CHAPTER III

EMPOWERMENT AND MOBILIZATION OF VILLAGE HEALTH WORKER IN THE USE OF PHENOBARBITONE TO BRING ABOUT BETTER COVERAGE AND QUALITY CARE OF EPILEPTICS IN KERABARI HEALTH POST OF MORANG DISTRICT OF NEPAL.

3.1 INTRODUCTION

There is a huge treatment gap in the case of epilepsy. Epilepsy, which accounts for 1/2 to 1% of the world's burden of disease and where, with appropriate treatment,3/4 could be symptom free, only a small percentage of sufferers are actually coming in contact with health services. It is reported that at any point in time, in developing countries, only 8-20% of the active cases are receiving treatment. In Nepal, the situation is no way even near the 'developing world' figure. In the area where this study has been proposed, a survey was done in 1997 and the prevalence of epilepsy was reported as 7/1000. In case of epilepsy, underreporting is a constant phenomena. This is much below the figure of 10-15 per thousand as reported for the developing world by textbook. Even if we accept the 7/1000 figure quoted in the Morang study, the approximate number of cases with epilepsy should be around 4,500, whereas the actual number of cases receiving treatment from the various rural health posts is much less. Of course the patients seeing private physicians and attending the one general hospital are not included in the figure, but it will definitely not account for the rest of the patient population.

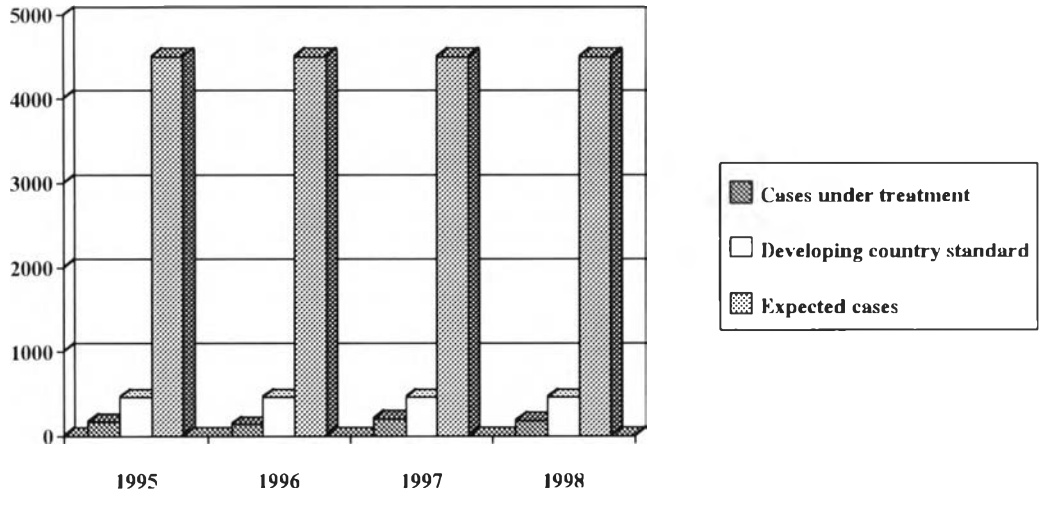

Figure 3.1 Figure showing the total number of epilepsy cases attending the different health posts in Morang District

(Source Annual Report, Mental Health Project, 1998)

The various factors contributing to this have been extensively discussed in the essay portion of this thesis. To address and rectify this issue I am proposing a plan to increase the involvement of the health post village health workers (VHW) in finding cases and management of epilepsy patients.

Operational Definitions:

Mobilization - The VHW's are traditionally involved in health education and other preventive services so they are already indirectly involved in case finding. This role will be strengthened by giving them new knowledge.

Empowerment - The VHW's will be taught to monitor the progress that the patient is making during regular visits. They will recognize the side effects appearing in any patient and promptly refer him to the health post for further

evaluation. Within a narrow range and following a strict protocol, they will actually alter the dose of antiepileptic medication that the patient is taking. This is a completely new role that will be given to the VHW in the context of Nepal. They will also aid in dispensing the medicine

Quality care - The VHWs will ensure that the treatment protocol is followed from both the patient and service side. This will help in bringing about better control of fits.

