CHAPTER II

IMPROVING MANAGEMENT IN EPILEPSY: COMMUNITY BASED MANAGEMENT PROGRAM INVOLVING THE VILLAGE HEALTH WORKER

2.1 INTRODUCTION

The history of epilepsy can be summarized as 4000 years of ignorance, superstition and stigma followed by 100 years of knowledge, superstition and stigma (BMJ-- Jul 97, Ed). Epilepsy affects 40 million people worldwide, yet three-quarters are untreated. Paradoxically, with early diagnosis and treatment, the disease can be controlled in about three-quarters of those affected. There is almost universal suspicion, and social, cultural and legal stigma surrounding it. In many developing countries the disease is associated with "possession by evil" or is seen as a punishment. Even in the developed world, until recently, various laws allowed discrimination against people with epilepsy. For example, in the US nearly 20 states prohibited people with epilepsy from marrying and provided for their eugenic sterilization until 1956, and until 1970, these people could be excluded from restaurants and theaters (Lancet, 1997). In fact when it comes to epilepsy, every country is a developing country.

2.2 WHY IS EPILEPSY A PUBLIC HEALTH CONCERN IN NEPAL?

There is not much hard data on the prevalence of epilepsy in Nepal, but there is ample reason to believe that it follows the same pattern as in other developing countries of the region. This is not an infectious disease so it does not follow any seasonal or regional variation in prevalence. The reported incidence of epilepsy for developing countries differs from study to study and author to author and ranges from 10 - 15 per thousand. In the Indian subcontinent, the range reported is of 22.2 per thousand in Kerala, South India (Hackett, Hackett and Bhakta, 1997) to 4.2 in Haryana (Singh, Kaur, 1997).

There are a number of explanations put forward for these vastly differing When a general screening Questionnaire is used, partial seizures are often rates. missed as the patients may have ignored or misinterpreted the symptoms or indeed have been unaware of them, and this is particularly likely with absence seizures or brief partial seizures (Zielinski, 1974). Sometimes the condition may be denied or concealed which has been seen in field studies where patients known to have epilepsy from medical records refused to answer a questionnaire more often than the rest of the population (8% verses 1.4%) and in the findings of Beran et al that approximately 1 in 4 people proven to have epilepsy denied this fact when sampled by a postal questionnaire (1985). In a survey done in the Morang district of Nepal, the prevalence of epilepsy is reported at a rate of 7 per thousand (Nepal, Sharma & Shrestha, 1996). In some parts of Nepal, fainting episodes carry with it a culturally accepted explanation that it is not an illness but a curse of God. Even in situations where it may be recognized as an illness it is associated with a stigma, so is mostly under reported.

Epilepsy accounts for 1% of world's burden of disease and with appropriate care, 3/4 of them could be seizure free (Kale, 1997). Only a small proportion of the

patients with active epilepsy in the developing countries (8-20%) are at any point of receiving treatment (Feksi, Kaamusisha, Sanders, Gatiti & Sharvon 1991). Epilepsy is the root cause of many domestic accidents like burns which are sustained by falling onto open fires while cooking.

2.3 **PROBLEM SITUATION**

People suffering from epilepsy in Nepal are not coming forward to the health services for treatment. The causal web explaining the existence of this problem is given below. The description of this web of causation is explained in detail in the following section (2.4).

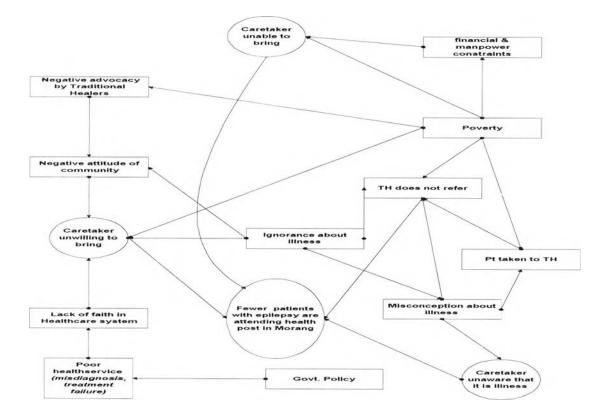


Figure 2.1 Causal web of under-utilization of services in relation to epilepsy.

