OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011

A collaborative project of World Health Organization and *Lifting The Burden*



Lifting The Burden

The Global Campaign against Headache

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FOREWORD

Headache disorders are among the most common disorders of the nervous system, causing substantial ill-health and disability in populations throughout the world. Despite this, they are underestimated in scope and scale, and there is little recognition of their public-health impact. It is not known how, or how effectively, health-care and other resources are utilized to mitigate their effects.

WHO has a number of important initiatives in the field of clinical neuroscience designed to promote international collaboration, enhance research capacity and, above all, develop programmes to benefit communities worldwide affected by neurological disorders. Among them is *Project Atlas*, a series of publications now including the *Atlas of Headache Disorders*, the result of a collaborative study by WHO and the nongovernmental organization, *Lifting The Burden*: the Global Campaign against Headache. The Global Campaign involves multiple nongovernmental organizations, academic institutions and individuals worldwide, with objectives not only of better professional, public and political awareness of the global burden of headache but also of solutions to it.

It might appear that production of an Atlas would be difficult in relation to headache disorders, but this publication, carefully and expertly designed and covering, as it does, very important causes of population ill-health and disability, is highly appropriate and timely. Its introduction provides a clear description of its purpose, definitions and descriptions of the principal headache disorders and an account of barriers to care that must be overcome if these are to be managed effectively. The results, gathered from respondents from more than half the world's countries, are set out in themes: epidemiology, the impact of headache disorders on society, health-care utilization, diagnosis, assessment and treatment, professional training and the importance of national professional organizations are all given full consideration.

The key messages derived from this project can be expected to have major influence upon the recognition and management of headache disorders across the world. This publication is likely to be widely read; it is an important resource for doctors and others interested in headache disorders or concerned with their management, especially policy-makers.

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Former President, World Federation of Neurology Crossbench Life Peer, UK House of Lords

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PROJECT TEAM AND PARTNERS

The *Atlas of Headache Disorders* is a project of WHO headquarters, Geneva, supervised and coordinated by Dr Shekhar Saxena and Dr Tarun Dua. Dr Benedetto Saraceno provided guidance and Dr Colin Mathers gave technical input.

The project was carried out in close collaboration with Lifting The Burden as a key component of the Global Campaign against Headache, directed by Professor Timothy Steiner. Professor Lars Jacob Stovner and Professor Steiner provided expert support, and they and Dr Dua designed the survey methods and questionnaire. Professor Steiner, assisted by Mrs Ulla Schultz, was responsible for project management on a practical level. Respondents were found with help from the International Headache Society, European Headache Federation, World Headache Alliance and World Federation of Neurology. Professor Stovner and Ms Gøril Gravdahl, supported by the Norwegian University of Science and Technology, undertook questionnaire distribution, query resolution and data collection and management. Dr Dua and Dr Nelly Huynh conducted the analyses. Professor Steiner, with assistance from Dr Huynh, took primary responsibility for writing this report.

The information from various countries, areas and territories was provided by neurologists, headache specialists, general practitioners and patients' representatives identified from multiple sources by Professor Steiner, Mrs Schultz and Ms Gravdahl. The list of the respondents is included at the end of the Atlas.

The contributions of each of the team members and partners, along with input from many other unnamed people, have been vital to the success of this project.

Ms Adeline Loo provided administrative support in the preparation and production of the document. Assistance in preparing the Atlas for publication was received from Ms Erica Lefstad and Mr Christian Bäuerle (graphic design) and from Mr Christophe Francois A Grangier (map design). Professor Paolo Martelletti supported production through Sapienza University of Rome and the Italian League of Headache Patients. Dr Shekhar Saxena, Dr Tarun Dua, Dr Benedetto Saraceno and Dr Colin Mathers: World Health Organization, Geneva, Switzerland

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PREFACE

Headache is felt, at some time, by nearly everybody, and almost half the world's adults at any one time have recent personal experience of one or more headache disorders. In the Global Burden of Disease Study, updated in 2004, migraine on its own was found to account for 1.3 % of all years of life lost to disability worldwide. Other headache disorders, collectively, may be responsible for a similar burden.

