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Development of Modules for Identification and Management of Generalized Tonic-Clonic Seizures (Major Fits)

*Report of an Intercountry Workshop
Yangon, Myanmar, 23-25 September 2002*

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1. INTRODUCTION

A workshop was held in Bangkok in November 2001 to develop a regional strategy for implementing community-based approaches for mental health problems accessible to all segments of the population, in which all ten Member Countries participated. The technical experts recommended that Member Countries be assisted in the development of strategies to identify and manage epilepsy and psychosis in the community. These conditions were selected based on high prevalence, high morbidity, ease of identification in the community, availability of inexpensive medication and good outcome if treated. There is also a substantial amount of stigma attached to these illnesses which needs to be addressed.

In continuation of the Bangkok Workshop, another workshop was organized in Yangon, Myanmar to finalize community-based strategies to identify and manage epilepsy. Worldwide, prevalence rates of epilepsy vary between 5 to 8 per thousand population. It is reported to be higher in developing countries and in rural areas. WHO data suggests that there are about 50 million persons with epilepsy worldwide, of which 35 million live in developing countries. Thus, Member Countries of the SEA Region have many millions of patients with epilepsy.

The Workshop addressed three issues:

- (1) Finalization of the questionnaire to identify tonic-clonic seizurers (major fits);
- (2) Development of best practice guidelines for treatment of generalized tonic-clonic seizures (major fits), and
- (3) Review of a video on issues related to stigma against persons with generalized tonic-clonic seizures (major fits).

1.1 Finalization of a questionnaire to identify generalized tonic-clonic seizures (major fits)

A questionnaire was developed to identify generalized tonic-clonic seizures (major fits) in the community. This questionnaire had been extensively tested

in the epilepsy clinic of All-India Institute of Medical Sciences, New Delhi, India and in the community in Ballabgarh, Haryana, India, and in Sri Lanka and Myanmar. Prior to the workshop, participating delegates from each Member Country were sent this questionnaire with the request to implement it in at least five patients in their own country and discuss their observations during the workshop.

The objective of the questionnaire being developed is to enable GPs and community health care providers to identify cases with generalized tonic-clonic seizures (major fits). Patients thus identified would be either treated by the physicians or the community health care provider or referred for treatment, based on the practice of the country.

1.2 Development of best practice guidelines for treatment of generalized tonic-clonic seizures (major fits)

A “best practice guideline” for the management of generalized tonic-clonic seizures (major fits) is also being developed, based on advice from experts. These guidelines take into account the cost-effectiveness of medications, their availability, toxicity and probability of compliance.

1.3 Review of a video on issues related to stigma against persons with generalized tonic-clonic seizures (major fits).

There is a substantial amount of stigma and misunderstanding about generalized tonic-clonic seizures in the community. Myths range from the person being incarcerated with evil spirits to penance for sins committed in previous life. Many of these myths are detrimental in obtaining appropriate medical care to the patient. Thus, there is a need to develop a video addressing issues relating to stigma with which the community can identify and learn from.

During the workshop, the experiences of all Member Countries had been discussed and the questionnaire finalized. Delegates were also able to observe implementation of the questionnaire in a rural health care centre in Myanmar.

Yangon, Myanmar was selected as the venue for the workshop as Myanmar has an excellent public health care delivery system, which reaches out to rural and remote areas. Also the Department of Neurology in the Yangon General Hospital provided the technical support for the workshop.

2. OBJECTIVES OF THE CONSULTATION

2.1 General Objectives

To finalize a community-based approach for identification and management of generalized tonic-clonic seizures (major fits) in the community.

2.2 Specific Objectives

- (1) To discuss the country experiences in implementation of the draft questionnaire to identify generalized tonic-clonic seizures (major fits) in the community.
- (2) To finalize the questionnaire to identify generalized tonic-clonic seizures (major fits) in the community.
- (3) To finalize the “best practice guidelines” for management of generalized tonic-clonic seizures (major fits) in the community, and
- (4) To review a video on stigma against persons with generalized tonic-clonic seizures (major fits)

See Annex 1, 2 and 3 for Agenda, Programme and List of Participants

3. SUMMARY OF PROCEEDINGS

3.1 Inauguration

The Workshop was inaugurated by His Excellency, Major General Ket Sein, Minister of Health. He gave the inaugural address on behalf of the Government of Myanmar. WR Myanmar addressed the audience on behalf of WHO.