2.4 WHAT ARE THE CAUSES, CONSEQUENCES AND REMEDIES OF THE PROBLEM ?

When epileptic patients do not present themselves to the orthodox medical services, it is not because they are happy living with their disease, but because (1) they either believe that no medical treatment exists, or (2) had past negative experience with doctors which led them to believe it was a waste of time. In the following sections an attempt will be made to look into the dynamics of the different factors contributing to the sub-optimal level of health service available to the people suffering from epilepsy, with special reference to Nepal. To aid in the description and formation of the diagnosis of the problem, an adapted version of the Health Utilization model put forward by Anderson-Newman will be used.

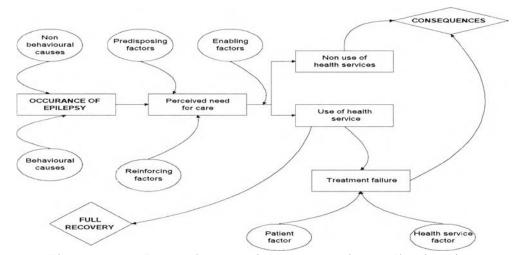


Figure 2.2 Determinants of health service utilization in relation to epilepsy services. (Adapted version of health utilization model of Anderson & Newman 1973 (Source: Health and human behaviour, Ed. Kaplan R.M., Salis, J.F., Patterson T.L.. Mac-Graw Hill Inc. 1993)

2.4.1 Non behavioral factors

Primary or idiopathic. In 70% of the cases, no identifiable cause can be found even with the best available investigations. These are known as primary or idiopathic epilepsy.

Secondary (Lowenstein, 1996). The common causes include structural lesions like head injury, cerebrovascular disease, CNS tumors and degenerative conditions, CNS infectious and infestations like neuro-cysticercosis, post meningitis /post encephalitis sequale, and AIDS. These are the epilepsies that occur as a manifestation of some other disorder that is present in the brain. Most of the adult onset cases belong to this category. The etiological profile of this type of epilepsy in different parts of the world, however does show true variations depending on the circumstances. A number of chronic infectious diseases results in epilepsy, such as schistosomiasis, cysticercosis, and hydatid disease. Epilepsy is the commonest clinical manifestation of cerebral cysticercosis (Alarcon & Olivares, 1975). The most important of these is cysticercosis which is endemic in parts of Nepal. So much so that in the Nepali soldiers bases in Hong Kong with adult onset epilepsy, 7 out of 8 cases were due to cerebral cysticercosis, and the evidence suggested that the Gurkhas had acquired their infection in Nepal (Heap, 1990). Viral encephalitis, where approximately one third of the sufferers end up with irreversible post encephalitic sequlae which commonly manifests as epilepsy, is also common in the Terai region of Nepal. It is commonly claimed that poor perinatal care will result in a high frequency of epilepsy in developing countries. Some other causes like those due to head injury are relatively few.

2.4.2 Behavioral factors

Alcohol -- Alcohol abuse and dependence is a very common factor in Nepal. Alcohol is known to induce fits both during the intoxication state and the withdrawal state. Brain damage from prolonged use of alcohol is also common. Moreover when alcohol is used concomitantly in the case of epilepsy, the seizure threshold is decreased causing the worsening of epilepsy.

2.4.3 Predisposing factors

Age -- Old people in the family, unless they are the wage earners, do not get priority for treatment.

Sex -- As Nepal is a male dominated society, the females do not get priority for treatment. The Muslim community of Nepal is very conservative with most families having restrictions on the movement of the female members. This increases the probability of cases being hidden.

Marital status -- When the disease occurs in an unmarried person, especially if it is in a daughter, the disease tends to be hidden.

Education -- The lower the level of education of the patient or the party, the lower the chances of seeking help.

2.4.4 Reinforcing factors

Nature of the illness -- The fits in epilepsy occur only episodically, and in between the attacks, the person apparently can function normally. As only minor disruptions are caused in the family, the motivation to seek treatment is low.

Belief system -- Any type of fainting (epileptic and/ or non epileptic) is taken as being possessed by God or Devil, occurring as a curse or product of evil behavior during the previous life, or unsatisfied sexual drive. The predominant belief is that not only will medicine not cure it, but if attempted, God will get angry aggravating the problem.

