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BRAIN DISORDERS WHERE RESOURCES ARE SCARCE: THE UNFINISHED AGENDA

In the aggregate, neurologic, psychiatric, and developmental disorders (NPDDs) are the largest contributor to the global burden of disease. Further, more than 90% of the world's NPDDs occur in low- and middle-income countries, while less than 10% of global resources that are intended to alleviate these problems are available to these countries. The "burden" is even larger than usually cited, since many of the disorders that neurologists are called upon to manage are the result of factors arising outside the nervous system, and these entities are not fully captured, as currently tabulated. For example, dementia and depression caused by HIV/AIDS is not fully accounted for within NPDDs. Awareness of the enormous impact of NPDDs globally, and in low- and middle-income countries specifically, is increasing.¹ However, translation of this awareness into improved patient care has proceeded slowly. I will explore some of the factors involved in attempting to reduce the health disparity affecting the hundreds of millions of individuals with NPDDs in low- and middle-income countries.

NPDDs occur in often-difficult local environmental contexts. Where famines occur, the consequences of malnutrition dominate. Where HIV is prevalent, its nervous system consequences overwhelm other NPDDs. Armed conflict and forced migration make health care delivery difficult to impossible. Where immunization programs are impeded, brain infections flourish. Where alcohol abuse is epidemic, its developmental and adult effects on the nervous system are also epidemic. Local belief systems, stigma, and other cultural features impede recognition and treatment. Poverty alone produces both human capital and facility shortages. All of these fundamental issues are interwoven with national and regional politics and corruption, and all lead to enormous disparities in comparison with wealthy countries. While many of these issues are beyond our control, the input from the neurology community can serve as a valuable aid to those in positions to make changes.

Many efforts are under way that will contribute to improving the situation in developing countries. These include, among others, the World Federation of Neurology's (WFN) initiatives to train health care workers, build institutional capacity, and bring the relevant professional organizations together to develop a common voice.^{2,3} Epidemiologic studies to document local service needs and identify causation are essential. The importance of these and other research approaches designed to develop prevention, treatment, and rehabilitation measures for disorders endemic in low-income countries cannot be overemphasized. Despite these efforts, most international funding agencies still do not seem to recognize the enormous burden imposed by NPDDs.

The American Academy of Neurology has recently sponsored the development of a Global Health Section. This represents an important increment in organizational support for international efforts by a leading professional organization.

A critical function of the WHO is to advocate for improved health care based on its data collection and development of standards. WHO reports and recommendations carry enormous weight throughout the world, particularly in resource-poor countries. Thus WHO is an extremely important ally in advocating on behalf of NPDDs. Through its Division of Mental Health, Developmental Disabilities and Substance Abuse Services, WHO has published important accounts of the problems posed by some NPDDs. However, the name of the Division exemplifies part of the problem. It does not specifically include neurologic disorders. Partially as a result of this, the United Nations, the parent agency of WHO, failed to highlight NPDDs in recent conferences designed to increase attention to noncommunicable diseases.⁴ The WFN has taken the lead in addressing this problem.³

A critical strategy in efforts to close the gap is to persuade local and national health ministries, other governmental agencies, and the organizations that provide external funding to assign much higher priorities to addressing NPDDs. This task, to advocate for data-driven policy formulation, is complex and difficult.

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ADVOCACY: PAST AND PRESENT Several examples of successful advocacy in the United States can be cited. Sylvia Lowry founded the National Multiple Sclerosis Society, as she sought answers to her sister's illness. Her initiative contributed to the establishment of the National Institute of Neurological Diseases and Blindness (now NINDS) within the NIH. Years later, while he served as NINDB Director, Murray Goldstein stimulated the development of the US "Decade of the Brain" in the 1990s. That initiative led to much-needed increased Congressional funding for research in the brain sciences. Similar initiatives followed in many countries.

