

“With this report go my best wishes that it be disseminated world-wide and that it receive the deserved attention of the Global Health Community in all the countries of the world.”

Rita Levi-Montalcini, Nobel Prize in Medicine, 1986

Neurological disorders are common and represent a major public health problem. For example, 50 million people have epilepsy. It is projected that the number of people affected by dementia will double every 20 years.

Neurological disorders and some of the other conditions with neurological impairments and sequelae constitute over 6% of the global burden of disease. This burden is especially high in many low and middle income countries.

Neurological disorders: public health challenges describes and discusses the increasing global public health importance of common neurological disorders such as dementia, epilepsy, headache disorders, multiple sclerosis, neuroinfections, neurological disorders associated with malnutrition, pain associated with neurological disorders, Parkinson’s disease, stroke and traumatic brain injuries. The document provides the public health perspective for these disorders and presents fresh and updated estimates and predictions of the global burden borne by them.

This report provides information and advice on public health interventions that may be applied to reduce the occurrence and consequences of neurological disorders. It offers health professionals and planners the opportunity to assess the burden caused by these disorders in their country and to take appropriate action.

A clear message emerges from this report: unless immediate action is taken globally, the neurological burden is likely to become an even more serious threat to public health.

RECOMMENDATIONS FOR ACTION

- Commitment from decision makers is the first essential step to decrease the burden caused by neurological disorders.
- Societal and professional awareness of public health aspects of neurological disorders needs to be raised through global and local campaigns and initiatives.
- Innovative strategies to address the associated stigma and discrimination needs to be part of the public health activities for neurological disorders.
- The most promising approach for reducing the burden of these disorders is to strengthen neurological care within the existing health systems.
- Rehabilitation needs to complement the other key strategies for neurological care such as promotion, prevention and treatment.
- Defining the priorities for research, building national capacity and intensifying international collaboration are some of the important ways for bringing about the changes that people with neurological disorders need.

The above recommendations need to be implemented across a wide range of sectors and disciplines appropriately adapted to local conditions and capacities.

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NEUROLOGICAL DISORDERS

public health challenges



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World Health Organization

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foreword

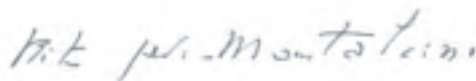


In the 19th century and at the beginning of the 20th, brain research belonged to many different areas that differed in methodology and targets: the morphological, the physiological and the psychological. The latter used to consider the brain as a black box where only the input and output were known but not at all the neuronal components and the way they interact with each other.

At the beginning of the third millennium, due to prolonged ageing, neurodevelopmental disorders are growing and a much deeper knowledge of the brain is necessary. Scientific and technological research, from molecular to behavioural levels, have been carried out in many different places but they have not been developed in a really interdisciplinary way. Research should be based on the convergence of different interconnected scientific sectors, not in isolation, as was the case in the past.

As this report demonstrates, the burden of neurological disorders is reaching a significant proportion in countries with a growing percentage of the population over 65 years old.

With this report go my best wishes that it be disseminated worldwide and that it receive the deserved attention of the Global Health Community in all the countries of the world.



Rita Levi-Montalcini
1986 Nobel Prize in Medicine

preface

Within its remit to provide leadership on all matters concerning health, one of the core functions of the World Health Organization (WHO) is to engage in partnerships where joint action is needed. WHO plays an important role in bringing crucial health-related topics to the agenda of policy-makers and health planners and in raising awareness of them among health-care professionals and all who have an interest in health matters.

WHO's Department of Mental Health and Substance Abuse carries out this role for the three different sets of issues for which it is responsible: mental disorders, substance abuse and alcohol-related issues, and neurological disorders. Two recent publications have focused attention on its work. *The world health report 2001 – Mental health: new understanding, new hope* is an advocacy instrument to shed light on the public health aspects of mental disorders, and the report *Neuroscience of psychoactive substance use and dependence* produced by the department in 2004 tackles the area of substance abuse and alcohol. We realized a similar exercise is needed in the field of neurological disorders.