Traditional Healers -- Most of the Traditional Healers are equally ignorant of the problem. Among those who do recognize the type of fainting which they cannot manage, only a few know that help is available and are unwilling to send the patient to the HP. Another discouraging factor is that these people form a majority of their clientage and sending them away to another mode of treatment will have a direct impact on their financial resources and livelihood.

The perceived need is further modified by the enabling factors to determine how the patient behaves - responds i.e. uses or does not use the health services.

2.4.5 Enabling factors

Accessibility -- Some health posts are far away and are less accessible to the people. There is another variable that has to be considered while dealing with Mental Health. Just the physical accessibility and proximity of any mental health facility does not guarantee optimum utilization of the services because it has been noticed that some people prefer travelling longer distances to anonymous centers to avoid being labeled (Huxley, 1993). In Western Nepal, far from being a deterrent, distance afforded welcome anonymity for leprosy cases anxious to disguise their diagnosis and thereby avoid social ostracism which could result (Pearson, 1988). Epilepsy, which also has stigma attached to it, may follow the same pattern.

Availability -- One of the medicines used for epilepsy which is for free distribution is not always available at the health post.

Affordability -- Even in situations where the patients have to buy the medicine, phenobarbitone, is very cheap and within the buying capacity of most people except for a few (Lancet, 1997).

Acceptability --For complete treatment of epilepsy drugs have to be continued for at least 2 years after the last fit which means that the person takes the medicine for an average of 3 years. Mostly this leads to amotivation resulting in temporal non compliance which results in relapse or reoccurrence of the condition.

2.4.6 Treatment failure:

Health services related -- The diagnostic skill of the person responsible for the primary management has to be taken into account. With a lack of clinical supervision and CME, it is not uncommon to come across epileptics diagnosed as hysteria and hysterics put on phenobarbitone. The more frequent problem encountered is inadequate advice about the nature of treatment, so the patient thinks that taking the full course as prescribed in the first prescription is all that is needed to cure the disease. The non availability of the drugs has been described elsewhere. The general sense of malaise prevalent in the Ministry of Health also has its toll. Due to the lack of orientation for the VHW's who are responsible for home visits and active case findings, the message has not reached the community.

Patient related -- One of the most common causes of reoccurrence of fits in a patient who had been well controlled, is missed drug doses. Forgetting to take the medicine, willfully stopping the treatment and unavailability of drug (either not available or cannot afford anymore) are some of the factors responsible. As already mentioned above, the sheer length of treatment causes frustration in the patient resulting in dropout. The concomitant use of alcohol which is contra indicated, is very common, and gives rise to relapses.

2.4.7 The consequences of the problem.

Physical complications -- (1) Short term : The short term complications are related to the fits and include accidents like sustaining burn injuries by falling onto a fire or scalding, drowning while bathing or crossing rivers and falling from heights

or into machinery. (2) Long term - There is evidence, especially in the case of children, that prolonged uncontrolled fits can cause progressive brain damage.

Economic -- The chances of employment for a person suffering from epilepsy is less. Moreover, the spectrum of available job opportunities is reduced as they are unfit for to certain types of jobs. People already in these high risk occupations will have to find new jobs. Moreover, very poor people need all the hands available to plant and harvest crops. The family cannot afford to spare someone to keep full time watch on the sufferers even though uncontrolled falls may involve hazards.

Social discrimination -- The hypothesis generally is that epilepsy is a disease incurring considerable social disadvantage, not to mention stigma. It has been observed that fear of infection was the most significant reason for shunning of epileptic patients. In the third world, all cooking is done in open fires. Epilepsy is sometimes actually known as the 'burn disease'. Watts (1985) found that the first patients she encountered were all presented with burns rather than epilepsy. The problem is exacerbated by the fear that those pulling the sufferer out may be contaminated by his saliva. It is the same case with drowning. The level of prejudice against epilepsy borne by observations made in Kenya and Equador is illustrated by non epileptics who would not let their children play with known epileptics, would not marry them or let their children do so. Indian physicians also have observed that in Hindu society, a woman known to have epilepsy has virtually no chance of an arranged marriage. After a fit, children are assumed to be unfit to study further and about one third of epileptics suffer delays in their education. In India, only 25% of the patients felt that epilepsy had not affected their daily activities (Virmani, 1977). Parental attitude towards epilepsy is at times harmful. In a study of the parents of 352 children with epilepsy, it was found that the most common form of care provided was to force liquids by mouth (50.6%) followed by pressure over the body to restrain convulsive movement (13%) or to put some object to force the teeth open (11.9), all of which are harmful and at times hazardous in epilepsy (Bains & Raizada, 1992).