3.2 Technical Session

The objective of WHO Regional Office’s programme to develop basic services to the community for epilepsy and psychosis, is to reach out to the community including rural and marginalized population groups and provide services to them within the community, using the existing health care delivery system.

Ms Hanneke De Boer presented the Global Campaign Against Epilepsy launched jointly by WHO, International League against Epilepsy and International Bureau for Epilepsy.

Drs Kapoor and Anand serving as resource persons to the workshop, presented the results of the meta analysis of the data collected in India, Myanmar and Sri Lanka. Based on their presentation, an extensive discussion followed on the wording of the questions in the screening instruments and the optimum sensitivity and specificity to identify cases of generalized tonic-clonic seizures (major fits) in the community.

Bhutan, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka and Thailand briefly described their experiences in translating and implementing the screening questionnaire to patients.

Based on the report of the resource persons and the country experiences, the screening instruments to identify generalized tonic-clonic seizures (major fits) were revised (Annex 4).

Review of training manual for community health care providers

A draft of a training manual for community health care providers was reviewed by the delegates. It was suggested that the manual be divided into two, one for a village level health worker and one for a medical officer. The essential components of the two manuals suggested are as follows:

Village level health worker training manual

- The village level health worker manual should be made simpler with all references to differentiation from pseudoseizure deleted. This training manual should be supported by a video which includes how to ask each question and other medical information.
- In the village level worker manual, more about compliance and additional management issues, such as diet, key, shoe etc. should be added.
- In the section on pregnancy, include “refer urgently”.
- There should be an explicit instruction that the health worker is not to demonstrate the meaning of the question.
- Clarify that respondents usually remember the most recent episode, but the information being asked applies to all episodes.

Medical officer training manual

- A more advanced training manual should be developed for medical officers. This should have reference to differentiation between seizures and pseudoseizures. This manual should also be supported by a video which deals with how to ask questions, differentiation between seizures and pseudoseizures (video tapes will be provided by William Theodore and Hanneke de Boer).
- Publication entitled “Epilepsy for Medical Officer Training” developed for Africa, will be provided by Hanneke de Boer.

3.3 Phenobarbitone as the drug of choice for treating generalized tonic-clonic seizures (major fits).

Dr William Theodore reviewed the pros and cons of using phenobarbitone for treatment of generalized tonic-clonic seizures (major fits). He emphasized that phenobarbitone is a cost-effective drug in the management of generalized tonic-clonic seizures. Its benefits far exceed the side effects, and relative to the newer anti-convulsants, it remains the drug of choice for large scale community-based programmes particularly in rural and remote areas. Unfortunately, its abuse potential and side effects, both of which are minimal, have been given too much prominence because of which the drug has fallen into disrepute. The cost of phenobarbitone is extremely low. The cost of 1 000 tablets of phenobarbitone of 30 mg each in Myanmar is 227 Kyats. This is equivalent to US cents 25 per person per year for treatment. Alternate drug to phenobarbitone should be left to local practice guidelines depending on cost and availability.

3.4 Field visit to township hospital and community health centre

The delegates visited a township hospital and a community health centre where they were able to interact with the doctors, health care providers and patients. Delegates were able to observe implementation of the screening instruments and discuss with patients the impact of major fits on their lives and treatment opportunities.

3.5 Review of video on stigma against persons with epilepsy

The draft of a video prepared on behalf of the Regional Office to address issues related to stigma against persons with epilepsy was reviewed by the participants. This video has been prepared for mass screening in the

community, so that the entire community can understand the true nature of generalized tonic-clonic seizures (major fits). The comments for modification of the video were noted and will be forwarded to the producer. All participants emphasized that the video should be very graphic with lots of pictures, so that even illiterate persons could understand the contents easily.

4. FUTURE PLANS

All Member Countries participating in the workshop were requested to test the revised questionnaire on 50 cases with two or more generalized tonic-clonic seizures and 10-20 cases of pseudoseizures. The cases could be identified within their clinical practice. The data were to be transferred to the Regional Office by 30 October 2002.