Better coverage - It is envisioned that due to the penetration of the message down to the grassroots, more patients will be motivated/ encouraged to come for treatment .

3.2 PURPOSE OF THE STUDY

The purpose of the study is to reduce morbidity and mortality from epilepsy through early detection, facilitation of diagnosis, early institution of appropriate treatment, proper maintenance and referral if/when needed. This can be achieved by providing training to VHWs on case finding, referral, monitoring of treatment and methods of continued psychological support to the patient and family. It is envisioned that in the process, the stigma and misconceptions relating to epilepsy that are prevalent in the community will be reduced. So the purpose of this study is double pronged, to strengthen the care delivery system and provide general advocacy directed towards the community.

3.3 OBJECTIVES

The objectives of this study will be as follows:

3.3.1 GENERAL OBJECTIVES

- The general objective of this study is to reduce the treatment gap in epilepsy by mobilization of VHWs to motivate more people to come for treatment and to strengthen the care delivery system.

3.3.2 SPECIFIC OBJECTIVES

The specific objectives of the study will be:

- To increase the coverage of epileptic patients receiving treatment.
- To minimize the default rate.
- To provide quality care.
- To increase Quality of Life of patients.

3.4 STRATEGY OF IMPLEMENTATION

This program will be horizontally integrated at the level of DPHO and will be run in close collaboration with DPHO using its manpower and machinery. Process and outcome evaluation will be built-in so that at the end of one year of implementation, there will be a holistic evaluation of the program. With this approach, the DPHO can easily replicate this program, if found to be productive, in

other health post areas under its jurisdiction as their own trainers will be trained during the implementation of this one health post pilot project.

3.4 STUDY DESIGN

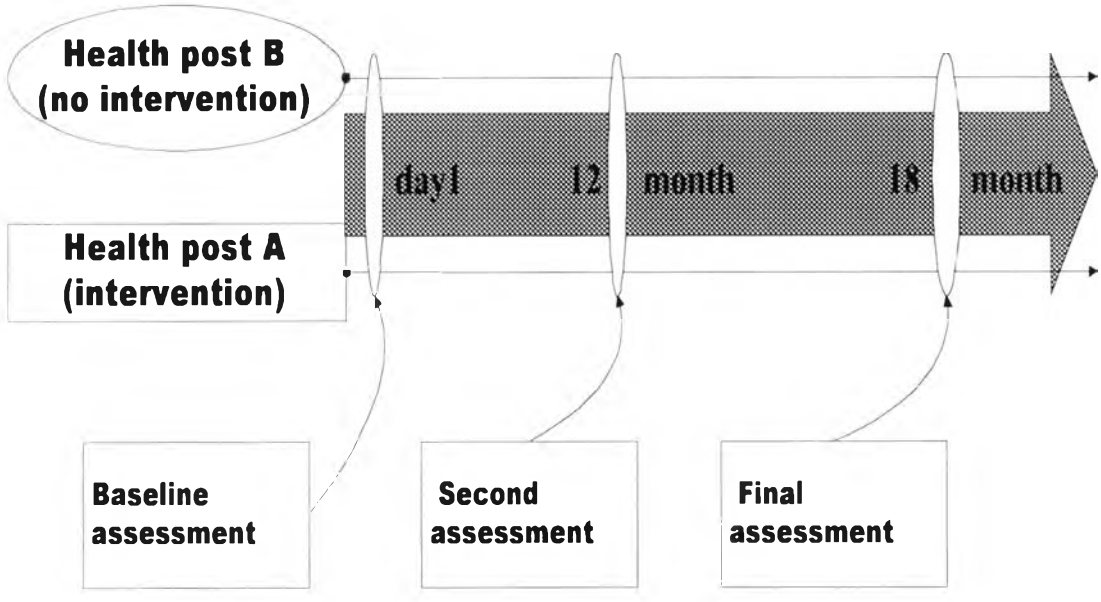

Figure 3.2 The study design

The study design is quasi experimental. The findings will be compared with another health post in the same area but far enough to avoid contamination of data.

