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EDUCATIONAL AND MANAGEMENT IMPLICATIONS

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PREVENTION OF SUBSTANCE ABUSE
WORLD HEALTH ORGANIZATION

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This document results from the meeting of the WHO Working Group on Parkinson's Disease held at WHO, Geneva, 27 & 28 May 1997. The following experts participated:

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Dr Douglas MacMahon, UK
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PARKINSON'S DISEASE AND PUBLIC HEALTH

EDUCATIONAL AND MANAGEMENT IMPLICATIONS

Introduction

Movement disorders contribute substantially to the burden of illness globally. The prototypical movement disorder is Parkinson's disease (PD), first described by James Parkinson in 1817. However, many patients have difficulty with spatial and temporal patterns of movement, without paralysis, yet are often excluded from movement disorder categories because of the conventional disease classification categories commonly used. For example, patients with multiple lacunar strokes, including many individuals with diabetes mellitus and hypertension, have some degree of rigidity and bradykinesis that is poorly responsive to currently available pharmacotherapy. These people would be classified on morbidity and mortality tables as having cerebrovascular disorders, yet an important part of their disability reflects the impact of the movement disorder upon their quality of life. Likewise, patients with schizophrenia and other mental illnesses may have their disorders of thought reasonably well controlled with neuroleptic therapy, yet be unable to function effectively in the workplace or participate in the social life of the community because of a medication-related movement disorder that would not be reflected in national data banks of morbidity.

This document has been prepared by Dr M. Menken (World Federation of Neurology) and Dr A. Janca (World Health Organization).

Even if one limits data to PD as such, the annual incidence for this disorder is about 20 per 100,000 people, and the prevalence about 165 per 100,000 people. The average general practitioner (primary care physician) available to provide care for 2000 people will therefore encounter 2 new patients every 5 years. A neurologist available to provide care for 250,000 people would have 50 new patient encounters annually for PD, whereas a neurologist who is available to provide care for only 25,000 people will have 5 such encounters.

To delineate the public health aspects of PD, and to enhance care for all people with PD, a Working Group on Parkinson's Disease was established by the Division of Mental Health and Prevention of Substance Abuse of the World Health Organization (WHO). The Working Group consisted of 12 physicians including representatives of the World Federation of Neurology, WHO and several experts in Parkinson's Disease as well as 3 non-physicians, including the President and Vice-President of the European Parkinson's Disease Association. Of the 15 participants, 2 suffer from PD. The Group met in Geneva, Switzerland, during May 1997 and its discussions and recommendations were focused upon the public health aspects of PD including: Epidemiology; Organization of Services and Treatment; Education, Training and Information; and Direct and Indirect Costs of Care. This publication follows the consensus and recommendations of the Group and is specifically focused on educational and management aspects of PD. Issues related to the epidemiology of PD will be addressed in a separate document.

Educational Implications

Clearly, all medical students and other health care workers need to learn about PD. But what shall they be

taught? They certainly need to have some information from the basic sciences about the physiology, biochemistry, and pathology of the disease, and they need the opportunity to have sufficient clinical exposure to patients with PD under competent mentoring. In sum, they need to have the appropriate information, skills, and attitudes needed to diagnose and treat PD patients whom they are likely to encounter from time to time in most clinical practices. But is this enough? Should not medical education look beyond the care of individual patients and provide all future doctors and other health care providers with a population-based perspective about the disorders they study? Should not doctors be trained as educators, not only of their students and allied health personnel, but also as teachers of the public at large? Should not doctors acquire the attitudes that enable them to learn open-mindedly from their patients' experiences and insights, and from social support groups within society?

In support of WHO's Health for All programme, the Edinburgh Declaration (1988), sponsored by the World Federation for Medical education (WFME), outlined 12 principles for reform of medical education. Emphasis was given to national health priorities in curricular design, an examination system that focused upon competence and values (not mere retention and recall of facts), and a community setting for learning experiences, among others. In 1993, a Working Group for Neurology, including representatives of WHO and WFME, showed how these 12 principles for reform of medical education might be applied to a specialized clinical field such as neurology. This Group called for collaboration among teachers representing several disciplines in undergraduate medical education, to include primary care educators in the teaching of neurology to medical students, and recommended that doctors be generally educated in the cultural traditions of

the communities in which they provide care. More recently, the World Health Assembly urged WHO to undertake reform in the education of health care workers in further support of Health for All, including the concept that quality in medical education be measured in part by the relevance of educational programmes to the health needs of individuals and communities.

Recommendation 1

The WHO Working Group on Parkinson's Disease urges support for these global efforts to reform medical education in support of the WHO Health for All initiative. Steps to increase public awareness of PD as a priority health problem should be pursued vigorously, including the collection of salient information about all aspects of PD, (epidemiology, available treatment modalities, costs of care, consequences to patients and families resulting from a loss of independence, types of care givers and support services for PD sufferers, and so forth), along with widespread dissemination of this information to the public, health authorities, medical schools, and teaching hospitals. Experts in PD should acquire the attitudes necessary to participate in health care teams, especially in those situations where other groups of health workers or patients serve as team captains.

