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Developing Country Specific Community-Based Strategies for Reduction of Treatment Gap in Common Neuropsychiatric Conditions

*Report of an Intercountry Workshop
New Delhi, India, 18-20 November 2004*

WHO Project: ICP MNH 001



**World Health
Organization**
REGIONAL OFFICE FOR **South-East Asia**
New Delhi

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1. BACKGROUND

Traditionally, neurological and psychiatric services have been concentrated in tertiary care hospitals. Thus large segments of the population, particularly those who live in rural and remote areas have been deprived of such services despite the common occurrence of both neurological and psychiatric disorders in the communities.

The priority of South-East Asia Regional Office (SEARO) of WHO is to concentrate on community-based projects and programmes. Thus, every effort is being made to develop projects and programmes which are capable of delivering at least the basic minimum level of services for neuropsychiatric disorders to everyone regardless of where they live. Ideally, such services should be delivered within the community rather than expecting people to travel long distances to tertiary care hospitals. The primary health care system should be utilized. Health manpower delivering health care in the community should be trained to identify and manage these conditions, and affordable and appropriate medications should be made available to the community. Finally, the programmes should address psychosocial issues such as stigma.

Ideally, complete and comprehensive services for all neuropsychiatric disorders should be available to all members of the community. However, such comprehensive services cannot be delivered to all within the community, especially in rural and remote areas. Thus, projects and programmes for delivery of such services must address select disorders. The selection of disorders should be guided by the following principles:

- High prevalence of the disorder in the community;
- High morbidity from the disorder;
- Easy to diagnose with resources available in the community;
- Availability of effective and low-cost medication, and
- Good prognosis with treatment.

Many neuropsychiatric disorders meet the above criteria e.g. epilepsy, psychosis and depression, etc. Some communities may have their own unique problems which meet the above criteria. Although it would be ideal to develop projects to deal with all major neuropsychiatric conditions, and implement them at one time, it is not practical or possible. Thus it is proposed to target two disorders in the first phase of this project to reach out to the community. The disorders selected are epilepsy and psychoses.

The Regional Office of WHO SEA Region has launched an initiative to deliver at least minimum services for neuropsychiatric disorders to the community, in the community, using community-based health care providers. This initiative aims to reach the unreached in rural and remote communities. The objective of the initiative is to enhance the capacity of the existing health care delivery system to identify and manage epilepsy and psychoses in the community.

1.1 Epilepsy

Epilepsy is one of the most common serious neurological disorders. Globally the prevalence of epilepsy is estimated to be about 5 to 8 per 1000 population. In developing countries the prevalence is reported to be higher (ranging from 10 per 1000 in South-East Asia to 30 per 1000 reported from South America), probably due to the common occurrence of brain infections such as neurocysticercosis.

Assuming a prevalence of 10 per 1000, there are an estimated 15 million persons with epilepsy in the 11 Member States of the SEA Region. About 70-80% of these people live in rural areas where appropriate services for neuropsychiatric disorders are very limited. Despite global advances in modern medicine, and availability of phenobarbital since 1912, epilepsy continues to be surrounded by myths and misconceptions. It is not unusual for patients with epilepsy to be taken to faith-healers rather than to medical doctors. According to the Global Campaign Against Epilepsy, 80-90% of people with epilepsy in developing countries are not treated properly. In rural areas, this proportion is probably higher, with very few persons getting proper treatment. Thus, it is clear that the mere availability of treatment does not guarantee that the treatment will be delivered to all those affected by a

condition. Also, that a new and innovative approach needs to be taken to address epilepsy management in totality.

The project on epilepsy, at this stage is aimed at identifying and managing Generalized-Tonic Clonic Seizures (GTCS) which are usually called “major fits” by the lay person. Though the GTCS contribute to the highest morbidity, a good outcome is very much possible if they are treated with easily available, effective and low-cost anti-convulsant medication.

The Regional Office programme is part of the Global Campaign Against Epilepsy which is a collaborative effort by International League Against Epilepsy (ILAE), International Bureau for Epilepsy (IBE) and the World Health Organization.