3.6 STUDY SITE

This proposal is planned to be implemented in the Kerabari Health Post of the Morang District in eastern Nepal (Appendix 1), as a pilot project. There are 6 villages under this health post with a total population of 23,687. The health post is around 5 hours drive (local bus) from the district headquarters. The main occupation

is agriculture and there are 8 schools. The health manpower situation is presented in the following table.

Table 3.1 The manpower situation in Kerabari health post

Manpower situation of Kerabari Health Post	
Health Assistant	1
Auxiliary Health Worker	2
ANM	2
VHW	6
FCHV	63

(Source: Annual report of Mental Health Project, Kathmandu, 1998)

3.7 PRE TRAINING GROUNDWORK

The following activities will have to be done prior to the start of the formal training.

3.7.1 Development of curriculum: --

A training curriculum will have to be developed encompassing the various aspects of epilepsy. This will be more of a job oriented course than an academic one, made with the job responsibilities of the VHWs. in mind. The sample of the curriculum is given in Appendix 2.

3.7.2 Diagnostic and screening guidelines: --

Diagnosis of epilepsy in the community using paramedical staff has to be carefully planned because once diagnosed, the patient is committed to treatment for at least three years, and has to face social complications. The aim is to minimize the chances of missing possible patients and in same time taking care that people with no disease will not be unnecessarily included. For this purpose, the diagnostic criteria suggested by Sander & Shorvon (1987) and used extensively in studies in rural Africa, Asia and South America will be used.

Table 3.3 Diagnostic criteria used in studies in rural Africa, Asia and South America.

Criteria for the diagnosis of tonic-clonic seizure
1. Loss of consciousness from 1 to 30 min. 2. Tonic phase 3. Clonic phase 4. Sphincter disturbance 5. Tongue biting 6. Fall 7. Injury due to fall 8. Post ictal muscle soreness 9. Post ictal drowsiness, sleep or confusion 10. Transient post ictal focal paralysis
A tonic-clonic convulsion is considered to have definitely occurred if criteria no. 1,2,3 are present with any two of the criteria no 4 - 10.

(Source: Epilepsy in developing countries: A review of epidemiological, sociocultural and treatment aspects., in Epilepsia ed. Shorvon, S. D. & Farmer, P. S., Raven Press Ltd, New York, 1988).

The disease of epilepsy will be considered if there are two or more seizures within the last two years. A guideline for initial screening of the patients will also have to be developed for the use of the VHWs with the components as mentioned in the patient record care (Appendix VI).

3.7.3 Treatment Protocol

The following will be the treatment protocol to be used.

Drug of choice: Phenobarbitone will be used as drug of choice as recommended by WHO and which has been extensively discussed in the essay portion of this thesis. Moreover this is the drug that is available in the essential drug list of the health posts in Nepal, as per the recommendation of WHO. To date, phenobarbitone is supplied by the DPHO for free distribution even though the quantity is often insufficient and supply erratic.

Dose schedule: The standard dose schedule of phenobarbitone for epilepsy in adults is to start with 60 mg daily with increments of 30 mg / fortnight, if needed, until a maximum of 180 mg is reached (Marks & Garcia, 1998). Considering the probability of dose related side-effects over 120 mg, the VHWs will be limited to the upper limit of 120 mg per day. If fits are not controlled at this dosage, the VHW is suppose to refer the patient to the health post for re-evaluation. The decision to use the 150 and 180 mg dose can be made only by the health assistant. Even in these cases the follow-up will be done by the VHWs.

When to start treatment ? Treatment will be started after the occurrence of the syndrome of epilepsy i.e. two or more seizures within the last two years.

When to refer the patient ? The VHW will have to refer the patient to the health post in the following conditions:

- Initially, after case detection for confirmation of the diagnosis and initiation of treatment.
- Reemergence of fits where 'missed dose' can be excluded.
- Emergence of severe side effects or complications.
- Fits not being controlled even after reaching dosage level of 120 mg per day.
- Every patient (even the controlled ones) should be sent to health post once every 6 months for assessment.

