



CHAPTER 4

conclusions and recommendations

in this chapter

- 177** Evidence on which to base a public health framework for neurological disorders
- 179** Recommendations for action

The relationship between neurology and public health has not been adequately explored to date. This report provides considerable detail about the increasing global public health

importance of various common neurological disorders. Public health interventions that may be applied in an attempt to reduce their occurrence and consequences have been considered. A clear message emerges: unless immediate action is taken globally, the neurological burden is expected to become an even more serious and unmanageable threat to public health.

This final chapter highlights a number of overall patterns and themes that cut across the neurological disorders discussed in the previous chapters. It reiterates what is known about neurological disorders and makes the case for a public health approach; it then considers what can be done and provides a set of recommendations for decision-makers and health-care providers.

EVIDENCE ON WHICH TO BASE A PUBLIC HEALTH FRAMEWORK FOR NEUROLOGICAL DISORDERS

The burden is already high and is increasing further

Neurological disorders and their sequelae are currently estimated to affect as many as a billion people worldwide. These disorders are found among all age groups and in all geographical regions. Increased life expectancy and reduced fertility have resulted in a demographical transition from predominantly youthful popula-

tions to older and ageing ones, causing increases in the neurological disorders such as Alzheimer and other dementias and Parkinson's disease. As a consequence, many low income countries face the double burden of a continuing high level of infections — including some that result in neurological disorders (e.g. HIV and malaria) — and increases in noncommunicable diseases. The number of people with neurological disorders is estimated to increase considerably in years to come. It is forecast that the number of people affected by dementia (already counted in tens of millions) will double every 20 years. While predictions point to higher risk among poor people, children, adolescents and elderly persons, no population group is immune to neurological disorders.

Because most of the neurological disorders result in long-term disability and many have an early age of onset, measures of prevalence and mortality

vastly underestimate the disability they cause. Pain is a significant symptom in several neurological disorders and adds significantly to emotional suffering and disability. Even burden estimates combining mortality and disability do not take into account the suffering and social and economic losses affecting patients, their families and the community. The socioeconomic demands of care, treatment and rehabilitation put a strain on entire families, seriously diminishing their productivity and quality of life.

A study conducted in Europe estimated that the annual economic cost of neurological diseases (dementia, epilepsy, migraine and other headaches, multiple sclerosis, Parkinson's disease and stroke) amounted to € 139 billion (approximately US\$ 180 billion) in 2004. This study only partially included direct non-medical costs (e.g. community care and informal care) and indirect costs and omitted intangible costs. The results also demonstrated that the cost of dementia increases by 25% when informal care is included and the cost of multiple sclerosis increases by at least 50% when intangible costs are included. In the same study, the annual cost of traumatic brain injuries was estimated as € 3 billion; this figure is, however, a gross underestimate as it was based only on hospitalization attributable to trauma and omitted rehabilitation and lost workdays and production, which are substantially higher. Unfortunately, no equivalent estimates are available for developing countries.

Stigma and discrimination are associated with most of these disorders

The stigma often associated with neurological disorders adds to the social and economic burden. One of the most damaging results of stigmatization is that affected individuals or those responsible for their care may not seek treatment, hoping to avoid the negative social consequences of diagnosis. Indeed, in some communities, the stigma leads to the denial of basic human rights. Stigma aggravates the vicious cycle of illness and social negative reaction and leads to social exclusion and discrimination.

Epilepsy, one of the most common neurological conditions, is well understood and accepted in many societies. Yet in many others, particularly in developing countries, epilepsy is considered contagious or the sign of a curse or possession, with blame for the condition attached to the family as well as to the patient. The direct and indirect discriminatory behaviour and factual choices by others cause substantial reduction in societal opportunities such as education, marriage or work, or may result in being excluded from community activities. Fortunately, stigma and its negative effect on quality of life can be substantially reduced by better seizure control, highlighting the need for effective treatment.