5. RECOMMENDATIONS

- (1) All Member Countries to test the revised questionnaires in 50 cases with generalized tonic-clonic seizures and 20 cases with pseudoseizures. The WHO Regional Office should compile the data received from all Member Countries and conduct a meta analysis to determine the optimum cut-off point for optimum sensitivity and specificity in identifying cases with generalized tonic-clonic seizures (major fits).
- (2) The Regional Office should modify the draft of the training manual and divide it into two, one for village level health workers and one for medical officers.
- (3) The producer of the video on stigma should incorporate the changes recommended by the participants.
- (4) Three Member Countries should be identified to test the final version of the screening questionnaire training manual and video film in a community setting.

6. CONCLUSION

Dr Vijay Chandra thanked the Government of Myanmar and the local organizers for their kind hospitality and the excellent arrangements made during the workshop. All participants also thanked the organizers.

Annex 1

AGENDA

- (1) Presentation of the background of the basic minimum services in neuropsychiatric disorders project.
- (2) Selection of generalized tonic-clonic seizures (major fits) for community-based management.
- (3) Development of screening questionnaire to identify cases of generalized tonic-clonic seizures (major fits).
- (4) Exchange of country experiences in application of the screening instrument to identify cases of generalized tonic-clonic seizures (major fits) and pseudo-seizures.
- (5) Observation of application of the screening instrument in a rural health care centre in Myanmar.
- (6) Finalization of the instrument to identify cases of generalized tonic-clonic seizures (major fits) in the community.
- (7) Discussion of the training manual for community-based health care providers on identification and management of major fits.
- (8) Review of the proposed classification of epilepsy.

Annex 2 PROGRAMME

23 September 2002

0830 to 1200 hrs Inauguration
 Registration

Plenary:

- Background of the SEARO Project on basic minimum services in neuropsychiatric disorders to the community - Dr Vijay Chandra
- Global Campaign against Epilepsy – Ms Hanneke de Boer
- Development of screening questionnaire to identify cases of major fits – Drs Kapoor and Anand
- Discussion

1330 to 1700 hrs ➤ Country experience in application of screening instrument to identify cases of major fits BHU, INO, MAV, MMR, NEP, SRL, THA

 ➤ Presentation and discussion of meta-analysis of data from all countries.

24 September 2002

0930-1030 hrs **Plenary:**

- Review of training manual for community-based health care providers on identification and management of major fits – Dr William Theodore and Dr Vijay Chandra
- Review of proposed seizure classification of epilepsy – Dr William Theodore

1300 to 1700 hrs ➤ Field visit to health centre to observe application of screening instrument

25 September 2002

0900 to 1200 hrs **Plenary:**

- Review of video – Epilepsy: Myth and Reality
- Finalization of the screening instrument for major fits

1300 to 1700 hrs ➤ Working session for each country to translate and adapt final screening instrument

- Country presentation and future plan
- Conclusion

Annex 3

LIST OF PARTICIPANTS

Bhutan

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Annex 4

SCREENING QUESTIONNAIRE

Date: _____

Patient's Name: _____ Age: _____ Sex: _____

Respondent's name: _____ Relationship to patient: _____

A PERSON IS BROUGHT TO YOU BY THE FAMILY, AFTER HAVING AN EPISODE WITH JERKY MOVEMENTS OF THE BODY OR WITH THE BODY BECOMING STIFF DURING THE EPISODE.

Obtain the following information about the episode(s)* from a person who has witnessed the attack:

No	Questions#	Yes/No/ Don't Know*
1.	Has an episode ever occurred WITHOUT preceding mental/emotionally stressful events?	
2.	Did he/she pass urine or stool in his/her clothes during an episode?	
3a.	Did he/she ever injure himself/herself during an episode?	
3b.	Did he/she ever have a tongue bite/cheek bite during an episode?	
4a.	Was there any frothing from the mouth during an episode?	
4b.	Was there any drooling of saliva during an episode?	
5.	Did he/she ever have such an episode while asleep?	
6.	Was the patient completely unconscious during an episode?	

About how many attacks of major fits has the patient had in the last one year _____

* If too many (50% or more) "do not know", change the respondent.

Many of these events would have happened in one episode, but not in others. It will be taken as yes, if it has happened even in one episode.