The Global Burden of Disease study, the ongoing international collaborative project between WHO, the World Bank and the Harvard School of Public Health, has produced evidence that pinpoints neurological disorders as one of the greatest threats to public health. A clear message emerges that unless immediate action is taken globally, the neurological burden is expected to become an even more serious and unmanageable problem in all countries. There are several gaps in understanding the many issues related to neurological disorders, but we already know enough about their nature and treatment to be able to shape effective policy responses to some of the most prevalent among them.

To fill the vast gap in the knowledge concerning the public health aspects of neurological disorders, this document *Neurological disorders: public health challenges* fulfils two roles. On one hand, it provides comprehensive information to the policy-makers and on the other hand, it can also be used as an awareness-raising tool. The document has unique aspects that should be stressed. It is the result of a huge effort bringing together the most significant international nongovernmental organizations working in the areas of various neurological disorders, both in a professional capacity and in caring for people affected by the conditions. It is the fruit of healthy interaction and collaboration between these organizations and WHO, with its network of country and regional offices: health experts on

one hand working together with the extensive and competent world of professionals and researchers on the other. Some of these organizations have also contributed financially to this endeavour. This exercise thus demonstrates that such collaboration is not only possible but can also be very productive.

The document is distinctive in its presentation as it provides the public health perspective for neurological disorders in general and presents fresh and updated estimates and predictions of the global burden borne by them. Separate sections discuss some of the most important disorders in detail: dementia, epilepsy, headache disorders, multiple sclerosis, neuroinfections, neurological disorders associated with malnutrition, pain associated with neurological disorders, Parkinson's disease, stroke and traumatic brain injuries.

The document makes a significant contribution to the furthering of knowledge about neurological disorders. We hope it will facilitate increased cooperation and innovation and inspire commitment to preventing these debilitating disorders and providing the best possible care for people who suffer from them.

A handwritten signature in black ink, appearing to read "Benedetto Saraceno". The signature is written in a cursive, flowing style.

Benedetto Saraceno

Director, Department of Mental Health
and Substance Abuse

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PROJECT TEAM

WRITING GROUP

Johan A. Aarli, Tarun Dua, Aleksandar Janca, Anna Muscetta

MANAGEMENT GROUP

José Manoel Bertolote, Tarun Dua, Aleksandar Janca, Frances Kaskoutas-Norgan, Anna Muscetta, Benedetto Saraceno, Shekhar Saxena, Rosa Seminario

EDITORIAL COMMITTEE

Johan A. Aarli, Giuliano Avanzini, José Manoel Bertolote, Hanneke de Boer, Harald Breivik, Tarun Dua, Nori Graham, Aleksandar Janca, Jürg Kesselring, Colin Mathers, Anna Muscetta, Leonid Prilipko, Benedetto Saraceno, Shekhar Saxena, Timothy J. Steiner

AUTHORS AND CONTRIBUTORS

INTRODUCTION

Tarun Dua, Aleksandar Janca, Anna Muscetta

CHAPTER 1. PUBLIC HEALTH PRINCIPLES AND NEUROLOGICAL DISORDERS

Tarun Dua, Aleksandar Janca, Rajendra Kale, Federico Montero, Anna Muscetta, Margie Peden

CHAPTER 2. GLOBAL BURDEN OF NEUROLOGICAL DISORDERS: ESTIMATES AND PROJECTIONS

Tarun Dua, Marco Garrido Cumbreira, Colin Mathers, Shekhar Saxena

CHAPTER 3. NEUROLOGICAL DISORDERS: A PUBLIC HEALTH APPROACH

3.1 Dementia

Amit Dias, Cleusa Ferri, Nori Graham (chair), Bernard Ineichen, Martin Prince, Richard Uwakwe

3.2 Epilepsy

Giuliano Avanzini (co-chair), Ettore Beghi, Hanneke de Boer (co-chair), Jerome Engel Jr., Josemir W. Sander, Peter Wolf

3.3 Headache disorders

Lorenzo Gardella, Zaza Katsarava, David Kernick, Hilka Kettinen, Shireen Qureshi, Krishnamurthy Ravishankar, Valerie South, Timothy J. Steiner (chair), Lars Jacob Stovner