Yet, much is unknown about the public-health impact of these conditions. While our view of the global burden attributable to headache disorders is incomplete, and our knowledge of health-care resource allocation to headache is scant, there is good evidence that very large numbers of people disabled by headache do not receive effective health care. The barriers responsible for this vary throughout the world, but poor awareness in a context of limited resources generally – and in health care in particular – is undoubtedly high among them everywhere.

The World Health Organization (WHO) initiated *Project Atlas* with the objective of collecting, compiling and disseminating relevant information on health-care resources in countries. Within *Project Atlas*, information has been collected for various domains of mental and neurological services and conditions of public-health priority. The *Atlas of Headache Disorders* is an important addition to this series. The *Atlas of Headache Disorders* presents the results of the survey carried out by WHO in collaboration with the nongovernmental organization, *Lifting The Burden,* in order to collect and disseminate

information on the burden of headache disorders and the resources available to reduce them. The facts and figures presented within it illuminate the worldwide neglect of a major cause of public ill-health and reveal the inadequacies of responses to it in countries throughout the world.

The findings of the *Atlas of Headache Disorders* have specific implications for the work of public-health professionals, academicians, service user groups, health planners and other stakeholders. We are aware of severe limitations in the data presented in this Atlas and welcome suggestions to improve the quantity and quality of data, especially for countries where no information is available or it is scarce.

The eventual objective of the project is to use the information collected through the *Atlas of Headache Disorders* to enhance global and national awareness and improve care and services for people with headache disorders. We hope it will assist health planners and policy-makers as well as professionals at every level involved in caring for people with headache disorders, and that nongovernmental organizations, wherever they exist, will use the *Atlas of Headache Disorders* in their advocacy efforts for more and better headache care.

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EXECUTIVE SUMMARY

ATLAS OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011

KEY MESSAGES

- Headache disorders are ubiquitous, prevalent and disabling. Yet they are under-recognized, underdiagnosed and under-treated worldwide:
- a minority of people with headache disorders are professionally diagnosed;
- management guidelines are used routinely in 55% of responding countries, but much less commonly in low-income countries;
- despite there being a range of drugs with efficacy against headache, countries in all income categories identify non-availability of appropriate medication as a barrier to best management;
- worldwide, only four hours are committed to headache disorders in formal undergraduate medica training, and lack of education is seen as the key issue impeding good management of headache;

- illness that could be relieved is not, and burdens, both individual and societal, persist unnecessarily;
- financial costs to society through lost productivity are enormous.
- Among proposals for change:
- better professional education ranks far above all others;
- a third of responding countries also recommend improved organization and delivery of health care for headache.
- Given the very high indirect costs of headache, greater investment in health care that treats headache effectively may well be cost-saving overall.

Despite that headache is felt at some time by nearly everybody, and almost half the world's adults at any one time have recent personal experience of one or more of the three very common headache disorders, much is unknown about the public-health impact of these conditions. It is not known how, or how much, they affect many of the populations of the world, or how healthcare and other resources are utilized to mitigate their effects.

This first global enquiry into these matters illuminates the worldwide neglect of a major public-health problem, and reveals the inadequacies of responses to it in countries throughout the world.

METHODS

The *Atlas of Headache Disorders* presents data acquired by WHO in collaboration with *Lifting The Burden:* the Global Campaign against Headache. Most of the information was collected in a questionnaire survey of neurologists, general practitioners and patients' representatives from 101 countries, performed from October 2006 until March 2009. Epidemiological data were compiled from published studies through a systematic review, and supplemented by data gathered in population-based studies undertaken within the Global Campaign.

EXECUTIVE SUMMARY

KEY FINDINGS

The burden of headache

- Headache disorders, including migraine and tension-type headache, are among the most prevalent disorders of mankind.
 - The prevalence studies estimate that half to three quarters of adults aged 18–65 years in the world have had headache in the last year.
 - According to these studies, over 10% have migraine, and 1.7-4% of the adult population are affected by headache on 15 or more days every month.
- Information on the societal impact of headache exists in only 18% of countries that responded.
- Headache disorders are included in an annual health reporting system in only 12 % and in national expenditure surveys in only 7 % of countries that responded.