The Global Campaign Against Epilepsy advocates the use of phenobarbital for closing the currently high treatment gap (as much as 90%) in low-income countries. In resource-poor countries, low-cost anti-epileptic drugs (AED) such as phenobarbital can be provided for approximately US\$ 5-10 per person per year.

1.2 Psychoses

Psychotic disorders also occur all over the world. Schizophrenia, one of the major types of psychotic disorders affects about 3 per 1000 of the world's population. It occurs commonly in the most productive age group of 15-35 years. If left untreated or partially treated, schizophrenia can cause significant and long-lasting impairment and disabilities, encompassing all aspects of human functioning. It makes heavy demands on hospital care, and may require prolonged medical care, rehabilitation and support services. The social costs and burden on the family can be enormous.

In the community, the broad category of psychotic disorders would be easier to diagnose and treat than schizophrenia specifically. All psychotic disorders constitute about 15 per 1000 population. The illnesses which are included under psychotic disorders include schizophrenia, mania, delusional disorder, unspecified psychoses and acute and transient psychotic disorder. It is not necessary to make a detailed diagnosis of the exact type of psychotic disorder as generally the treatment is the same for all conditions included

under it. With adequate treatment, prognosis is good in most cases specially if treatment is started early. On some occasions excessive intake of intoxicants like cannabis and alcohol, or serious physical or neurological diseases, or even severe head injury may lead to psychosis which is known as organic psychosis. Though the medicines given to control psychotic symptoms are the same, in these cases one needs to evaluate the underlying organic condition and manage it appropriately, if needed, with appropriate referral.

2. TREATMENT IN THE COMMUNITY FOR COMMON NEUROPSYCHIATRIC DISORDERS

2.1 Phenobarbital for Treatment of GTCS

Phenobarbital is a cost-effective drug in the management of epilepsy. Its benefits far exceed its 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. Alternative but more expensive AEDs such as carbamazepine and valproic acid have become the drugs of choice in developed countries due to the perceived lower risk of possible long-term side-effects, including cognitive impairment in children. Unfortunately, these are also being extensively promoted in developing countries.

Phenobarbital has many advantages for epilepsy treatment. Its cost is very low. It can be given once daily. It has simple, well-understood kinetics, and there is little evidence for inter-patient variability. Thus, blood level monitoring is usually not necessary. There are few serious systemic side-effects, and they are well known. All these factors will increase compliance, which is the *sine qua non* of effective epilepsy treatment.

2.2 Risperidone for Treatment of Psychoses

Drugs which are used in the treatment of psychoses are called antipsychotics. They have been classified into two broad categories: traditional or typical

antipsychotics and the atypical or newer drugs. The atypical antipsychotics have a similar efficacy as compared to typical drugs. However they have a better side-effect profile leading to better tolerability and improvement in compliance. Risperidone belongs to the class of atypical drugs and has been chosen because of its efficacy and better side-effect profile in the doses recommended in this project. There are only a few serious systemic side-effects, that are uncommon in frequency. The better side-effects profile leads to improved compliance which is an essential requirement for the successful management of patients with psychoses. Risperidone was chosen as the antipsychotic after evaluating the pros and cons of all the currently available antipsychotic medication.

3. OBJECTIVES OF THE WORKSHOP

An intercountry workshop on "Developing Country-Specific Community-Based Strategies for Reduction of Treatment Gap in Common Neuropsychiatric Conditions" was organized at WHO's Regional Office from South-East Asia, New Delhi, from 18-20 November 2004. Experts from India, Indonesia and Myanmar participated in the workshop.

3.1 General Objective

The general objective of the workshop was:

- Capacity building in Member States on management of most common and disabling neuropsychiatric conditions in the community.

3.2 Specific Objective

The specific objectives were:

- Review the existing health care delivery system for neuropsychiatric conditions in participating Member States;
- Review the reasons for high treatment gap for neuropsychiatric conditions in participating Member States and

- Discuss community-based strategies for reduction of treatment gap in common neuropsychiatric conditions and finalize the process and impact indicators to evaluate these strategies.