The development of the study that led to the publication of the 2001 Institute of Medicine Report on NPDDs in developing countries⁵ led to a new stream of research funding via the NIH Fogarty Center, "Brain Disorders Across the Lifetime: Research in Developing Countries." The inclusion of NPDDs in subsequent international studies and publications further increased the visibility of these disorders on the international stage. NIH as a whole now targets research on disorders most common in developing countries as part of its mission.

The organizers of the Global Burden of Disease (GBD) 2010 Study, updating the original GBD study, made a key decision: separate sections on nervous system disorders have been organized, which represents important recognition, and will provide valuable data.

Advocacy that takes place within resource-poor countries is critically important. Many agencies, such as The World Bank, respond primarily to requests by the country requesting assistance, requests that have made their way through the local evidence base and bureaucracy. At least 2 successful advocacy programs on behalf of NPDDs that took place in resource-poor countries can be identified. An excellent example in a low-income country was the response to a pioneering epidemiologic survey of children's disability in Bangladesh. Simply the conduct of the study, and then the unveiling of its results, stimulated parents to petition their government, leading to the development of significant changes in public policy.⁶ An example that originated in a middle-income country is the virtual elimination of cerebral cysticercosis in Ecuador, due largely to the efforts of a neurologist who was at that time Minister of Health, Marcelo Cruz.⁷ His success illustrates one of the methods that neurologists can employ, i.e., to become personally involved in the political system.

ADVOCACY TODAY AND TOMORROW **Workforce.** Most Sub-Saharan African (SSA) countries have fewer than 1 neurologist per 1 million citizens,

and similar shortages exist elsewhere. Since, at best, it will take many years to train and place adequate numbers of physicians and nurses to provide care at the village and small town level, other solutions must be pursued. For example, the preparation of village health care workers to recognize, treat, or refer those with NPDDs can be greatly expanded at little cost. An example of a successful program that illustrates the success of a short-term training period is a 1-day course for village health care workers in Kenya who deal with neurologic manifestations of HIV.⁸

An example of the possibilities to be gained from longer training periods is the program that led to the development of Iran's primary health care networks. In this program, started in the early 1970s, locally selected village residents were trained for weeks to months to equip them to deal with a variety of disorders, including common neurologic problems. The village personnel were supervised by a regional center of excellence, Shiraz University. Ongoing development of this system nationally has become integral to Iran's health care system.⁹

It is very likely that many countries would develop their own versions of similar village NPDD programs, were the funds made available for this purpose. Neurologists are beginning to contribute to this development as faculty and supervisors, and by fund raising. Since SSA alone numbers 1 billion people, the potential impact of providing trained village health care workers is evident.

A major contributor to the workforce shortage is the exodus of physicians, nurses, and therapists from poor to wealthy countries. Although the brain drain is directly related to a country's economic circumstances, many other factors underlie this problem. The neurology community can help to develop opportunities for trained professionals to remain in the country that provided their expensive training.

Medication and equipment supply. Medications are often unavailable, only intermittently available, or more expensive in low-income countries than in wealthy nations. The economics alone are daunting. Yearly health expenditures per capita range from \$15 in Ethiopia to \$7,400 in the United States. However, many other local factors interfere with distribution of the drugs that are available: priority setting, transportation, and other supply chain factors, to name a few. Relatively few voluntary health organizations address this problem in treating NPDDs; a notable exception is the International League Against Epilepsy.

An under-recognized, unmet need is the provision of opiates for pain control. These are inexpensive but forbidden or severely restricted in many countries, often for lack of understanding of their role in palliative care, where addiction is not an issue.

Neurologists can help by developing education programs designed to change policy.

Many of the barriers to obtaining medications or neurosurgical instruments are not specific to NPDDs, but rather are issues in the overall health care delivery system of a country. Problems such as transportation to clinic or hospital where long distances, rutted dirt roads that are impassible in the rainy season, or lack of motorized vehicles prevail must be addressed at the policy level.

