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SECOND MEETING OF THE WHO WORKING GROUP ON PARKINSON'S DISEASE

Barcelona, Spain, 3 April 1998

REPORT

This meeting reviewed the ongoing WHO activities on Parkinson's Disease, discussed and agreed on the WHO strategy and new projects related to the public health aspects of this disorder.



DEPARTMENT OF MENTAL HEALTH
WORLD HEALTH ORGANIZATION

1999

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CONTENTS

1.	INTRODUCTION	3
	1.1 Opening	3
	1.2 Adoption of the agenda	3
2.	EPIDEMIOLOGY OF PARKINSON'S DISEASE	3
	2.1 Global Parkinson's Disease Survey (GPDS) - A development update	4
	2.2 Discussion and conclusions	5
3.	NEUROLOGY AND PUBLIC HEALTH - CURRICULAR AND EDUCATIONAL IMPLICATIONS	6
	3.1 Strategy and perspective	6
	3.2 General discussion	7
	3.3 Implications for Parkinson's disease	8
4.	CONSENSUS STATEMENT ON TREATMENT AND MANAGEMENT OF PARKINSON'S DISEASE	8
5.	CONCLUSIONS AND CLOSURE OF THE MEETING	9
	Appendix 1 - Agenda	11
	Appendix 2 - List of participants	13

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Report

1. INTRODUCTION

1.1 Opening

Dr L. Prilipko, Chief, Unit of Neuroscience, WHO opened the meeting and welcomed participants thanking them for their comments on the report of the first meeting of WHO Working Group on Parkinson's Disease held at WHO, Geneva on 27 and 28 May 1997. The report of the first meeting had been produced and a brochure on public health aspects of Parkinson's disease had been published by WHO and distributed to the WHO Regional Offices and WHO collaborators in many countries. During this period WHO has been trying to create a network of centres and individuals who will be involved in WHO/EPDA activities and this will continue in the future. Dr Prilipko pointed out that this meeting was a continuation of what was discussed last year and outlined the objectives for this second meeting as follows:

1. to review recommended projects and activities in the field of epidemiology of Parkinson's disease;
2. to discuss the merits of a project on medical education in support of the WHO Global initiative on Neurology and Public Health; and
3. to gain agreement on developing a consensus statement on the treatment of Parkinson's disease.

1.2 Adoption of the agenda

After the introductory remarks by Dr Prilipko, the agenda of the meeting was reviewed and adopted. Professor Janca was elected Chairman for the opening session and Dr Menken for the second. Mr Brown and Ms Graham were elected as official rapporteurs. Professor Janca agreed to finalize the report of the meeting.

2. EPIDEMIOLOGY OF PARKINSON'S DISEASE

Introducing the topic of epidemiology of Parkinson's disease, Professor Janca outlined some of the key objectives for such an initiative including that:

- epidemiological studies should be expanded in scope and incorporate patient perceptions and preferences;

- studies should review the relationships between duration of disease, duration of treatment and quality of life;
- studies should assess the interface between the extent of disability, impairment, handicap and quality of life;
- new measurement techniques were required for reliable comparisons between and among different cultural groups and nations;
- new studies should employ methodologically consistent data collection;
- multi-centre studies of different epidemiological aspects of Parkinson's disease should be used as a resource for local and regional centres and projects.

2.1 Global Parkinson's Disease Survey (GPDS) - A development update

Professor Findley presented an update of the GPDS, a project initiated partly as a response to issues raised at the first meeting of the WHO Working Group on Parkinson's Disease and aimed at elucidating the impact of factors other than disease severity and medication on the quality of life in people with Parkinson's disease. It was acknowledged that only by identifying such factors could guidelines be improved for the overall management of Parkinson's disease globally.

Since the first WHO Working Group meeting, an advisory board to the GPDS had been established. This comprised of a central steering group and an external advisory board, which included representatives from WHO and WHO Working Group on Parkinson's Disease, EPDA, NPF working alongside specialists and people with Parkinson's disease. A pre-pilot had taken place in the UK in September and its findings indicated that the quality of life may not correlate strongly with disease severity, and may be more closely related to duration of Parkinson's disease and other factors. A small scale "Internet survey" of patients, carers and specialists was then used to identify some of these potential factors and a meeting of the external advisory board called in December 1997 to refine the protocol and hypotheses for the survey.