4. SUMMARY OF PROCEEDINGS

4.1 Review the Existing Health Care Delivery System for Neuropsychiatric Conditions in Participating Member States

The findings of the survey of health care providers conducted in study areas of participating Member States were presented. The survey was undertaken to assess the different types of health care providers providing treatment for epilepsy and psychosis in the community, and their treatment practices for these conditions; the number of patients suffering from epilepsy and psychosis seen by these health care providers in the last year, and to estimate the treatment gap for these conditions.

The “treatment gap” was defined as the difference between the number of people with the disease (either epilepsy or psychosis) and the number of people who were being appropriately treated (taking treatment from qualified allopathic physicians) in a given population at a given point in time, expressed as a percentage.

India

The survey of health care providers was undertaken at five sites in India.

(i) Namkum, Ranchi

The survey was conducted in Namkum block of Ranchi with a population of 1 14 068 (91.1% rural and 8.9% urban). There were 407 health care providers in this area who were providing services for epilepsy and psychosis. Out of these only 21 (5.2%) were qualified allopathic physicians. Others who were providing service were: qualified indigenous system physicians (3.2%); village/local health care providers other than qualified physicians (6.4%), and majority of them were faith- healers (85.3%).

(ii) Sarsol, Kanpur

The survey was conducted in Sarsol, Kanpur with a population of 1 05 401 (80.9% rural and 19.1% urban). There were 234 health care providers in this area who were providing services for epilepsy and psychosis. Out of these only 16 (6.4%) were qualified allopathic physicians. Others who were providing service were: qualified indigenous system physicians (4.7%); faith-healers (25.3%), and the majority were village/local health care providers other than qualified physicians (63.7%).

(iii) Manimajra, Chandigarh

The survey was conducted in Manimajra, Chandigarh with a population of 110 000 (5.5% rural and 94.5% urban). There were 95 health care providers in this area who were providing services for epilepsy and psychosis. Out of these only 30 (6.4%) were qualified allopathic physicians. Others who were providing service were: qualified indigenous system physicians (51.6%); faith-healers (10.5%), and local health care providers other than qualified physicians (6.3%).

Based on the number of patients seen by qualified allopathic physicians and the estimated prevalence in the area, the treatment gap for epilepsy was 46.4% and for psychosis 82.0%. This being an urban area, the treatment gap was relatively low as compared to other rural sites in India but it was still high for psychosis.

(iv) Chattarpur, Delhi

The survey was conducted in Chattarpur block in south district of Delhi with a population of 1 25 000 consisting primarily of urbanized villages. There were 84 health care providers in this area who were providing services for epilepsy and psychosis. Out of these only 11 (13.1%) were qualified allopathic physicians. Others who were providing service were: qualified indigenous system physicians (28.6%); faith-healers (19.0%), and local health care providers other than qualified physicians (34.3%).

Based on the number of patients seen by qualified allopathic physicians and the estimated prevalence in the area, the treatment gap for epilepsy was 81.5% and for psychosis 72.3%. In spite of its proximity to Delhi the treatment gap was still very high.

(v) Sitla, Uttaranchal

The survey was conducted in the rural hilly area of Ramgarh block of Nainital district, Uttaranchal with a population of 8684. There were 30 health care providers in this area who were providing services for epilepsy and psychosis. Out of these majority were qualified allopathic physicians (58.6%), and the others were qualified indigenous system physicians (42.4%). There were no faith-healers and local health care providers in this area providing services for epilepsy and psychosis.

Summary of observations in India

Treatment gap

The treatment gap for epilepsy at four sites in India exceeded 80% and reached a level of 90% in Sarsol, Kanpur. The only site with a modest treatment gap was Manimajra, Chandigarh which being a relatively developed urban area, perhaps had more people seeking treatment.

The treatment gap for psychoses exceeded 80% at four sites reaching a level of 97% in Namkum, Ranchi. Perhaps this indicates the lack of awareness of psychosis being a medical illness and therefore the need for medical treatment. A modest treatment gap of 72% perhaps indicates the services being utilized at the outreach centre of the Institute of Human Behaviour and Allied Sciences, Delhi. This institute has a long history of community service in psychiatric disorders.