Diagnosis of headache

- A minority of people with headache disorders worldwide are professionally diagnosed.
 - The rates for migraine and tension-type headache are about 40%; for medication-overuse headache only 10%.
- Specialists use International Headache Society diagnostic criteria to support diagnosis in 56% of countries that responded. Usage is lower in Africa, the Eastern Mediterranean and South-East Asia and very low in lowincome countries generally. Little is done to encourage their use in low-income countries.
- Investigation rates, mainly for diagnostic purposes, are high, despite that investigations are usually not needed to support diagnosis.
- Instruments to assess impact of headache are used routinely in only 24% of countries that responded, and very little in lower middle- or low-income countries.

Management of headache

- Worldwide, about 50% of people with headache are estimated to be primarily self-treating, without contact with health professionals.
 - Up to 10% are treated by neurologists, although fewer in Africa and South-East Asia.
 - The top three causes of consultation for headache, in both primary and specialist care, are migraine, tension-type headache and the combination of these.
 - Medication-overuse headache as a cause of specialist consultation (1 10 %) is related to country income.
 - Other secondary headaches as a cause of specialist consultation (5–12%) are inversely related to country income.
- Management guidelines are in routine use in 55 % of responding countries worldwide. Usage is much less common in low-income countries.
- There are many widely available drugs for use against headache, generally reflecting their efficacy. They offer an adequate range, but with some obvious limitations.
 - Among specific anti-migraine drugs, ergotamine is more widely available than triptans. The latter are more efficacious and less toxic, but more expensive.
 - Drugs for use against headache are fully reimbursed in fewer than half of countries, with partial reimbursement for most in up to two thirds of countries.
 - Countries in all income categories identify non-availability of appropriate medication as a barrier to best management. This probably refers to limited reimbursement.
- Among alternative and complementary therapies, physical therapy, acupuncture and naturopathy are clear preferences, at least one of these being in the top three such therapies in all regions and all income categories.

Organization of headache services

• A third of responding countries recommend, as a proposal for change, improved organization and delivery of health care for headache.

Education in headache

- Worldwide, just four hours are committed to headache disorders in formal undergraduate medical training, and 10 hours in specialist training.
- Better professional education ranks far above all other proposals for change (75% of countries that responded), and lack of education is seen as the key issue impeding good management of headache.

National professional headache organizations

- A national professional organization for headache disorders (or headache chapter in another organization) exists in two thirds of countries that responded. There is a very marked difference between high- and upper middle-income (71–76%) and low-income countries (16%).
 - The true figures may be much lower, as respondents were much more readily identified in countries where such organizations exist.
- Over one third of professional headache organizations arrange conferences, raise awareness of headache-related issues or are involved in setting guidelines in the management of headache disorders.
 - These are the top three activities in all regions and income categories.
- Fewer professional headache organizations (20%) participate in the construction of postgraduate training curricula, and only 10% do so in the development of undergraduate curricula on headache.

CONCLUSIONS

Headache disorders are ubiquitous, prevalent, disabling and largely treatable, but under-recognized, under-diagnosed and under-treated. Illness that could be relieved is not, and burdens, both individual and societal, persist. Financial costs to society through lost productivity are enormous – far greater than the health-care expenditure on headache in any country.

Health care for headache must be improved, and education is required at multiple levels to achieve this. Most importantly, health-care providers need better knowledge of how to diagnose and treat the small number of headache disorders that contribute substantially to public ill-health. Given the very high indirect costs of headache, greater investment in health care that treats headache effectively, through well-organized health services and supported by education, may well be cost-saving overall.

INTRODUCTION

ATLAS OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011

Despite that headache is felt, at some time, by nearly everybody, and almost half the world's adults at any one time have recent personal experience of one or more of the three very common headache disorders (1), much is unknown about the public-health impact of these conditions. It is not known how, or how much, they affect many of the populations of the world, or how healthcare and other resources are utilized to mitigate their effects.

This first global enquiry into these matters, consulting specialist and general physicians and people who have headache, is an attempt to document from country to country, region to region, the responses to a public-health priority.