3.7.4 Teaching Learning Material

It has been noted that while conducting training where the trainees are grassroots level workers, dialectic lectures are not very effective. The principles of adult learning will be used in the conduction of the training and will be based more on active participation involving group discussion, problem solving and story telling approach. The T/L material produced will be mostly preliminary audio visual type.

Flip chart -- A flip chart will be produced with graphic representation of stages in epilepsy, causes, prevalent treatment, first aid and proper management, based on a story line (Appendix 3). This will help in the initiation of group participation and discussion e.g. "What do you see in this picture?..... What is happening?..... ". The figures will be those seen in everyday life with which the participants can identify. This chart can also be used by the VHWs for community meetings. This chart will remain at the health post.

Brochure -- This will be a mini representation of the flip chart with added information as quick reminders to the VHW's about diagnosis, treatment protocol, management and referral. The VHW will be given one of these to take home as a reminder. (Appendix 4)

Video -- A short video clip will be made showing actual patients having epileptic fits and other non epileptic type of faints for the participants to actually witness it. While dealing with epilepsy, it is not possible to show VHWs actual cases as is the practice in medical teaching because of the intermittent nature of the illness.

Reading material -- This will be compiled for the trainers as background study.

3.8 TRAINING ACTIVITIES

3.8.1 Training for VHW

The purpose of this training will be to equip the VHWs with knowledge, attitude and practices (KAP) needed to fulfil his job description. This will also act as a refresher session to the curative staff of the health post This will be a three day training conducted with the health post as the focal point. The contents of the training will be as outlined in Appendix 2, comprised broadly of recognition, differential diagnosis, acute and long term management including treatment protocol, prevalent misconceptions and the role of traditional healers. The staff of the health post involved in the diagnosis and treatment (HA & CMA) will be used as co-trainers

working in close collaboration with the main trainer who will be a supervisor of the District Public Health Office (DPHO). In the initial stages the trainer will be supervised by a specialist and this opportunity will be used to provide on-the-job training to the trainers. Initial evaluation of the training will be built into the package as pre and post assessment in the form of T/F, MCQ, and short answer questions as shown in Appendix 5. Teaching learning materials will be developed in the form of a flip chart (Appendix 3) and a take home brochure (Appendix 4). Appropriate reading material will be made available to the trainers. The method of instruction used will be group discussion and mini lectures. The tentative schedule will be as shown in Appendix 2.

3.8.2 Refresher training

At the end of the 8th and 14^{h} month of the study i.e. 6th and 12th month after initial training, one day refresher training will be held at the health post to share experiences and manage problems encountered by the VHWs. This will be a chance of meeting them as a group and the input will complement that which has been taking place between the supervisor and the VHWs during the ongoing supervision activity. At the second refresher time K/A/P assessment of the VHWs will also be done.

3.9 SUPERVISION AND MONITORING

Appropriate methods of supervision and monitoring will be devised with the help of DPHO so that the supervision of health post and VHW activities will be carried out as a component of general office supervisory activities. Epilepsy is already a component of the reporting system so it will not be necessary to introduce

any new reporting forms i.e. there will be no increase in the workload of the DPHO. When the supervisors visit the health post they will see the history sheet of the new cases to assess the adequacy of diagnosis and answer any questions.

3.10 EVALUATION

3.10.1 Process-- (KAP)

At the start of the training, the pre training KAP will be assessed using a semi structured questionnaire (Appendix 5). The same questionnaire will be administered at the end of the training, on the third day. The process will be repeated at the time VHWs are called in for the refresher/ assessment session at the end of 6 months and 12 months when they will be reassessed. This time the questionnaire will not be the same but similar. The difference between pre and post test scores will be an indication of the amount of knowledge and understanding imparted by the training. The difference between second and third will be an indication of the residual knowledge after the decay of memory (a normal psychological phenomena involved in any learning process) and the effectiveness of continued technical supervision.

3.10.2 Outcome --(Patient coverage)

Secondary data from the health post register will be used to see the trend of new cases i.e. patient load and change in coverage related to epilepsy. This will give an idea about the effectiveness of the message going to the community.