Cost-effective interventions are available

For many of the neurological disorders there are inexpensive but effective interventions that could be applied on a large scale through primary care. Phenobarbital for the treatment of epilepsy is one such cost-effective intervention: up to 70% of people with epilepsy could become seizure free with antiepileptic drug treatment, but the proportion who remain untreated at any given time is greater than 80% in most low income countries. This massive treatment gap is attributable to a paucity of epilepsy services, trained personnel and antiepileptic drugs.

Aspirin is by far the most cost-effective intervention both for treating acute stroke and for preventing a recurrence. It is easily available in developing countries, even in rural areas. Nevertheless, the coverage of the affected population with this inexpensive treatment is still extremely low.

Many neurological disorders can be prevented and treated

One of the important actions required by the health sector is an immunization programme for the prevention of neuroinfections, such as poliomyelitis, and the neurological consequences of infections (e.g. *Hemophilus influenzae* type B (Hib)). Meningitis caused by Hib has been nearly eliminated in the industrialized world since routine vaccination with the *H. influenzae* type B con-

jugate vaccine was initiated. BCG vaccination does not prevent transmission of tuberculosis but is still recommended because of its high protective efficacy against serious forms of the disease in children (73% for meningitis and 77% for miliary tuberculosis).

A number of strategies implemented at policy level by governments through legislation, tax or financial incentives can reduce risks to health. For example, in the area of road safety, a significant number of people might not choose to drive safely or to use seatbelts or motorcycle helmets, but government action can encourage them to do so, thereby preventing injuries to themselves and to other people. This would also result in prevention of other disorders secondary to trauma such as epilepsy.

Control of cardiovascular diseases including stroke can be handled through a comprehensive approach taking account of a variety of interrelated risk factors including blood pressure, cholesterol, smoking, body mass index, low levels of physical activity, diet and diabetes. A comprehensive national strategy thus combining prevention, community-based health promotion and access to treatment can substantially decrease the burden associated with cardiovascular diseases, including stroke.

Disability consequent to neurological disorders can be decreased by rehabilitation programmes and policies. For example, building ramps and other facilities to improve access by disabled people falls beyond the purview of the health sector but is nevertheless very important for comprehensive management of people with disability.

Resources are inadequate and inequitably distributed

Despite the huge burden they cause, neurological conditions are largely absent from the international health agenda. Moreover, country health plans frequently do not cover neurological disorders at the same level as other illnesses, creating significant economic difficulties for patients and their families. In all but the least developed countries of the world, poor people are much more likely than the wealthy to develop neurological disorders, and everywhere they are more likely to die as a result. Thus poverty and neurological disorders tend to reinforce each other; this vicious cycle is frequently exacerbated by gender inequalities.

A large survey undertaken by WHO/WFN to collect expert information on aspects of neurological care provision around the world (analysis of which was published as the *Atlas of Country Resources for Neurological Disorders*) found that, on average, there was one neurologist per 100 000 population worldwide in the reporting countries, ranging from one per 20 000 population in the European Region of WHO to one per three million population in the African Region. Not only are resources inadequately allocated for neurological services, there is also inequity in their distribution across countries and populations. This is particularly true for people living in low and middle income countries as well as for poor population groups in high income countries.

RECOMMENDATIONS FOR ACTION

This report offers health professionals and planners the opportunity to assess the burden caused by neurological disorders in their country and to take appropriate action. All the following recommendations need to be implemented across a wide range of sectors and disciplines if they are to achieve success. They are not a universal blueprint, however, and will have to be adapted to local conditions and capacities. The actions recommended can be beneficial directly — by decreasing the mortality, morbidity and disability caused by neurological disorders — and indirectly by improving the functioning and quality of life of patients and their families.

In certain low income and middle income countries with limited human and financial resources, it may be difficult for governments to apply some of these recommendations on their own. In these circumstances, it is suggested that countries work with international agencies, nongovernmental organizations or other partners to put their plans into practice.