Epilepsy is a legally valid ground for divorce in Nepal. When episodes of fainting (epileptic or non epileptic) occur especially in the unmarried girl, it is taken as a sign of unsatisfied sexual desire, which results in many early teen marriages without the husband's party being aware of the existence of the disease. This marriage eventually breaks down. The patient suffers more from the attitude of others than the seizure (Lancet, 1997).

2.4.8 Treatment

The treatment of epilepsy has two major components -- drugs and psychological support. The drug of choice depends on the type of epilepsy, side effect profile best suited for the patient, affordability, availability and the familiarity of the physician with it. The treatment recommended by WHO for the developing world is phenobarbitone, largely because of cheapness, with phenytoin as a second choice (Lancet, 1997). Phenobarbitone is a long acting member of the barbiturate group which is losing its popularity in the affluent West because it has some not-sopleasant but non life threatening side effects like sedation and in a small proportion of children it induces hyperactivity and Westerners can afford more costly alternatives. Comparing the four commonly used drugs for epilepsy phenobarbitone, phenytoin, carbamazepine and sodium valproate, no significant differences have been noticed in their clinical efficacy at 1, 2 or 3 years of follow-up (DeSilva, 1996). In a 12 month prospective study done in the rural setting comparing the efficacy and safety of phenobarbitone and carbamazepine, no significant differences between them were found (Placencia, Sanders, Shorvon, Roman, Alarcon, Bimos, & Cascente, 1993). Recent studies in the west show that phenobarbitone was therapeutically as effective as other costly anti-epileptic drugs but had an unacceptable incidence of side effects necessitating withdrawal in a randomized trial (DeSilva, MacArdle, McGowan, Hughes, Stawart, Neville, Johnson & Reynolds, Similar studies done in the rural setting of the Indian subcontinent do not 1996). support this findings and recommend that phenobarbitone had no more side effects than the other anti-epileptics: phenytoin, carbamazepine, and sodium valproate (Pal, Das, Chaudhury, Johnson & Neville, 1998). The cost of the anti-epileptic drugs varies enormously; in many developing countries phenobarbitone is the cheapest drug and phenytoin may cost five times as much, carbamazepine fifteen times and sodium valproate 20 times as much (Shorvon & Farmer, 1988). There is evidence that supports the acceptability of phenobarbitone as a first-line drug for childhood epilepsy in rural settings in developing countries (Pal, Das, Chaudhary, Johnson, Neville, 1998)

Although anticonvulsant polytherapy has been widely and traditionally used in the treatment of epilepsy, there is little evidence of its advantage over monotherapy. Studies in new, previously untreated referrals suggest that there is considerable potential for monotherapy (Reynolds & Shorvon, 1995). The recent protocols suggests to start with one drug and give it a full therapeutic trial before adding another.

One of the major controversies actively debated in relation to epilepsy, especially in the context of developing countries, is "What is the most effective treatment protocol ?" WHO has recommended phenobarbitone as the first line drug for the treatment of partial and generalized tonic-clonic epilepsy in developing countries. The dosage schedule recommended for adults is begin with 60 mg. daily with increments of 30 mg. per fortnight until seizure is controlled or unacceptable side effects occur or a total dose of 180 mg. is reached (Marks & Garcia, 1998).

When to start treatment is another question confronted by a clinician for which there is no definite answer. Some studies suggest that treatment should be started as early as possible, as the drugs may also influence the natural history of epilepsy which is a process that has a potential to develop into an intractable disorder, and effective treatment may reduce this risk of chronicity (Reynolds, 1995). Some others are of the opinion that there has been no difference in the response to treatment by patients with short histories and long histories of seizure prior to onset of treatment. The six month remission rates were similar to both groups (Chadwick, 1995).

2.5 THE PROBLEM IN RELATION TO NEPAL

All the different subsets of the problem are parts of a total picture and each factor is equally important and not mutually exclusive. For the sake of simplicity, it can be said that they are :

- Sub optimal health care system for epileptics in rural environment.
- Low level of service utilization by people with epilepsy.
- Social and cultural apathy.