Organization of Services and Treatment

Since PD is treatable, but not yet curable, the duration of treatment grows ever longer as new medications become available. The aging of the population has increased the number of patients with PD who make demands upon the

health services of all countries. The way in which health services are organized and financed impacts critically upon the comprehensiveness of care for patients. Moreover, there is a need to study carefully the range of health care, social and other services received by these patients as a function of social class or socioeconomic status. The care received by patients with PD may be considered within three overlapping time frameworks, or tiers: first, diagnostic investigations and treatment options during the early years of PD, when response to medication is usually quite good; second, maintenance therapy as the disease progresses and becomes progressively more difficult to control sufficiently for patients to function effectively in the workplace, and to discharge activities of daily living without assistance; third, palliative care, when patient comfort and relief for care givers is all important, since no presently available pharmacologic agents control physical symptoms amply, and cognitive and psychological deterioration are likewise difficult to treat.

Clearly, neurologists alone cannot meet all of the care requirements of patients with PD. The World Health Organization in 1977 proclaimed that Health for All in each nation is contingent upon an effective primary care infrastructure for each health system. In developing countries, this will mean that primary health care is obtained in community health centers, and provided by primary care workers whose training is measured in months. In more affluent nations, nurses and general practitioners (primary care physicians) will provide the majority of services. It is part of the Health for All concept that patients usually obtain access to specialized services upon referral from primary care. In the USA, the transformation to integrated care networks that rely upon primary health care (so-called managed care), has demonstrated that even a rich nation cannot provide a full

range of services for its people at a cost that society can afford when health services are organized to deliver services on a specialty-by-specialty basis, without coordination of effort.

Recommendation 2

The WHO Working Group on Parkinson's Disease recommends that all health authorities worldwide support the WHO Health for All concept, and implement the programme in the case of PD consistent with the resources that are available at each stage of industrial development. To provide the greatest number of the most important services for the largest number of people, priority health problems must be identified in each society. For disorders such as PD, there should be a national steering group comprised of patients, care givers, and national organizations that advocate patients' interests, and should include health care providers of all types, including doctors who represent specialist, subspecialist, and general practitioner viewpoints and experiences.

Since current pharmacologic therapy is for some patients with PD a qualified success, and for other patients a failure, a dual population-based approach that promotes biomedical research to develop new therapies should be coupled with development of support services for people whose PD is now poorly responsive to available medications and other treatment modalities at disparate stages of the disease trajectory.

Recommendation 3

The WHO Working Group on Parkinson's Disease recommends that health authorities take steps to achieve coordination of effort by health workers within the three-tier model of service delivery presented in broad outline above, and to arrange care that is structured in accordance with results of cost-effectiveness studies of alternative provider arrangements and sites of care provision across the full spectrum of illness.

Direct and Indirect Costs of Care

All societies now recognize that it is impossible to provide all of the care that might possibly be of benefit to all of its citizens at an affordable cost. For patients with PD, there are often huge costs that quickly exhaust family resources unless there is a comprehensive social insurance scheme or national health service in place. A Delphi panel examining national needs for neurologists in the USA estimated that the average patient with PD would require 140 minutes of a neurologist's time during the first year of illness (50 minutes during the first visit and a total of 90 minutes during subsequent visits), and would require 60 minutes annually during the remaining 9 years of illness. The direct (accounting) cost to patients includes not only the cost of primary care and specialist services, medications, laboratory tests, and so forth, but also the many hidden costs that arise as a result of falls, incontinence, dementia, psychological changes including depression, and sometimes residential care.

Moreover, there are many indirect costs such as loss of earnings, inability to use public transportation, the burdens

that accrue to care givers, and the opportunity costs resulting from the time lost obtaining care and coping with disabilities and handicaps which could otherwise be spent in economically productive activity or at leisure. Finally, there are psychological costs that arise for sufferers from negative attitudes by the public about PD as a hopeless, end-stage illness for which little can be done other than temporary palliation.

Recommendation 4

Given total national costs and individual financial burdens that exceed private and governmental resources, the WHO Working Group on Parkinson's Disease recommends a partnership between neuroscientists and health workers to devise ways to improve access to needed care and treatment for all PD patients, and to foster practice guidelines to assist health care workers in the management of medication side effects, especially among the elderly.

Recommendation 5

The WHO Working Group on Parkinson's Disease likewise recommends a partnership between doctors and other health care workers with voluntary (non-governmental) organizations that represent patient interests to promote better public understanding of PD, to reach out to all ethnic and cultural groups of patients, and to overcome negative attitudes in society toward chronic neurologic and psychiatric illness.

Conclusions

The WHO Working Group on Parkinson's Disease urges support for global efforts to reform medical education in support of the WHO Health for All initiative. Steps to increase public awareness of PD as an important health problem should be pursued vigorously, including the collection of salient information about all aspects of PD, along with widespread dissemination of this information to the public, health authorities, medical schools, and teaching hospitals.

It is an integral part of the WHO Health for All concept that patients with PD will usually obtain access to specialized services upon referral from primary care. The Working Group recommends that all health authorities worldwide support the WHO Health for All concept, and implement the programme in the case of PD consistent with the resources that are available at each stage of industrial development. To provide the greatest number of the most important services for the largest number of people, priority health problems must be identified in each society. For disorders such as PD, there should be a national steering group comprised of patients, care givers, and national organizations that advocates patients' interests, and includes health care providers of all types.

Given total national health care costs and individual financial burdens that exceed private and governmental resources, the Working Group recommends a partnership between neuroscientists and health workers to develop more effective treatments, as well as a partnership between doctors and other health care workers with voluntary (non-governmental) organizations that represent patient interests.

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