1. Gain commitment from decision-makers

Much of the success of public health efforts in countries ultimately depends upon the degree of political commitment they receive. Support from decision-makers is not only necessary to ensure proper funding and effective legislation and policies, but also to give prevention efforts increased legitimacy and a higher profile in the public consciousness.

Public health professionals have an important contribution to make to the process of gaining political support, by providing decision-makers with solid information on the prevalence, consequences and burden of neurological disorders, and by carefully documenting the proven and promising interventions that can lead to their prevention or management. Information on population needs must be synthesized and disseminated in a way that encourages commitment from decision-makers. Communication methods such as media features and the identification and engagement of community leaders can be used to help build alliances between different stakeholders.

2. Increase public and professional awareness

Public and professional awareness of public health aspects of neurological disorders needs to be raised through the launch of global and local campaigns and initiatives that target health professionals, general practitioners and primary care physicians, specialists in public health, neurologists, health planners, health economists, the media and the general public. Another route of sensitization is the development of educational programmes on the public health aspects of neurology (taking into account local practices and traditions) and including them in the teaching and training curricula of all institutions where neurology is taught.

Self-help groups, patient information programmes and basic educational and training interventions for caregivers need to be encouraged and facilitated. Patients, their families and carers should be represented and fully involved in the development and implementation of policies and services for people with neurological disorders.

3. Minimize stigma and eradicate discrimination

Stigma and discrimination against people with neurological disorders (including epilepsy, dementia, Parkinson's disease, AIDS-related conditions and other neurological disorders) exist globally and need to be eliminated through public education, global and local campaigns and a variety of public health actions involving governments, health professionals, patients, carers and the mass media. The ultimate goal of all such efforts should be to prevent the isolation of patients with neurological disorders and their families and to facilitate their social integration. The dignity of people with neurological disorders needs to be preserved and their quality of life improved. Development of social and health policies for minimizing stigma must take into consideration such key issues as access to care and financing health care, as well as basic human rights. Driving privileges for people with controlled epilepsy indicates practical needs for policy to examine not just personal and public safety, but also how stigma, culture, liability and ethics interact.

Legislation represents an important means of dealing with these problems and challenges. Governments can reinforce the efforts with laws that protect people with brain disorders and their families from abusive practices and prevent discrimination in education, employment, housing and other opportunities. Legislation can help, but ample evidence exists to show that alone it is not enough.

The kind of intervention needed to mitigate stigma varies with the condition. For example, efforts to alleviate the stigma of epilepsy need to be focused on helping individuals acknowledge and adjust to life with treatable disease in a large number of cases. Information, education and communication and social marketing campaigns need to enhance compassion and reduce blame. In the case of other diseases, for example leprosy, the control programme can be made effective by use of a simple message that leprosy can be cured with medicines.

4. Strengthen neurological care within the existing health systems

The most promising approach for reducing the burden of neurological disorders in developing countries is a comprehensive system of primary health care: primary care services supported by secondary and tertiary care facilities, physicians and specialists. Primary care is the point of entry for the vast majority of people seeking medical care — indeed, for many people it is their sole access to medicine. Moreover, because primary care teams work in the community, they are well placed to recognize factors such as stigma, family problems and cultural factors that affect treatment for neurological disorders. Thus, primary care is the logical setting in which neurological disorders need to be dealt with. The important role of primary care is also founded on recognition that decisions in primary care take account of patient-related factors — family medical history and patients' individual expectations and values — of which the continuity and long-term relationships of primary care generate awareness, while promoting trust and satisfaction among patients. For example, effective management of headache disorders can be provided in primary care for all but a very small minority of patients, as the common headache disorders require no special investigation and they can be diagnosed and managed with skills generally available to health-care professionals working in primary care settings.

A careful analysis is required of what is and what is not possible for the treatment and care of neurological disorders at different levels of care. It is thus very important to establish a referral system for management of severe cases and patients requiring access to diagnostic and technological expertise. What is needed is a continuing, seamless care approach to handle the long-term nature of neurological disorders and the call for ongoing care.