It was agreed that the survey would randomly sample approximately 200 clinicians from each participating country, from whose lists 5 patients and their carers would be randomly selected. Physicians would assess the patients for disease severity, depression and dementia using a variety of standardized measures and instruments. Physicians, carers and patients would then be interviewed by trained interviewers to assess disease severity, quality of life, disability and handicap using a combination of generic and specific measures.

One of the objectives of the study would be to assess the relationship between disease severity, related disability and quality of life by correlating items and scores on WHO DAS-S, PDQ 39 and Hoehn & Yahr.

The survey was currently in the pilot stage, these taking place in the UK and USA, with initial results expected in May 1998. The main survey was anticipated to commence in June 1998.

One of the initial findings from the pilot had been the apparent difficulty in recruiting neurologists to participate in such a survey. It was agreed that a number of measures could be

taken to improve recruitment, the most important of which is that the survey is seen to carry the full seal of approval of WHO.

2.2 Discussion and conclusions

Dr Lieberman commented that the goals of the survey were laudable and should not be questioned, as it was imperative to ascertain the impact of Parkinson's disease upon the world. Mrs Baker agreed and stated that it was necessary to be very focused on how resources were being used and to encourage self-management. To do this, appropriate information had to be made available and the information obtained from the GPDS would enable patient organizations to seek appropriate services so that countries could assist with self-management. It was agreed that the word "patients" should be removed from the protocol and report and replaced with "people".

Dr Prilipko mentioned that one of the criteria for gaining WHO endorsement was that the study involves countries from at least two WHO geographical regions. Professor Findley confirmed that this was the case and that participating countries Japan, USA, UK, Italy, and Spain were in fact from three WHO geographical regions.

Professor Poewe indicated that he would like to investigate the possibility of Austria participating and Dr Mizuno also stated that he would be delighted to see additional countries from Asia participating.

Professor Findley concluded that other countries would be welcomed to participate providing they could guarantee to meet the strict guidelines set out in the protocol for collection of data so as not to compromise the quality and consistency of the data obtained. It was also important that the taking on new participating centres did not slow the overall study.

Mr Mendoza reinforced the overriding objective of maintaining the momentum for this survey and gaining agreement to go forward with the current participating countries. This was reinforced by Dr Lieberman who proposed that the study should proceed in the current participating countries, whilst leaving it open for other countries to participate at a later date, to ensure that the study was not perceived as only being open to Western countries, providing they could meet the strict inclusion criteria. Dr Tewarie pointed out that financial considerations might also influence the final number of participating countries.

It was suggested that one way of assuring full WHO endorsement could be to use WHO collaborating centres to carry out the study in each of the participating countries. This proposal was seen as time-consuming endeavour, which would also take away the randomization of the selected neurologists as an important aspect of the survey protocol. However, participation of a WHO collaborating centre in the overall coordination of the project was seen as another possibility for WHO's involvement in this project.

On the basis of the efforts of all concerned in developing and refining the project, Dr Prilipko agreed to submit the GPDS protocol to the appropriate WHO authorities for approval and endorsement. It was therefore agreed that the following steps should be taken:

- the internal steering group should finalize the protocol pending the results from the pilot (which should include a detailed description of the data collection procedures);
- this should be circulated as an appendix to the draft report of the meeting to all the WHO Working Group members for their information, comments and approval. It was agreed that no significant revision of the protocol will be made at this point of time;
- the comments on the protocol and report should be sent to Dr Prilipko by an assigned deadline; and
- Dr Prilipko will submit the final protocol to respective WHO authorities who would have the final say on the level of WHO endorsement.

If endorsed by WHO, the data collected in the survey would, according to WHO rules, belong to WHO. The results of the survey would be initially published as a formal WHO study report and later submitted for publication in scientific journals.

The data could subsequently be disseminated through the various other WHO channels proposed at the external working group meeting in December (e.g. through the network of WHO Collaborating Centres). It was also agreed that the data would form the basis of numerous secondary publications.