3.4 Multiple sclerosis

Ian Douglas, Jürg Kesselring (chair), Paul Rompani, Bhim S. Singhal, Alan Thompson

3.5 Neuroinfections

Reyna M. Duron, Hector Hugo Garcia, Ashraf Kurdi, Marco T. Medina (chair), Luis C. Rodriguez

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3.6 Neurological disorders associated with malnutrition

Amadou Gallo Diop (chair), Athanase Millogo, Isidore Obot, Ismael Thiam, Thorkild Tylleskar

3.7 Pain associated with neurological disorders

Michael Bond, Harald Breivik (chair), Troels S. Jensen, Willem Scholten, Olaitan Soyannwo, Rolf-Detlef Treede

3.8 Parkinson's disease

Mary Baker (chair), Oscar S. Gershanik

3.9 Stroke

Julien Bogousslavsky (chair), Ming Liu, J. Moncayo, B. Norrving, A. Tsiskaridze, T. Yamaguchi, F. Yatsu

3.10 Traumatic brain injuries

Armando Basso (chair), Ignacio Previgliano, Franco Servadei

CHAPTER 4. CONCLUSIONS AND RECOMMENDATIONS

José Manoel Bertolote, Tarun Dua, Aleksandar Janca, Anna Muscetta, Benedetto Saraceno, Shekhar Saxena

EXTERNAL REVIEWERS

Mario A. Battaglia, Donna Bergen, Gretchen Birbeck, Carol Brayne, Vijay Chandra, Amit Dias, M. Gourie-Devi, Rajendra Kale, Maria Lucia Lebrao, Itzhak Levav, Girish Modi, Theodore Munsat, Donald Silberberg (*whole document*); Daniel O'Connor, Carlos Lima (*Dementia*); Satish Jain, Bryan Kies (*Epilepsy*); Anne MacGregor, Fumihiko Sakai (*Headache disorders*); Chris H. Polman, Ernie Willoughby (*Multiple sclerosis*); Peter G. E. Kennedy (*Neuroinfections*); Redda Tekle Haimanot (*Neurological disorders associated with malnutrition*); Ralf Baron, Maija Haanpää (*Pain associated with neurological disorders*); Zvezdan Pirtosek, Bhim S. Singhal, Helio Teive (*Parkinson's disease*); Vladimir Hachinski, David Russell (*Stroke*); Vladan Bajtajic, Jacques Brotchi, Jeremy Ganz, Haldor Slettebø (*Traumatic brain injuries*)

PEER REVIEWERS IN WHO

Regional Office for Africa: Thérèse Agossou

Regional Office for the Americas: José Miguel Caldas De Almeida, Itzhak Levav

Regional Office for South-East Asia: Vijay Chandra

Regional Office for Europe: Matthijs Muijen

Regional Office for the Eastern Mediterranean: R. Srinivasa Murthy, Mohammad Taghi Yasamy

Regional Office for the Western Pacific: Xiandong Wang

Headquarters: Bruno de Benoist, Siobhan Crowley, Denis Daumerie, Dirk Engels,

Jean Georges Jannin, Daniel Olivier Lavanchy, Dermot Maher, Kamini Mendis, Shanthi Mendis,

François Meslin, William Perea, Pascal Ringwald, Oliver Rosenbauer, Michael J. Ryan,