3.10.3 Impact --

Seizure response -- The history and continuation sheet that will be kept at the health post is constructed such that the details of the progress of the patient can be registered (Appendix 6 & 7). Periodically, this case sheet will be reviewed by the supervisor and the data entered in the database maintained at the district health office. This will provide the responses of individual patients and will be analyzed for effectiveness of fit control. This will give an indication of the effectiveness of phenobarbitone as a drug of first choice in the treatment of epilepsy in rural settings of Nepal.

Quality of Life assessment Quality of Life of the patients will be assessed at the first visit and at the end of one year of treatment. This will give a measure of physical health, mental health, social health, general health, perceived health and self esteem. Moreover it also gives a measure of anxiety, depression, pain and disability as symptoms. The forms will be completed by the health assistant at the health post as a part of a follow up record. This will provide an in-depth assessment of the effectiveness of the overall program and act as a indicator as to whether the program is to be replicated in other areas.

3.11 EXPECTED OUTCOME

If everything in the proposal goes according to plan, the net outcome should be that more of the hidden cases of epilepsy will surface and be under treatment leading to better productivity. Among the measurable indicators of the effectiveness of the program will be a net positive change in the KAP of the health workers even though

there will be a sharp rise in the second assessment followed by a gradual fall due to natural decay process. The case load is expected to rise. The second QOL score should also be better than the first.

3.12 ACTIVITY PLAN

The exact dates will have to be set by coordination with DPHO so that this program does not coincide with other activities taking place at the health post and /or availability of the staff. It is tentatively planned that the activity will be started in November of 1999 and end in the end of April, 2001.

Table 3.4 Activity plan of proposed study

	Year /Month (number denotes the month --Nov-11, Apr-4)																
	1999		2000											2001			
	11	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4
Meeting with DPHO																		
Preparation of material																		
Training of VHW																		
Refresher training																		
Evaluation KAP																		
Evaluation Pt. load																		
Evaluation Seizure response																		
Final evaluation																		

3.13 ANTICIPATED HURDLES

The proposed program is to be implemented by integrating it with the other ongoing activities which are being carried out by the DPHO under the Ministry of Health (MOH). I do not belong to the MOH so have no administrative control over the DPHO or its machinery. This program is not a donor driven vertical program where a lot of financial incentives exist for the implementers. As a result, success will depend on my ability to creat a perceived need for such a program and the commitment that can be generated in the DPHO planners. I am already involved in other mental health related activities under the same office where this program is planned, so a good working relationship already exists. If this has to be implemented in other districts, careful ground work has to be done.

While looking at it from the consumer side, epilepsy is a disease with stigma where denial of its existence is a major factor. Breaking this barrier of denial may pose a major problem. Another point to note is that traditionally these patients have been looked after by the traditional healers who may take this program as a threat to their subsidence and existence and take a stand of opposition. If this occurs, the program is destined to fail because the traditional healers are much more influential in the rural community than the health service staff. To overcome this the other supportive activities as explained in the second chapter (2.6 pp. 22-26) and proposed later in this section have to be undertaken to create social pressure.

3.14 BUDGET

The budget break down will be as follows:

(The figures used are in Rupees which is the Nepalese currency. The total amount has been converted to US dollars at the end).

3.14.1 VHW Training --

There are 6 VHWs who will be involved in this program. The budget proposed is to cover the daily allowance of the trainee (Rs. 100 per day according to DPHO regulations), teacher cost of Rs. 200 per block and stationary for the participants. The training will run for three days. The cost of snacks to be supplied on the days of the training is included with the cost of transportation of the trainers from the district headquarters to the site of training. So the cost of the training will be:

DA 100× 6× 3	1800
Snacks 25×(6+10) ×3	1200
Stationary 35×6	210
Teacher cost 200×6	1200
Transportation 500×3	1500
Total	**5910 ≈ 6,000**

3.14.2 Refresher training

There will be three such trainings (of one day each (at the end of 6^{th} , 12^{th} and 18^{th} month) and the budget breakdown is similar to the one above.

DA 100× 6	600
Snacks 25×(6+10)	400
Stationary 35×6	210
Teacher cost 200×2	400
Transportation 500	500
Total	2110 per training

i.e. 2110×3 = 6330 ≈ 7,000

3.14.3 Material development

This will involve production and printing (e.g. charts, brochure, history sheets, posters etc), and the production of video clip. The budget separated under this heading is Rs. 25,000.