Stigma reduction. In many countries, local belief systems, including stigma, interfere with identification and treatment for those with problems such as neurodevelopmental disorders, epilepsy, stroke, and the need for pain control. Research and training programs designed to reduce stigma toward epilepsy in Zambia serve as an example of what can be accomplished at a local level, and may show the way for successful advocacy at the national level in many countries.¹⁰

Primary and secondary prevention and rehabilitation. Few countries have developed preventive programs relevant to NPDDs, other than the use of vaccines (many of which seek to prevent brain infections or complications of infection), salt iodination to prevent cognitive impairment, and folic acid supplementation to prevent neural tube defects. Although stroke is the number 1 cause of death and disability in many resource-poor countries, prevention and treatment programs are few in number. Injuries in motor vehicle accidents remain a major problem in most low- and middle-income countries, and yet automobile seatbelt use is increasing only very gradually. Sadly, rehabilitation programs are almost unknown in many low-income countries.

Develop the expertise needed for effective advocacy. Committed neurologists are working at every level, from the bedside to training, research, and advocacy. However, since many of these issues must be addressed at the level of health ministries and other governmental organizations, ways must be found to increase the number of neurologists and other clinical and basic neuroscientists who are able to analyze the costs of providing and not providing services. These skills are linked to an understanding of how health care policy is developed, and the ways in which governments make decisions.

In order to be able to act on behalf of individuals with NPDDs, governments must be aware of the problems, assign appropriate priorities, and have ac-

cess to adequate funding. Influencing public policy in proportion to the deaths, disabilities, and expenditures consequent to NPDDs is incompletely addressed in most countries, low and high income. The necessary skill sets are applicable in virtually all nations. Academic departments, professional organizations such as the WFN, and funding agencies should be asked to help support those who seek this training.

Finally, we now can employ mobile phone technology, a variety of social networking techniques, crowdsourcing, and other electronic media tools in ways that remain to be developed on behalf of those with NPDDs in resource-poor countries.

As clinicians, investigators, and members of professional and other nongovernmental organizations, academic departments, or governments, neurologists can contribute to reducing this major part of health disparity. By utilizing advocacy, training, research, and fundraising, we can make a difference. The cup is now half-full and we all have the opportunity to improve the lives of those with disorders of the nervous system in resource-poor countries.

DISCLOSURE

The author reports no disclosures relevant to the manuscript. **Go to Neurology.org for full disclosures.**

REFERENCES

1. Silberberg D. The high impact of neurologic disorders in developing countries: the struggle for global recognition. *Neurology* 2011;77:307–308.
2. Ahmad K, Aarli J. Global perspectives. *Neurology* 2011; 77:1565–1567.
3. Hachinski V. The World Federation of Neurology: the way forward. *Neurology* 2012;78:286–288.
4. Birbeck G. The 2011 United Nations General Assembly on Non-Communicable Diseases: how neurologic disorders got left out. *Neurology* 2011;77:2067–2069.
5. Institute of Medicine. *Neurological, Psychiatric and Developmental Disorders: Meeting the Challenge in the Developing World*. Seattle: Academy Press; 2001.
6. Khan N. Best resource use for disabled children. *World Health Forum* 1998;19:47–52.
7. Cruz M, Schantz PM, Cruz I, et al. Epilepsy and neurocysticercosis in an Andean community. *Int J Epidemiol* 1999; 28:799–803.
8. Cettomai D, Kwasa J, Birbeck G, et al. Training needs and evaluation of a neuro-HIV training module for non-physician healthcare workers in western Kenya. *J Neurol Sci* 2011;307:92–96.
9. Shadpour K. Primary health care networks in the Islamic Republic of Iran. *East Mediterr Health J* 2000;6:822–825.
10. Atadzhanov M, Haworth A, Chomba EN, Mbewe EK, Birbeck GL. Epilepsy-associated stigma in Zambia: what factors predict greater felt stigma in a highly stigmatized population. *Epilepsy Behav* 2010;19:414–418.

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