Any intervention to address the issue will have to take a holistic view, and set priorities according to the possibility of maximum benefit and short lag time for results.

2.6 WHAT COULD BE DONE TO IMPROVE THE SITUATION AND HOW WOULD THEY BRING IMPROVEMENTS ?

While discussing the possible methods of intervention, it is easier to view them as Push factors, Pull factors and Facilitating factors. The same factor, e.g. sustaining a burn injury during a fit, may function as a push factor for the father-inlaw who does not want to be blamed for not caring for the daughter-in-law and act as a pull factor for the patient who would like to be cured. Similarly from the health post side, the attitude of the staff may either act as a pull factor for the patients (if helpful) or a push factor, discouraging them to attend the clinic if not good

2.6.1 Increase community awareness

This can be achieved by massive information dissemination in the community by the use of posters and pamphlets carrying messages with which the community can identify. These should be in the local language using appropriate words from the dialect used by the particular community.

2.6.2 Sensitization of the community

This can be achieved by community meetings with well identified target groups and the involvement of other volunteer health workers living in the community. The groups that are readily available for this kind of advocacy are female community health volunteers (FCHV) and traditional birth attendants (TBA).

2.6.3 Increment of social pressure

Local school teachers of are a respected group in the context of the village and their advice carries weight. Short orientation meetings can be arranged with the local school as the focal point This will enhance 'Teacher-to-community approach' and 'Teacher-children-parent approach.'

2.6.4 Involvement of the community

Active involvement of the community can be ensured using the Participatory approach, which has proven to be an effective method in altering belief systems and changing behavior. This can be used specifically in program areas with committed manpower but the sustainability as a self propagating process will be difficult.

2.6.5 Involvement of other healing systems of the community

In Nepal, just as in many other regions of South Asia, multiple indigenous healing traditions and a variety of traditional curing specialists co-exist in a pluralistic cultural environment. While forecasting the role of this system in Nepal, Parker argues:

".....Interaction of diverse medical tradition is a particular aspect of the more general tendency towards the accretion and super-imposition of cultural trait which has been a common feature of the Hindu influenced social systems. Allopathic medicine and its practitioners therefore, are less likely to displace traditional curing practices than to become integrated into a network characterized by continued pluralism....."

While dealing with epilepsy, traditional or indigenous healers locally known as Dhami, Jhakri, Phakir, are a group heavily relied upon by the community. While dealing with mental problems, these group forms a point of first contact for a majority of cases. The decision as to when, if ever, the patient will reach the orthodox health care system largely depends on the advice given by them to the patients. The time lag between the onset of illness and first contact for treatment has been noticed to be short when indigenous healers were consulted first. However the patients who first see the indigenous healers first usually took a longer time to reach the referral center than the patients who come directly to the referral center. (Banerjee & Banerjee, 1995). This group has to be approached cautiously in a delicate manner otherwise, if antagonized, they will act as a major hurdle to the total program. While dealing with leprosy, a disease having even more stigma than epilepsy, it has been noticed that when traditional healers have been used as intermediaries to overcome communication difficulties existing between rural health services and the community, there is improved attendance at the health facility (Oswald, 1983). A sizable number of them do realize the existence of a certain type of fainting that does not respond to their form of treatment, but do not know what to do with these cases. The approach to be used will be to create an atmosphere of mutual referral. The traditional healers referring epilepsy cases to health posts for use of medicine while they continue providing psychological support. This will ensure that they do not loose their clients. Other types of fainting (of psychological origin - dissociative disorders and conversion disorders - ICD 10) can be referred to them from the health posts for continued support.

2.6.6 Strengthening active case-finding

The involvement of FCHV and TBA as mentioned earlier will enhance the process. Both these groups of people are ingenuous people of the community and are looked upon as the messengers for the modern health system. They can be used to look for potential cases in their respective communities.

2.6.7 Strengthening the health post system

The primary pull factor is the care delivery system which depends on skill, knowledge and attitude of the staff and availability of medicine. KAP of the staff can be increased by continued supervision and provision for CME (continuing medical education). A continuous and affordable supply of medicine can be ensured by close liaison with the district public health office which is the supplier of free medicine and /or introduction of the medicine into the ongoing Community Drug Program (CDP) of the health post which has recently been introduced.