HEADACHE DISORDERS

Headache is a painful feature of a number of primary headache disorders, two of which – migraine and tension-type headache – are widespread, prevalent and often life-long conditions. These, together with medication-overuse headache, are disorders of substantial public-health importance because, collectively, they are the cause of much disability in populations throughout the world.

MIGRAINE

This is a disorder that almost certainly has a genetic basis (2), but environmental factors play a significant role in how it affects those who have it. Pathophysiologically, activation of a mechanism deep in the brain causes release of pain-producing inflammatory substances around the nerves and blood vessels of the head. Why this happens periodically in migraine attacks, and what brings the process to an end in spontaneous resolution of these attacks, are uncertain.

Usually starting at puberty, migraine is recurrent – in many cases throughout life. Adults with migraine describe episodic disabling attacks in which headache and nausea are the most characteristic features; others are vomiting and/or dislike or intolerance of normal levels of light and sound. Headache is typically moderate or severe in intensity, one-sided and/or pulsating, and aggravated by routine physical activity; it lasts for hours up to 2–3 days. Attack frequency is, on average, once or twice a month but can be anywhere between once a year and once a week, often subject to lifestyle and environmental factors that suggest people with migraine react adversely to changes in routine.

TENSION-TYPE HEADACHE

The mechanism of tension-type headache is poorly understood. It has long been regarded as a headache with muscular origins, but this may not be entirely correct (3). It may be stress-related or associated with musculoskeletal problems in the neck.

Tension-type headache pursues a highly variable course, often beginning during the teenage years and reaching peak levels in the 30 s. Headache is usually mild or moderate, and generalized, described as pressure or tightness, like a band around the head, sometimes spreading into or from the neck. It lacks the specific features and associated symptoms of migraine. There are distinct sub-types although, in any individual, one may give way to the other. As experienced by very large numbers of people, episodic tension-type headache occurs, like migraine, in attack-like episodes. These usually last no more than a few hours but can persist for several days. Chronic tension-type headache is less common but, occurring by definition on 15 or more days every month, and sometimes unremitting over long periods, this variant is much more disabling.

MEDICATION-OVERUSE HEADACHE

Chronic excessive use of medication to *treat* headache is the cause of this disorder (4), which also manifests as headache on 15 or more days every month. It is therefore wholly avoidable. All medications for the acute or symptomatic treatment of headache, in overuse, are associated with this problem, although the mechanism through which it develops undoubtedly varies between different drug classes. Frequency of use is important: even when the total quantities are similar, low daily doses carry greater risk than larger weekly doses.

Medication-overuse headache is oppressive, persistent and often at its worst on awakening in the morning. A typical history begins with episodic headache – migraine or tensiontype headache. The condition is treated with an analgesic or other medication for each attack. Over time, headache episodes become more frequent, as does medication intake. In the endstage, which not all patients reach, headache persists all day, fluctuating with medication use repeated every few hours. This evolution occurs over a few weeks or much, much longer. A common and probably key factor at some stage in the development of medication-overuse headache is a switch to pre-emptive use of medication, in anticipation of headache and with a wish to prevent it and its undesired consequences.

INTRODUCTION

EPIDEMIOLOGY AND BURDEN

Although headache disorders are among the most common of all health disorders (5), their epidemiology is only partly documented. Population-based studies have mostly focused on migraine which, although the most frequently studied, is not the most common headache disorder. Tension-type headache is more prevalent, while the group of headaches occurring on 15 or more days every month are generally more disabling, but both of these have received less attention. Furthermore, relatively few population-based studies exist for resource-poor countries. In these countries, limited funding and often largely rural (and therefore less accessible) populations, coupled with the low profile of headache disorders compared with communicable diseases, stand in the way of systematic collection of information.

Nevertheless, despite regional variations, there can be no doubt that headache disorders are highly prevalent everywhere, affecting people of all ages, races, income levels and geographical areas. Population-based data are in the process of being gathered, filling the knowledge gaps that exist in many of the world's regions. Present knowledge informs us meanwhile that migraine affects 11 % of adults worldwide (1), with a three-times higher rate in women, which is hormonally-driven. Migraine is less common in children and in the elderly. Extrapolation from figures for migraine prevalence and attack incidence suggests that 3,000 migraine attacks occur *every day* for each million of the general population (6).