Table 1: Treatment Gap

Sites in India	Treatment Gap for Epilepsy	Treatment Gap for Psychosis
Namkum, Ranchi	89.9%	97.6%.
Sarsol, Kanpur	90.2%	96.5%.
Manimajra, Chandigarh	46.4%	82.0%.
Chattarpur, Delhi	81.5%	72.3%.
Sitla, Uttaranchal	86.7%	96.3%.

Medications used

At all sites, the common medications such as phenobarbital, carbamazepine, sodium valproate and phenytoin for the treatment of epilepsy, and risperidone, chlorpromazine, trifluoperazine and haloperidol for the treatment of psychosis, were used primarily by qualified allopathic physicians while the other health care providers used traditional/local medicines, herbs and various other practices (rituals, prayers etc.) for the treatment of these patients.

Indonesia

The survey was conducted in the rural Leuwiliang sub-district, Bogor, West Java with a population of 177 454. There were 249 health care providers in this area. Out of these only 17 (6.8%) were qualified allopathic physicians. Others who were providing service were: indigenous health workers (*tabib, shinshe*, acupuncturist, reflexiologist) (4.0%); paramedics (midwives and nurses) (15.3%), and majority were traditional and spiritual faith-healers (73.9%).

The treatment gap for epilepsy was 90.6% and for psychosis 96.5%.

Medications such as phenobarbital, carbamazepine, diazepam and phenytoin were used only by qualified allopathic physicians and paramedics. The antipsychotic medications comprising chlorpromazine and haloperidol were used only by a few qualified allopathic physicians. The other health care providers used traditional practices (*mantra*) and herbs.

Myanmar

The survey was conducted in Ayeyarwady division of Nyaungdon township with a population of 239 632 (87.5% rural and 12.5% urban). There were 520 health care providers in this area. Out of these only 10 (1.9%) were qualified allopathic physicians. Others who were providing service were: qualified indigenous system physicians (10.4%); faith-healers (10.2%), and the majority were village/local health care providers other than qualified physicians (77.57%).

The treatment gap for epilepsy was 94.6% and for psychosis 98.4%. The survey from Myanmar did not include the type of treatment practices followed by health care providers. But based on information from others

sources, medications such as carbamazepine, sodium valproate and phenytoin were used primarily by qualified allopathic physicians. The antipsychotic medications used were risperidone, chlorpromazine, trifluoperazine and haloperidol. The other health care providers used traditional/local medicines, herbs and various other practices (rituals, prayers etc.) for the treatment of these patients.

4.2 Review of Reasons for High Treatment Gap for Neuropsychiatric Conditions in Participating Member States

The reasons for the treatment gap for both epilepsy and psychosis were discussed. For persons suffering from epilepsy – fear of stigmatization, cultural beliefs, lack of knowledge and illiteracy – all contribute to the fact that people with epilepsy or their proxies do not seek treatment. Other potential factors contributing to the treatment gap include economic issues, distance to health facilities, supply of antiepileptic drugs and lack of prioritization by health authorities.

The factors contributing to treatment gap in psychoses include the stigma associated with the illness, the perception that the illness is due to the effect of evil spirits or black magic, inadequate knowledge regarding the illness, lack of adequate treatment facilities for these illnesses, shortage of psychiatrists and other factors such as supply of drugs, distance to health facilities and lack of prioritization by health authorities.

4.3 Discussion of Community-based Strategies for Reduction of Treatment Gap in Common Neuropsychiatric Conditions

During discussions, the delegates supported the concept of providing minimum services to the community, in the community, no matter where the community was located. There was general agreement that new and innovative solutions needed to be considered for reduction of treatment gap. Delegates discussed and agreed on the process and impact indicators to assess the success of these projects so that they can be later extended nation-wide.

All delegates mentioned the wide range of practitioners who provided care and treatment to persons with epilepsy. The role of each type of

practitioners particularly the role of faith-healer and non-qualified medical practitioner was discussed. The role played by qualified medical practitioners of other systems of medicine such as AYUSH physicians in India was debated intensely. Legally, such physicians are not permitted to prescribe allopathic medication, but it is suspected that many of them do so.