2.6.8 Development of support systems for patients and families

It has been found that while dealing with chronic and long standing problems, the creation of self help groups composed of patients and /or caregivers helps to maintain group morale and reduce noncompliance.

2.7 CHOSEN INTERVENTION TO BE USED

Empowerment and mobilization of village health worker in the use of phenobarbitone to bring about better coverage, quality care and optimum management of epileptics in the community.

Operational Definitions:

Mobilization - The VHWs are traditionally involved in health education and other preventive services so are already indirectly involved in finding cases. 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 his 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 strict protocol, they will actually alter the dose 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

Optimum management - This is to ensure that the patients get the best possible treatment under the circumstances. This would mean a timely referral if and when needed. The patients will get continued psychological support from the VHW. He will institute any social intervention that may be necessary in the situation like reinforcement of the disease model of epilepsy over the religious/social model of the disease and avoid the consequences of the latter model. He will emphasize the physical nature and causation of the illness. He will try to remove the misconception that epilepsy is the product of ghosts or other social evil.

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

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 ...

2.8 HOW DOES IT WORK

One of the major problem is that the patients do not come for treatment. In the following section, the issue of "how can these patients be motivated to come for treatment" will be discussed. It follows naturally that there are two major contributing factors giving rise to this scenario, the human factor and the health service factor. Motivating a person from a state of relative inaction to that of action entails a basic change in his health related behavior. To increase the perception and change in behavior, there are three important elements -- knowledge, attitude and practices. These components are affected by the people's perception, i.e. perceived susceptibility to the disease, perceived threat of the disease, perceived benefit of action and perceived barriers to the action (Kaplan et all, 1993)

2.8.1 Human factor:

What motivates a person to go for treatment ? This question can be addressed by using the health belief model developed by Rosenstock (1966).

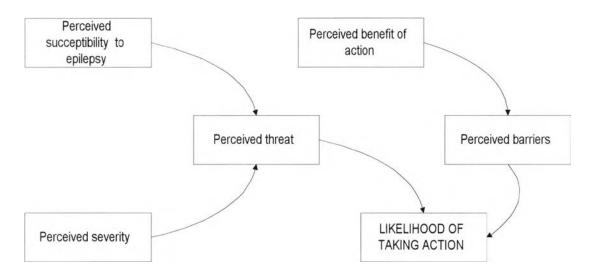


Figure 2.3 Determinants of health seeking behavior in relation to epilepsy (Adapted version of Health Belief Model of Rosenstock, 1966). (Source: Health and human behaviour, Ed. Kaplan R.M., Salis, J.F., Patterson T.L. Mac-Graw Hill Inc. 1993)

In this model the major assumption is that people do not change behavior because they do not perceive the gravity of the situation as unhealthy. In case of epilepsy, this human factor comes into play in two discreet but not mutually exclusive situations:

- How to change the relative inaction on the part of the patient by not going for help even after being ill ?
- How to motivate him to continue with the treatment regime for time as long as 2 3 years ?

Perceived susceptibility -- In a large number of cases of epilepsy, the cause cannot be well delineated. Except for avoiding accidents and alcohol, no particular behavior on the part of the public will prevent or enhance the probability of his being ill, so this factor is insignificant.

Perceived severity -- Epilepsy is an intermittent type of illness with the majority of fits occurring for only a few minutes and the other side effects lasting for a maximum of one day. As far as the patient or the party is concerned, it causes only a minor disruption in overall functioning so the perceived severity is low. This has to be modified by more information dissemination.

Perceived threat -- Once the likelihood of accidents (burns & drowning which are very common occurrences in this area) is correlated with the disease, the level of perceived threat can be increased thus creating motivation to seek treatment.

Perceived benefit -- The general public does not realize that getting any treatment for such an episodic illness is worth the effort. This concept has to be changed gradually by health education.

Perceived barriers -- This is an area which needs to be addressed tactfully because of the high probability of antagonizing traditional healers who are a very influential group. For this, concomitant supportive activity of traditional healer awareness raising training, as mentioned later, will have to be undertaken.