Episodic tension-type headache is the most common headache disorder, reported by over 70% of some populations (7). Worldwide its 1-year prevalence appears to vary greatly, with an average of 42% in adults (1), rather higher in women than in men. Chronic tension-type headache affects 1-3% of adults (1).

In terms of prevalence, medication-overuse headache far outweighs all other secondary headaches (8). This iatrogenic disorder affects more than 1 % of some populations (9), women more than men, and some children also.

Overall, the global prevalence among adults of current headache disorder (symptomatic at least once within the last year) is 47 % (1).

No significant mortality is associated with headache disorders, which is one reason why they are so poorly acknowledged. On the other hand, among the recognizable burdens imposed on people affected by headache disorders are pain and personal suffering, which may be substantial, impaired quality of life and financial cost. Above all, headache disorders are disabling: worldwide, migraine on its own is the cause of 1.3% of all years of life lost to disability (YLDs) (10). Together, all headache disorders probably account for double this burden (1). Repeated headache attacks, and often the constant fear of the next, damage family life, social life and employment (11). Headache often results in the cancellation of social activities while, at work, people who suffer frequent attacks are likely to be seen as unreliable – which they may be – or unable to cope. This can reduce the likelihood of promotion and undermine career and financial prospects.

While those actually affected by headache disorders bear much of their burden, they do not carry it all. Employers, fellow workers, family and friends may be required to take on work and duties abandoned by headache sufferers. Because headache disorders are most troublesome in the productive years (late teens to 50s), estimates of their financial cost to society – principally from lost working hours and reduced productivity due to impaired working effectiveness (12) – are enormous. In the United Kingdom, for example, some 25 million working- or school-days are lost every year because of migraine alone (6).

Therefore, while headache rarely signals serious underlying illness, the public-health importance of these headache disorders lies in their causal association with these personal and societal burdens of pain, disability, damaged quality of life and financial cost.

BARRIERS TO CARE

Not surprisingly, headache is high among causes of consulting both general practitioners and neurologists (13, 14). One in six patients aged 16-65 years in a large United Kingdom general practice consulted at least once because of headache over an observed period of 5 years, and almost one tenth of these were referred to secondary care (15). A survey of neurologists found that up to a third of all their patients consulted because of headache - more than for any other single complaint (16). Far less is known about the public-health aspects of headache disorders in resource-poor countries. Indirect financial costs to society may not be so dominant where labour costs are lower, but the consequences to individuals of being unable to work or care for children can be severe. There is no reason to believe that the burden of headache in its humanistic elements weighs any less heavily where resources are limited, or where other diseases are also prevalent.

Yet there is good evidence that very large numbers of people troubled, even disabled, by headache do not receive effective health care (17). For example, in representative samples of the general populations of the United States of America (USA) and of the United Kingdom, only half of those identified with migraine had seen a doctor for headache-related reasons in the last twelve months and only two thirds had been correctly diagnosed (18). Most were reliant solely on over-the-counter medications, without access to prescription drugs. In a separate United Kingdom general-population questionnaire survey, two thirds of respondents with migraine were searching for better treatment than their current medication (19). In Japan, awareness of migraine and rates of consultation by those with migraine were found to be noticeably lower (20). Over 80 % of Danish tensiontype headache sufferers had never consulted a doctor for headache (21). It is highly unlikely that people with headache fare any better in resource-poor countries.

The barriers responsible for this vary throughout the world, but they may be classified as clinical, social or political/economic.

CLINICAL BARRIERS

Lack of knowledge among health-care providers is the principal clinical barrier to effective headache management. This problem begins in medical schools where there is limited teaching on the subject, a consequence of the low priority accorded to it. It is likely to be even more pronounced in countries with fewer resources and, as a result, more limited access generally to doctors and to effective treatments.

SOCIAL BARRIERS

Poor awareness of headache extends similarly to the general public. Headache disorders are not perceived by the public as serious since they are mostly episodic, do not cause death and are not contagious. In fact, headaches are often trivialized as "normal", a minor annoyance or an excuse to avoid responsibility. These important social barriers inhibit people who might otherwise seek help from doctors, despite what may be high levels of pain and disability.