5. Incorporate rehabilitation into the key strategies

Rehabilitation complements the other key strategies, promotion, prevention and treatment. While prevention involves targeting risk factors of disease and treatment is dealing with health conditions, rehabilitation targets human functioning. Though rooted in the health sector, rehabilitation is also a relevant strategy that brings together other sectors such as education, labour and social affairs. It is thus a most relevant strategy in the community.

There is a wide range of rehabilitation interventions, programmes and services that have been shown to be effective in contributing to optimal functioning of people with neurological conditions. Rehabilitation services need to be made available to all people with disabilities, and this includes people with disabilities attributable to neurological disorders. Accessible public transport and other facilities must be provided for them.

Multidisciplinary rehabilitation is considered to be beneficial in early recovery of stroke and traumatic brain injury patients. Although options for treatment of multiple sclerosis are relatively limited, sufferers can gain significant improvements in quality of life with neurorehabilitation.

Since community-based rehabilitation programmes are a low-cost way to coordinate medical guidance and community resources in the rehabilitation of disabled people, they need to be encouraged. The programmes should be linked to and supported by institutional and hospital-based care, where appropriate, thus creating a comprehensive rehabilitation service.

6. Develop national capacity and international collaboration

The international implications of dealing with neurological disorders in low and middle income countries are similar to those for a variety of other health concerns. Building capacity in these countries to reduce the burden of neurological disorders will require international contributions of expertise and resources. Examples of such collaboration are the global campaigns against epilepsy (www.who.int/mental_health/management/globalepilepsycampaign/) and headache disorders (www.who.int/mental_health/neurology/headache/), which have been launched by WHO in partnership with leading international nongovernmental organizations working in these areas.

The donor community urgently needs to dedicate more of its resources to help low and middle income countries improve services for the prevention and management of neurological disorders. Nongovernmental organizations have an important role to play in this regard, and they should be encouraged to give greater support to their initiatives. Partnerships between health policy-makers, health-care providers and people affected by neurological disorders and their advocacy groups may be the best vehicle for determining, and bringing about, the changes that people with neurological disorders need.

7. Establish links to other sectors

The risk factors and strategies for prevention for many of the neurological disorders lie beyond the health sector, necessitating the participation of other sectors such as education, transport, welfare, housing and legislation; these sectors need to be fully involved in improving the programmes and services for people with neurological disorders. Partnerships are advantageous in enhancing the effectiveness of interventions, increasing the resources available through joint actions and avoiding a duplication of efforts. Sometimes different sectors may have different and even conflicting priorities; in such situations, the health sector needs the capacity to provide leadership and informed reasoning and to adapt to the agendas and priorities of other sectors.

Road traffic injury prevention and management strategies include the design of vehicles, the design of road networks and roads, urban and rural planning, the introduction and enforcement of road safety legislation and the care and treatment of crash survivors. These are some of the relevant areas for interventions to prevent neurological consequences of road traffic injuries, which are divided among many different sectors and groups.

8. Define priorities for research

The research agenda for developing countries, including operational research, needs to be developed to gain better understanding of the problem so that appropriate responses can be developed and evaluated. Specific areas for research and development could include conducting population-based epidemiological studies in developing countries where insufficient data limit evidence-based planning. It is also necessary to develop and evaluate simple models of care for management of neurological disorders by existing community-based health-care providers. Many currently available medications have significant side-effects and are too expensive for most patients in developing countries. Newer medications need to be developed with lower costs, fewer side-effects, better efficacy, and less frequent dose schedules. Multicentre epidemiological studies and trials of novel treatments should be facilitated through better funding, multidisciplinary approaches and international collaboration.

This report endeavours to contribute to the knowledge base regarding public health aspects of neurological disorders. It is hoped that it will inspire and facilitate increased cooperation, innovation and commitment in preventing neurological disorders and providing the best possible care for people suffering from them.