All the above mentioned factors can be modified by advocacy. The VHW, who normally comes from the same village can act as an effective vehicle for transfer of awareness and act as a contact point and link person between the community & health services. This will also aid him in active case-finding as has been experienced by other programs using the indigenous population as case finders (Chowdhury, Chowdhury, Islam, Islam & Vaugan, 1997).

2.8.2 Health service factor

Skill of diagnostic manpower -- This training activity will use the manpower responsible for diagnosis and management at the health post level, namely the Health Assistant (HA) and Community Medical Auxiliary (CMA) as co trainers under the master trainer. During the three days that they are involved in the training, they will get intensive CME on epilepsy and it is assumed that their knowledge and skill will be enhanced.

Active monitoring -- Since the VHWs are geographically and emotionally nearer the patient than other health post staff, it will be easier for them to keep track of the patients. In the closed communities of the village, everyone knows each other and the information gap is less. Any side effects or reoccurrence of fits will immediately be noticed. This will decrease the drop-out rate.

Alteration of the treatment -- When VHW's are involved, if and when minor problems (side-effects, break through fits) occur, these can be tackled on the spot without the patient having to go to the health post. This will decrease the non-compliance which is a common outcome of these problems.

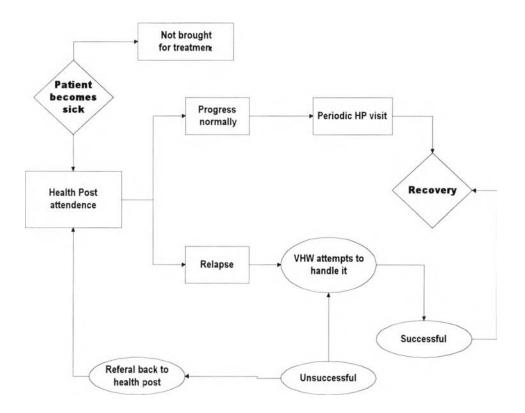
Dispensing of medicine -- The medicine will be dispensed at the village level cutting down the necessity for the patient to travel to the HP. This is thought to improve the accessibility and availability factor.

2.9 VILLAGE HEALTH WORKERS AS AGENTS OF CHANGE.

Village health workers are local people who are full time employees of the Ministry of Health , stationed at health posts and controlled by the district public health office (DPHO). These people have basic high school education. They are selected from the village they are suppose to serve by a team of local leaders, health post personnel and representatives of the community. They are given 3 months of basic training followed by time-to-time refresher training organized by the DPHO. As they come from the same village and the same community, they identify and

sympathize with the community and have the best access to people's home and families. They effectively act as a linkage between communities and health services. Every village has one VHW, so roughly one VHW is responsible for 100 to 300 families depending upon the size of the village. His primary role is in preventive services, health education, and finding cases.

To study how this proposed program is going to attain its objectives, the pathway followed by a person suffering from epilepsy has been traced in an attempt to identify the weak links of intervention.





When a person becomes ill he may or may not seek treatment at all. Here the VHW will function as one who identifies the illness as a case and motivates the patient and/ or party to visit the health post for confirmation and initiation of treatment. At this time he will be correcting the misconceptions the family may have about this illness and educating them. Once the patient enters the treatment regime, he will keep on monitoring progress, checking for side effects, and giving continuing psychological support. If the patient becomes ill again he will differentiate between defaulter and treatment failure and take the necessary follow up measures according to the protocol. He will act as a link between health services and the community.

In other words, in this type of intervention the VHW takes on the role of :

Educator -- Removal of misconceptions in the community and counteracting of negative advocacy from traditional healers.

Facilitator-- Motivate patients for treatment, facilitate the initiation of therapy at the HP, and dispense medicine at the doorstep and ensure a constant supply of medicine to the patient.

Case manager -- Carry on the supervision & monitoring of treatment, management of noncompliance, revise treatment (within fixed protocol) and prompt referral if/when needed. Case finder-- Proper identification of the cases.

Counselor Psychological support to the patient and family.

2.10 MOTIVATION FOR THE VHW TO TAKE THE ROLE.

This proposed program does not have any monetary benefit to the VHW so a question naturally arises - Why will the VHW take on this new responsibility? This program will be giving him the medicine dispensing role which is accompanied by a superior sense of recognition from the community which was not there before. It is expected that this factor will act as a intrinsic motivator for the VHW.