Surprisingly, poor awareness of headache disorders exists among people who are directly affected by them. A Japanese study found, for example, that many patients were unaware that their headaches were migraine, or that this was a specific illness requiring medical care (20). The low consultation rates in developed countries may indicate that many headache sufferers are unaware that effective treatments exist. Again, the situation is unlikely to be better where resources are more limited.

POLITICAL/ECONOMIC BARRIERS

Many governments do not acknowledge the substantial burden of headache on society – and may even be unaware of it. They fail to recognize that the direct costs of treating headache are small in comparison with the huge indirect-cost savings that might be made (e.g. by reducing lost working days) if resources were allocated to treat headache disorders appropriately.

PURPOSE OF THE ATLAS OF HEADACHE DISORDERS

Our view of the global burden attributable to headache disorders is incomplete, whilst our knowledge of health-care resource allocation to headache is scant. The *Atlas of Headache Disorders*, a project complementary to formal epidemiological studies, is part of defining the problem to be addressed. The purposes are to create awareness and, more importantly, to inform policy so that solutions can be proposed on the basis of knowledge.

This work is a key component of the Global Campaign against Headache (22).

METHODS

ATLAS OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011

The Atlas of Headache Disorders presents data acquired by WHO in collaboration with Lifting The Burden: the Global Campaign against Headache (22). Most of the information was collected in a large international survey performed from October 2006 until March 2009. Epidemiological data were compiled from published studies through a systematic review of all population-based studies performed up to May 2006 (1) and supplemented by data collected later through Global Campaign door-to-door surveys in China (23), India and the Russian Federation (24). The study by Stovner et al. provides the data sources and methodological details of the systematic review (1). The methods of the Global Campaign door-to-door surveys are described elsewhere (23, 24). Thus, only epidemiological data of sound provenance were accepted: i.e., those supported by peer-reviewed publication or, if not yet published, deriving from surveys of verifiably high quality.

QUESTIONNAIRE DEVELOPMENT

To gather the survey data in a consistent manner from each of the countries, three questionnaires were drafted, in English, by a group of WHO and *Lifting The Burden* experts. These questionnaires had similar structure but were different in emphasis: one questionnaire was intended for headache specialists or neurologists ("neurology version"), one for primary-care physicians ("GP version") and one for representatives of people with headache ("lay version"). A glossary of terms used in the questionnaires was also prepared to ensure that all respondents would understand the questions in the same way.

The questionnaires were piloted in one country in each WHO region, and changes made as necessary.

IDENTIFICATION OF RESPONDENTS

A list of respondents was built initially from the International Headache Society's membership register, European Headache Federation member-organization contacts, representatives of World Headache Alliance lay-member organizations, International Headache Congress and European Headache Congress attendance lists, World Federation of Neurology contacts (from national neurological societies) and previous respondents to WHO's data collection exercises for the *Atlas of Country Resources for Neurological Disorders* and *Atlas of Epilepsy Care in the World*. A number of geographical gaps remained; to fill these, additional contacts were found during the survey, some through other respondents and some as authors of relevant recently-published articles. The great majority of contacts located in these ways were headache specialists or neurologists. Each of these was asked to identify, if possible, likely respondents among primary-care physicians and lay representatives known personally to them.

DATA COLLECTION

The appropriate questionnaire was sent by email, directly by the project team to each person on the respondent list and indirectly by some of these contacts to others.

Respondents were asked to follow closely the glossary definitions, in order to maintain uniformity and comparability of responses. Questions and requests for clarification were answered. Repeat invitations were sent whenever there was delay in procuring the completed questionnaire. When incomplete or internally inconsistent information was submitted, the respondents were asked for further details or clarification.

In cases of non-response after repeated reminders, simplified and shortened versions of the three questionnaires were sent.

DATA MANAGEMENT AND ANALYSIS

All possible measures were taken to compile, code and interpret the information provided by countries using uniform definitions and criteria.