3.14.4 Seed money for Community Drug Fund

Phenobarbitone worth of Rs. 1,000 will be bought at the start of the program to be put into the community drug fund which is already operating at the health post. This will be sold to the patients on a no profit basis similar to other drugs in the CDP program and the money will be recycled to buy more drugs. This will be in addition to the phenobarbitone supplied by the DPHO for distribution. As for the patients who are very poor to buy the medicines, the DPHO guidelines and exiting mechanism will be used.

3.14.5 Transportation and communication --

This will be used to maintain contact between DPHO & the central office. It will also include the cost of transportation to the field for central staff and the supervisor while going for field visits. The budget line item under this heading is (1000×18months) Rs. 18,000.

3.14.6 Salary

One person will be hired part time for the coordination /supervision and will be stationed at the district headquarters and he will preferably be a loan from DPHO to insure smooth functioning. He will be paid Rs. 2,500 per month so the budget will be Rs. 45,000.

3.14.7 Contingency

A contingency budget line item of 8,000 has been separated to buffer any unforeseen expenditure.

Table 3.5 Table showing the budget layout of the study.

ACTIVITY	AMOUNT (Nepalese Rupees)
VHW training	6,000
VHW refresher	7,000
Material development	25,000
Seed money for CDP	1,000
Transportation	18,000
Salary	45,000
Contingency	8,000
TOTAL	**110,000**

(At the present exchange of 1$ = Rs.65, the total cost of the program is $ 1692 (US)

In this pilot project, a sizable amount is for in material development. The materials thus produced will be enough to run the program later on in the second and third year and the cost then will be comparatively less. To be cost efficient in printing, the jobs have to be done in a minimum bulk.

3.15 HUMAN RESOURCE AND TECHNICAL REQUIREMENTS

As mentioned previously, the co-trainers will be the health post staff. I will function as the master trainer; later on the supervisor working part time for the project will function as the trainer. He will also function as coordinator and a central point at the district level for the program. Audio visual equipment will be needed for the video session which will be rented for the purpose.

3.16 INFORMATION AND RECORDING SYSTEM

Information regarding the history, treatment and outcome will be maintained at the health post in the prescribed format of the history sheet (Appendix 6), follow up information in the continuation sheet (Appendix 7). The monthly reporting to the DPHO will not require any extra recording and reporting forms because epilepsy is already a component of the existing reporting format. . This information will be available from the record section of the DPHO.

3.17 SUSTAINABILITY

This program has been developed to be integrated into DPHO health delivery system to ensure its sustainability. The manpower trained will be that from the permanent staff of the DPHO, so the skill will remain within the system. The technical support will also be institutionalized with the Department of Psychiatry at Institute of Medicine, Kathmandu and will not be person dependent. Once the program is started, there is practically no operating cost involved as all the remaining activities are integrated into the daily functioning of the health system.

3.18 ETHICAL ISSUES

The main ethical consideration to be made is the right of the person to choose a) to be or not to be treated and b) the choice of treatment. The program depends on one drug whereas many other drugs are also available. If the patient prefers to be put on some other drug, he / she will not be denied the choice, but will be referred to the district headquarters to a specialist. The health post personnel are not, by their job description, allowed to use any other anti epileptic medication. Even in these cases the VHWs will be motivated to continue the psychological support even though these patients do not, strictly speaking, come under the umbrella of the program.

As far as the free distribution of the drugs to the very poor is concerned the guidelines of the DPHO will be followed and the drugs received from the government side will be used. If the village drug committee which manages the CDP decides, they may distribute free medicine from the program to some patients and the cost incurred will be shared by the other patients as a small increment of the price of the drug.

3.19 SUPPORTIVE ACTIVITIES

Other types of training aimed at increasing community awareness of epilepsy and reducing the misconceptions will have to be conducted to enhance the effectiveness of the total program. The following activities will aid to decrease the stigma.

- Training for community leaders
- Training for grass root level health manpower - FCHV, TBA,
- Training for Traditional Healers
- Training for School teachers
- Facilitation of community meetings.