Perez Simarro, Jos Vandelaer, Marco Vitoria

PRODUCTION TEAM

Production coordination: Caroline Allsopp

Editing: Barbara Campanini

Design and layout: Reda Sadki

Proofreading: Susan Kaplan

Indexing: David McAllister

Maps: Steve Ewart

Printing coordination: Raphaël Crettaz

abbreviations

| | |
|--------|--|
| AD | Alzheimer's disease |
| ADI | Alzheimer's Disease International |
| AED | antiepileptic drug |
| AIDS | acquired immunodeficiency syndrome |
| ART | antiretroviral therapy |
| BPSD | behavioural and psychological symptoms of dementia |
| CNS | central nervous system |
| CRPS | complex regional pain syndrome |
| CSF | cerebrospinal fluid |
| CT | computerized tomography |
| DALY | disability-adjusted life year |
| FAO | Food and Agriculture Organization of the United Nations |
| EEG | electroencephalography |
| EMSP | European Multiple Sclerosis Platform |
| EPDA | European Parkinson's Disease Association |
| EUREPA | European Epilepsy Academy |
| GBD | Global Burden of Disease |
| GDP | gross domestic product |
| GNI | gross national income |
| HAART | highly active antiretroviral therapy |
| HIV | human immunodeficiency virus |
| IBE | International Bureau for Epilepsy |
| IASP | International Association for the Study of Pain |
| ICF | International Classification of Functioning, Disability and Health |
| ICH | intracerebral haemorrhage |
| IHS | International Headache Society |
| ILAE | International League Against Epilepsy |
| MRI | magnetic resonance imaging |
| MS | multiple sclerosis |
| MSIF | Multiple Sclerosis International Federation |
| PD | Parkinson's disease |
| PET | positron emission tomography |
| RTA | road traffic accident |
| SAH | subarachnoid haemorrhage |
| SMR | standardized mortality ratio |
| TBI | traumatic brain injury |
| TIA | transient ischaemic attack |
| UNESCO | United Nations Educational, Scientific and Cultural Organization |
| UNICEF | United Nations Children's Fund |
| UNFPA | United Nations Population Fund |
| VaD | vascular dementia |
| WFN | World Federation of Neurology |
| WFNS | World Federation of Neurosurgical Societies |
| WHA | World Headache Alliance |
| WHO | World Health Organization |
| YLD | years of healthy life lost as a result of disability |
| YLL | years of life lost because of premature mortality |



introduction

One of the key constitutional responsibilities of the World Health Organization (WHO) is to foster partnership and collaboration among scientific and professional groups in order to contribute to the advancement of global health. To help prioritize health needs and design evidence-based health programmes globally, WHO initiates a large number of international projects and activities involving numerous governmental and non-governmental organizations, health professionals and policy-makers.

The Global Burden of Disease (GBD) study, a collaborative endeavour of the World Health Organization (WHO), the World Bank and the Harvard School of Public Health, drew the attention of the international health community to the burden of neurological disorders and many other chronic conditions. This study found that the burden of neurological disorders was seriously underestimated by traditional epidemiological and health statistical methods that take into account only mortality rates but not disability rates. The GBD study showed that over the years the global health impact of neurological disorders had been underestimated (1).

With awareness of the massive burden associated with neurological disorders came the recognition that neurological services and resources were disproportionately scarce, especially in low income and developing countries. Furthermore, a large body of evidence shows that policy-makers and health-care providers may be unprepared to cope with the predicted rise in the prevalence of neurological and other chronic disorders and the disability resulting from the extension of life expectancy and ageing of populations globally (2, 3).

In response to the challenge posed by neurological disorders, WHO launched a number of global public health projects, including the Global Initiative on Neurology and Public Health whose purpose is to increase professional and public awareness of the frequency, severity and costs of neurological disorders and to emphasize the need to provide neurological care at all levels including primary health care. This global initiative has revealed a paucity of information on the burden of neurological disorders and a lack of policies, programmes and resources for their management (4–6).

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In response to these findings, WHO and the World Federation of Neurology (WFN) recently collaborated in an international Survey of Country Resources for Neurological Disorders involving 109 countries and covering over 90% of the world's population. The survey collected information from experts on several aspects of the provision of neurological care around the world, ranging from frequency of neurological disorders to the availability of neurological services across countries and settings. The findings show that resources are clearly inadequate for patients with neurological disorders in most parts of the world; they highlight inequalities in the access to neurological care across different populations, especially in those living in low income countries and in the developing regions of the world (7). The results of the survey, which include numerous tables, graphs and commentaries, have been published in the WHO/WFN Atlas of Country Resources for Neurological Disorders (8). The atlas is available at http://www.who.int/mental_health/neurology/ or on request from WHO.