3. NEUROLOGY AND PUBLIC HEALTH - CURRICULAR AND EDUCATIONAL IMPLICATIONS

3.1 Strategy and perspective

Dr M. Menken chaired and presented the second subject of the meeting related to Phase II of the WHO Global Initiative on Neurology and Public Health. Phase I of this project began four years ago and was aimed at increasing public and professional awareness of neurological problems as a public health issue. Phase II aims to develop educational materials to convey this message and should be targeted to the following groups: medical students, primary and allied healthcare workers, nurses, physiotherapists and social service professionals.

The World Federation of Neurology research group agreed to develop an educational philosophy and a core set of principles to help overcome clinicians inherent discomfort with "medical education". They decided in 1993 to work with the World Federation of Medical Education (WFME) to produce a global report on medical education.

The key principles on which this group operated were:

1. To support the WHO Alma Alta 1977 Declaration promoting "health for all" concept ("No country can provide health for all unless there is a well structured primary care system, and through it, access to all specialised services.");
2. Medicine is a "social good" and not a "private consumption good".

The starting points for developing these principles were the 12 precepts of the Edinburgh Declaration. This was outlined by the WFME in 1988 as principles for the improvement of medical education. These were discussed and redefined as the “Barcelona Declaration”, which covered the following key aspects:

1. Identify priority healthcare problems in neurological disorders in each country, region and globally – i.e. need to teach medical students to recognize normality and the main deviations from this. From a public health perspective there is also the importance of a confident mother, decent housing and adequate nutrition, not much additional medical intervention will be required.
2. Address social and behavioural attributes as well as the biological knowledge and skills .i.e. if disease severity = quality of life on a 1:1 basis we need to address these other factors.
3. Reaffirm the importance of prevention and rehabilitation as well as diagnosis and treatment – ensure that medical students appreciate qualitative as well as quantitative research.
4. Clarify who is providing the care – currently primary health care physicians are trying to handle 95% of cases they see and are not giving timely referrals. This will gradually change as nurse practitioners take on an increasingly important role on the treatment of neurological conditions and they will not be so reluctant to refer.
5. Avoid/explain commonly used jargon terms – e.g. “Community orientated”, “Student centred” and “Problem based”. If you want to know about how patients cope in the community, then what do you do? Go and spend a day with them or discuss this with the Professor?
6. Listen to the patients – Establish what the patient needs and not necessarily what the clinician thinks they need.

Dr Menken clarified that the objectives of this session were to gain agreement on these basic principles or make appropriate modifications or suggestions. Especially on how these could be made generic to apply to all disease areas.

3.2 General discussion

There was some discussion about the discrepancies in the treatment of neurological disorders across healthcare systems globally with different emphasis on the roles of primary and specialist care e.g. in India there is 1 neurologist for 3 million people. It was also acknowledged that economics are a driving force behind this, particularly in the US. Professor Findley said it was important, from the WHO Working Group’s point of view to ascertain what could be done on a global level to promote education for people with Parkinson’s disease. Mrs Baker replied that if the principle is accepted for what it is then it has to be driven through, no matter the cost.

What is required is endorsement. After having Parkinson's disease for 7-9 years, people are then directed to social care because there is nothing else that the physicians can do. Therefore education is vital in improving quality of life and assisting those people on the journey of care.

The importance of social support and adequate training for all parties involved in the treatment and care of people with neurological illness was agreed by all in the group, along with the main focus of the "Barcelona Declaration".

Dr Menken summarized by confirming a consensus from within the group that this work: (i) should be pursued and to extend beyond public health issues; and (ii) should be multidisciplinary.

Dr Menken said that he would work with Professor Toole, President of the World Federation for Neurology, to develop a set of principles which would be circulated to all members for comments.

3.3 Implications for Parkinson's Disease

Dr Prilipko pointed out that the above-mentioned initiative would be developed as a joint project between the WHO and WFN. Members of the WHO Working Group would be invited to form a sub-committee to formalize these principles and derive a subset, specific to Parkinson's disease. Following this, educational materials should be developed to convey these principles to a global audience.