As they were received, data were entered into an electronic database applying suitable codes using Stata (special edition) version 8 software.

Analyses and group comparisons were made with SPSS 17 software. Values for continuous variables were analysed for frequency distributions and measures of central tendency (means, medians and standard deviations) were calculated as appropriate. Graphics were created using medians because of the skewed distributions of most data and, in some cases, occurrences of outliers.

Countries were grouped into the six WHO regions (African Region [AFR], Region of the Americas [AMR], Eastern Mediterranean Region [EMR], European Region [EUR], South-East Asia Region [SEAR] and Western Pacific Region [WPR]) and four World Bank income categories according to 2009 gross national income (GNI) per capita (low-income: US\$ 995 or less; lower middle-income: US\$ 996–3945; upper middle-income: US\$ 3946–12 195; high-income: US\$ 12 196 or more) (25).



REPRESENTATIVENESS

In full or simplified versions, the neurologist questionnaire was returned from 101 countries (in 65 cases the simplified version), the GP questionnaire from 47 countries (four simplified) and the lay questionnaire from 48 countries (16 simplified).

At least one questionnaire was obtained from each of 101 countries (figure 1.1): 18 in the African Region (39% of all countries in the region), 19 in the Americas (54%), 13 in the Eastern Mediterranean (62%), 38 in the European Region (72%), five in South-East Asia (46%) and eight in the Western Pacific (30%) (figure 1.2). These numbers might suggest less than 50% representation from three regions, but the data in fact pertained to 86% of the world's population: 71% of the population in Africa, 95% in the Americas, 83% in the Eastern Mediterranean, 86% in Europe, 82% in South-East Asia and 93% in the Western Pacific (figure 1.3).

Response rates (i.e., returns per contact made) for the neurologist questionnaire reflected country-income categories: the highest rate (77 %) was from high-income countries, with other categories following in order: upper middle- (54 %), lower middle- (46 %) and low-income (38 %). Response rates of GP and lay questionnaires are unknown since these were passed in many cases by neurologist-respondents to contacts known to them.



RESULTS

DATA QUALITY



FIG. 1.2 Country-based response rates (% of countries within each WHO region represented [any questionnaire returned] among responses)



FIG. 1.3 Population-based response rates (% of population within each WHO region represented [any questionnaire returned] among responses)

AFR = African Region AMR = Region of the Americas EMR = Eastern Mediterranean Region EUR = European Region SEAR = South-East Asia Region WPR = Western Pacific Region

LIMITATIONS

No data were obtained from 92 (48%) of the 193 Member States. Although responding countries represented a large majority (86%) of the world's population, some bias was possible. Particularly in low-income countries it was difficult to identify likely respondents; it may therefore be expected that unrepresented countries are those where health services for headache are least developed. If this is so, the most disadvantaged countries are under-reported.

At most, six key persons in each country (but in many countries only one) were the source of all information other than epidemiological data. Many respondents, particularly those from large countries, found it difficult to complete the questionnaire since there might be significant variation from area to area within the country. Hence, answers from one respondent might not be representative of the whole country. Many of the originallyidentified contacts did not respond, and in some countries there was nobody known to work in the field of headache medicine. Hence, the level of headache expertise of respondents might vary considerably.

For other reasons, the quality of responses was probably quite variable. In some countries, some answers could be based on empirical studies (for example, of use of health-care resources for headache), whereas in other countries the questions could be answered only on the basis of clinical experience, or by extrapolation of data from nearby countries. For most countries, the scientific basis of the responses could not be known.

In spite of these limitations, the *Atlas of Headache Disorders* is the most comprehensive compilation of resources for headache in the world ever attempted.

DATA ORGANIZATION AND PRESENTATION

The information is organized in eight themes and divided regionally and by income categories within each theme. Data are presented as graphics, world maps and written text. Bar and pie charts illustrate frequencies, medians or means as appropriate. Because the distributions of most of the data are skewed, the median has been used to depict the central tendency of most variables.

It has not been possible to present all the findings from the analyses. Limitations specific to each theme are to be kept in mind when interpreting the data and their analyses.

Implications of the findings for development of resources for headache care are highlighted within each theme.