It was agreed that only qualified allopathic practitioners should prescribe medications such as phenobarbital and resperidone. All other community-based health care providers should play a role in the identification of persons with epilepsy and psychosis, and then refer them to a qualified physician for treatment. Once the diagnosis has been made and treatment started by the physician, other community-based health care providers could also assist with monitoring of the patient in the community such as ensuring compliance with medication, monitoring and reporting of side-effects of medication.

4.4 Finalization of Process and Impact Indicators to Assess the Success of Projects

The Success of the project will be estimated by reduction of treatment gap as measured by the declining difference between the number of patients with active epilepsy and psychosis (based on the presumed prevalence of the disease) and the number of patients whose seizures are being appropriately treated in epilepsy and control of symptoms in psychoses.

The project design at each site should be such that it can be evaluated based on the following indicators:

(i) Process indicators

An assessment of successful completion of each of the steps in the project will be done, as a measure of the process of conducting the project according to study design. Specifically the following will be assessed:

- The number of training sessions held for each category of community-based health care providers;
- The number of community-based health care providers trained;

- Regular availability of medication to patients and delivery of medication to patients, and
- The number of stigma-removal campaigns conducted.

(ii) Impact indicators

The ultimate measure of the success of the programme will be based on assessment of the impact on the control of GTCS and psychoses in the community. Specifically the following will be assessed:

- The total number of patients identified and being treated by the project, and estimation of reduction of the treatment gap;
- The proportion of patients whose correct identification and appropriate management has been done as per project recommendations;
- The degree of compliance in the patients treated under the project;
- The level of seizure control/symptom control in identified patients over the duration of the project;
- The satisfaction level regarding treatment among patients/family, and
- The efficacy of stigma-removal campaign will be judged by increase in the number of persons seeking medical treatment for GTCS and psychosis.

5. CONCLUSION

The participants at the workshop agreed that:

- (1) Based on surveys conducted at various sites, there is a huge treatment gap for epilepsy and psychoses;
- (2) The factors contributing to treatment gap in epilepsy and psychoses include the stigma associated with the illness, the perception that the illness is due to the effect of evil spirits or black magic, inadequate knowledge regarding the illness, lack of adequate treatment facilities for these illnesses, shortage of psychiatrists and

other factors such as supply of drugs, distance to health facilities and lack of prioritization by health authorities;

- (3) Innovative strategies need to be developed to deliver neuropsychiatric services to the community in order to ensure widest possible coverage, and
- (4) All community-based projects for reduction of treatment gap need to be evaluated, based on process and impact indicators.

The meeting concluded with a strong support for the WHO project to deliver essential services for select neuropsychiatric disorders to the community using community-based health care providers.

Annex 1

PROGRAMME

Thursday, 18 November 2004

0830 – 0900	Registration
0900 – 1000	Inauguration
1015 – 1045	Introduction to strategies to reduce treatment gap in neuropsychiatric conditions: Dr Vijay Chandra
1045 – 1145	Development of the epilepsy protocol: Dr Rajesh Pandav
1145 – 1215	Discussion
1315 – 13-45	Development of the psychoses protocol: Dr Nimesh Desai
1345 – 1415	Discussion
1415 – 1515	Country presentations on survey of health care providers in study areas (30 minutes each country: Indonesia and Myanmar)
1545 – 1715	Country presentations on survey of health care providers in study areas (30 minutes each: three sites in India)

Friday, 19 November 2004

0900 – 1000	Country presentations on survey of health care providers in study areas (30 minutes each two sites in India)
1000 – 1030	Discussion
1100 – 1130	Guidelines for development and implementation of the model Dr Vijay Chandra
1130 – 1230	Country presentations on implementation plan : Indonesia
1330 – 1430	Country presentations on implementation plan : Myanmar
1430 – 1530	Country presentations on implementation plan : India Site 1 (Chandigarh)

1630 – 1730 hrs Country presentations on implementation plan :
India Site 2 (Delhi)

Saturday, 20 November 2004

0900 – 1000 Country presentations on implementation plan :
India Site 3 (Lucknow)

1000 – 1100 Country presentations on implementation plan :
India Site 4 (Ranchi)

1230 – 1330 Country presentations on implementation plan :
India Site 5 (Sitla)

1430 – 1530 Discussion regarding finalization of implementation plan

1600 – 1700 Discussion regarding finalization of implementation plan

1700 – 1730 Closing

Annex 2

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Annex 3

ADDRESS BY DR SAMLEE PLIANBANGCHANG, REGIONAL DIRECTOR, WHO SOUTH-EAST ASIA REGION

Distinguished Participants, Colleagues, Ladies and Gentlemen,

It is with great pleasure that I welcome you all to the WHO Regional Office for South-East Asia. This workshop, I am sure, will be of great help as we embark on a programme on community mental health.

