Geneva
  6. WHO (1997) Towards a common language for functioning and disablement: ICDH-2. WHO/MSA/MNH/EAC/97.3. World Health Organization, Geneva
  7. Headache Classification Committee of the International Headache Society (1988) Classification and diagnostic criteria for headache disorders, cranial neuralgias, and facial pain. *Cephalalgia* 8[Suppl 7]:1–96
  8. WHO (2001) Social consequences and economic aspects. World Health Organization, Geneva (Fact sheet N. 166)