After some discussion it was agreed that once the principles were finalized, a series of lectures should be developed which focused on the public health aspects of Parkinson's disease and the importance of the social aspects related to this. The synergy between this initiative and the GPDS which was aiming to elucidate and prioritize some of these factors, which impact most on quality of life in people with Parkinson's disease, was noted. It was suggested that these results should be incorporated in the educational materials on Parkinson's disease.

Professor Tolosa agreed to draft an outline for the series of lectures on Parkinson's disease. These would be developed in collaboration with other members of the WHO Working Group, for presentation at the EPDA Third Multidisciplinary Conference in Barcelona in the autumn.

Mrs Baker agreed to work with Professor Oertel and Professor Findley to provide some appropriate case studies highlighting the broader social implications of Parkinson's disease.

4. CONSENSUS STATEMENT ON TREATMENT AND MANAGEMENT OF PARKINSON'S DISEASE

At the end of the meeting Dr Prilipko asked the members of the WHO Working Group whether a consensus statement for the treatment and management of people with Parkinson's disease would be of use in raising the standards of their treatment and care.

Dr Lieberman opened the discussion by stating that with such large discrepancies on which medications or treatments were most appropriate, gaining agreement on such a consensus statement would be difficult. Professor Tolosa was also concerned that a consensus statement would not be broad enough to apply to all countries. Professor Koller was more optimistic and presented an algorithm on the management of Parkinson's disease, which he had helped to develop.

Mrs Baker also felt that a consensus statement would be particularly useful by setting out clear guidelines and standards for non-specialists and Professor Findley agreed. He also pointed out that it was important to define whom the guidelines were for Dr Mizuno supported this statement.

It was eventually agreed that broad guidelines would be of use for neurologists not specialized in treatment of Parkinson's disease, GPs, nurses, carers and patients. This would include common questions, such as how to diagnose Parkinson's disease, when to initiate treatment and when to refer to specialists. In addition with the variance in availability of medications from country to country, it was agreed to include a list of available medications in the guidelines.

Professor Gershanik also pointed out that to be broadly applicable, these guidelines should emphasize what doctors shouldn't do – e.g. once the patient is over 65, don't give anti-cholinergics.

Professor Janca concluded that guidelines on the treatment and management of Parkinson's disease should be developed as an ongoing WHO initiative carried out by a sub-group coordinated by Professor Poewe.

5. CONCLUSIONS AND CLOSURE OF THE MEETING

It was agreed that the initiatives discussed at this meeting would be developed further by those concerned, who would meet as often as was necessary. Mrs Baker proposed that the future meetings of the WHO Working Group on Parkinson's Disease coincide with the annual World Parkinson's Disease Day. This proposal was supported by Professor Tolosa who proposed that the Movement Disorder Society link in with the WHO and the EPDA to organize an annual World Parkinson's Disease Day event.

Dr Prilipko confirmed that the WHO would support this in principle, but would need to agree on the agenda beforehand. He also pointed out that the work of the assigned sub-groups would continue as agreed during the meeting.

Professor Janca closed the meeting thanking Dr Prilipko and the WHO for their support and co-sponsorship of the 2nd World Parkinson's disease Day; Dr Tewarie and Dr Currie Gnjesda of F. Hoffman La Roche for their unconditional financial support; and Dr Menken and the World Federation of Neurology for his work on curricular principles and especially for his support of educational activities in relation to Parkinson's disease.

Appendix 1**AGENDA AND TIMETABLE****Morning**

09.00-09.10	Opening and adoption of the agenda	
09.10-09.30	Objectives of the meeting	Dr L. Prilipko
09.30-10.30	WHO Global Initiative on Neurology and Public Health	Dr M. Menken
10.30-11.00	Coffee break	
11.00-12.30	Discussion of a project on medical education In support of the WHO Global Initiative on Neurology and Public Health	Dr M. Menken
12.30-14.00	Lunch break	

Afternoon

14.00-14.30	Presentation of a project on epidemiology of Parkinson's Disease	Professor A. Janca
14.30-15.45	General discussion	
15.45-16.00	Coffee break	
16.00-17.30	Consensus view and recommendations	
17.30	Closure	

Appendix 2

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