This report takes the collaboration with nongovernmental organizations and the Atlas Project one step further. It aims to inform governments, public health institutions, nongovernmental organizations and others so as to help formulate public health policies directed at neurological disorders and to guide informed advocacy. WHO has produced this report in collaboration with several nongovernmental organizations, including (in alphabetical order) Alzheimer's Disease International, European Parkinson's Disease Association, International Association for the Study of Pain, International Bureau for Epilepsy, International Headache Society, International League Against Epilepsy, Multiple Sclerosis International Federation, World Federation of Neurology, World Federation of Neurosurgical Societies and World Headache Alliance. It addresses the most important public health aspects of the following neurological disorders: dementia, epilepsy, headache disorders, multiple sclerosis, neuroinfections, neurological disorders associated with malnutrition, pain associated with neurological disorders, Parkinson's disease, stroke and traumatic brain injuries. These common disorders were selected after discussion with several experts and nongovernmental organizations and represent a substantial component of the global burden of neurological disorders.

The report is based on significant contributions by many individuals and organizations spanning all continents. Their names are indicated in the Acknowledgements section, and their input is acknowledged with thanks.

OUTLINE OF THE REPORT

Chapter 1 provides an overview of basic public health concepts and general principles as they apply to neurological disorders, including epidemiology and burden, health promotion, disease prevention, health policy, service provision and delivery of care, disability and rehabilitation, stigma, and education and training. Public health is defined as the science and practice of protecting and improving the health of the population through prevention, promotion, health education, and management of communicable and noncommunicable diseases including neurological disorders. In other words, public health is viewed as a comprehensive approach concerned with the health of the community as a whole rather than with *medical* health care that deals primarily with treatment of individuals. The focus of public health interventions could be primary, secondary or tertiary prevention. The above-mentioned concepts are illustrated by examples from the field of neurological disorders. Public health aspects of individual neurological disorders covered by the report are discussed in greater detail in Chapter 3.

Each chapter contains a numerical list of references to works that are cited in the text. A second list, arranged alphabetically, suggests reading material that is recommended to give an overview of the subject matter of the section or chapter; some of the key references may be repeated in the reading list.

Chapter 2 contains a series of tables and graphs that provide projected estimates of the global burden of neurological disorders for 2005, 2015 and 2030. The illustrations are accompanied by a summary of the GBD methodology, observations on its limitations and brief commentaries on the findings of the GBD study. The results are presented according to WHO regions, epidemiological subregions and World Bank income categories. Annex 1 lists WHO Member States and Annex 2 presents countries according to World Bank categories. Annex 3 provides the list of GBD cause categories, sequelae and case definitions used for calculation of estimates for neurological disorders. Annex 4 contains the GBD estimates for neurological disorders for 2005, 2015 and 2030.

Chapter 3 consists of 10 sections that focus on the public health aspects of the specific neurological disorders covered by the report. Although notable differences exist between relevant public health issues for each neurological disorder, most sections cover the following topics: diagnosis and classification; etiology and risk factors; course and outcome; magnitude (prevalence, incidence, distribution by age and sex, global and regional distribution); disability and mortality; burden on patients' families and communities; treatment, management and rehabilitation; delivery and cost of care; gaps in treatment and other services; policies;

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research; and education and training. Accompanying tables, graphs, boxes and other graphic material illustrate specific points made in the text. Details of relevant nongovernmental organizations, including their objectives, are given in Annex 5.

Chapter 4 gives the conclusions and recommendations of the report, which are based on the following findings. Neurological disorders are a significant and increasing public health problem. Many of them can be either prevented or treated at a relatively low cost. Resources for neurological disorders are grossly inadequate in most parts of the world. Significant inequalities in provision of neurological treatment and care exist between developing and developed countries. Stigma and discrimination against people with neurological disorders are ubiquitous and need to be eliminated through public education and global campaigns. Dignity of people with neurological disorders needs to be preserved and their quality of life improved. Long-term treatment and care of patients with chronic neurological disorders and conditions should be incorporated into primary care. Public health aspects of neurological disorders should be incorporated into undergraduate and postgraduate teaching and training curricula in neurology. More research on neurological disorders is needed and it should be facilitated through better funding, multidisciplinary approaches and international collaboration.

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