As you may recall, the World Health Report 2001 clearly pointed out that mental and neurological conditions cause a significant amount of morbidity all over the world. It is estimated that about 450 million people are affected by mental, neurological and substance abuse disorders. A large proportion of these people live in developing countries including the South-East Asia Region. It is estimated that the burden of disease from neuropsychiatric conditions measured by DALY's will increase from 9% of the total in 1990 to 14% in 2020. Thus, neuropsychiatric conditions are clearly an issue of emerging importance.

It is also known that a substantial proportion of persons with neuropsychiatric conditions, particularly in developing countries, do not get appropriate treatment. This is referred to as the treatment gap. It is very unfortunate that the treatment gap in developing countries can be as high as 80-90%. I am sure you will discuss this vital issue and develop appropriate community-based strategies to reduce the treatment gap in a phased manner.

Traditionally, neurological and psychiatric services have been concentrated in tertiary care hospitals. Thus, large segments of the population, particularly those who live in rural and remote areas, have been deprived of such services. This is despite the fact that both neurological and psychiatric conditions are common in these communities.

WHO's current priority is to concentrate on community-based activities. We are, therefore, making efforts to develop programmes capable of delivering at least the basic minimum level of services for neuropsychiatric conditions to everyone, everywhere. Ideally, such services should be delivered

within the community rather than expecting people to travel long distances to tertiary care hospitals. The primary health care system should be utilized. Those delivering health care in the community should be trained to identify and manage these conditions. In addition, affordable and appropriate medications should be made available in the community. Finally, the programmes should address psychosocial issues such as stigma and rehabilitation.

Our strategy is to address the most common causes of morbidity. The selection of the causes is being guided by the following principles:

- High prevalence of the condition in the community;
- High morbidity from the condition;
- Easy to identify with resources available in the community;
- Availability of effective and low-cost medication and
- Good prognosis with treatment.

Many mental health conditions meet the above criteria e.g. epilepsy, psychosis, depression, mental retardation, dementia, alcohol and substance abuse. Some communities may have their unique problems which meet the above criteria. The Regional Office has developed and is implementing community-based strategies to address most of these issues. For example, technical material on community-based rehabilitation of the intellectually challenged has been developed and tested. Training is currently in progress for participants from three Member States. There are projects on adolescent mental health promotion to deal with issues of special relevance to this vulnerable group. Also, there are projects to assist Member Countries to protect their communities from harm from alcohol and substance abuse. In addition, many other projects are being developed for community mental health programmes.

I notice from the agenda that this workshop will focus on community-based strategies for reduction of treatment gaps in the most common neuropsychiatric conditions, namely, epilepsy and psychosis. WHO estimates that there are approximately 15 million people with epilepsy and at least 20 million with psychosis in the 11 Member States of the SEA Region. Both

conditions are easily amenable to treatment with cheap and efficacious medications. Yet, unfortunately, the treatment gap is 80-90%.

Although the situation may not seem very good for persons with mental health problems in our Region, there are many positive and supportive cultural aspects. The deeply spiritual and religious traditions and strong family ties of populations in the Region help the prognosis of mentally ill patients. I can specifically mention the example of a community mental health programme in Thailand where monks in the community have taken a leadership role. The entire community is involved including community leaders, the police, businessmen and families of those affected. The programme is supported by the regional mental health hospital. In this community-based programme the treatment gap is almost zero, clearly showing that such initiatives can be successful.

I hope this workshop will further strengthen WHO's initiative to assist Member States to deliver at least the minimum services for neuropsychiatric conditions, using community-based health care providers.

In conclusion, I wish you success in your deliberations and a very pleasant stay in New Delhi.

Thank you.