2.11 HOW TO IMPLEMENT IT

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. With this approach, the DPHO can easily replicate this program to other health post areas under its jurisdiction as their own trainers will be trained during implementation of this pilot project in one health post.

- Alarcon G., Olivares L. (1975). Cysticercosis cerebral. Manifestations en un medico de prevelancia. *Rev Invest Clin 27*, 209-15. { as cited by Shorvon, S. D., Farmer, P.J., (1988). Epilepsy in developing countries: A review of epidemiological, socio-cultural and treatment aspects. *Epilepsia, 29*(Supp. 1):S36-S54.
- Bains, H. S., Raizada, N. (1992). Parental attitudes towards epilepsy. Indian Peditr 29 (12):1487 - 90.
- Banerjee T., & Banerjee G. (1995). Determinants of help seeking behaviour in cases attending a teaching hospital in India : *Int J Soc Psychiatry* 41 (12):217-30
- Beran R. G., Michelazzi J., Tsimnadis P., & Loh S. (1985). False negative response rate in epidemiological studies to define prevalence ratio of epilepsy. *Neuroepidemiology* 4, 82-5.
- Chowdhury, A. M. R., Chowdhury, S., Islam, M. N., Islam, A., & Vaughan, J. P. (1997). Control of tuberculosis by community health workers in Bangladesh.
 Lancet, 350, (127) 169-73.
- Chadwick, D. (1995). Case for early treatment is not established. BMJ 310 (6973):1778-79.
- DeSilva, M., MacArdle, B., McGowan, M., Hughes, E., Stwart, J., Neville, B. G.
 R., Johnson, A. L., & Reynolds, E. H. (1996). Randomized comparative monotherapy trial of phenobarbitone, phenytoin, carbamazepine, or sodium valproate for newly diagnosed childhood epilepsy. *Lancet*, 347, 709-714.

I 19336949

- Feksi, A. K., Kaamugisha, J., Sanders, J. W. A. S., Gatiti, S., & Sharvon, S. D., (1991). Comprehensive primary health care antiepileptic drug treatment program in rural and semi-urban Kenya. *Lancet 337*, 406-10.
- Hackett R. J., Hackett L. & Bhakta P. (1997). The prevalance and associated factors fo epilepsy in childern in Calicut district, Kerala, India. Acta Paediatr 86 (11):1257-60.
- Heap B. J. (1990) Cerebral cysticercosis as a common cause of epilepsy in Gurkhas in Hong Kong. J. R. Army Med Corps. 136 (3):146-9
- Huxley, P. (1993). Location and stigma: a survey of community attitudes to mental illness part II: community mental health facilities - anonymity or invisibility. *Journal of Mental Health*, 2, 157-65.
- Kaiser, C., Asaba, G., Mugisa, C., Kipp, W., Kasoro, S., Rubaale, T., &
 Kabagambe, G., (1998). Antiepileptic drug treatment in rural Africa: involving the community. *Trop Doct* 28, 73-77.
- Kale, R. (1997). British Medical Journal 7099, 2-4. (Editorial).
- Lancet (1997) Lancet 349, 1851 (Editorial).
- Marks, J.W., Gracia, P.A. (1998). Management of seizure and epilepsy. American Family Physician, 57(7):1589-1600.

Nepal, M. K., Sharma, V. D., & Shrestha, P. (1996). Epilepsy prevalence: A case study of Morang. Paper presented at International Workshop on Epilepsy, conducted jointly by EPICADEC (Epilepsy Care Developing Countries) and Department of Psychiatry, IOM.

Oswald, I. H. (1983). Are traditional healers the solution to the failures of primary health care in rural Nepal? Soc Sci Med 17(5):255-57.

- Pal, D. K., Das, T., Chaudhary, G., Johnson, A. L., & Neville, B. G. (1998).
 Randomised controlled trial to assess acceptability of phenobarbitone for childhood epilepsy in rural India. *Lancet 351*, 19-23.
- Parker, B. (1988) Ritual coordination of medical pluralism in highland Nepal. Implications for policy. Soc Sci Med 27(9):919-925 abst.
- Pearson, M. (1988). What does distance matter? Leprosy control in West Nepal. Soc Sci Med 26(1):25-36.
- Placencia, M., Sanders, J. W., Shorvon, S.D., Roman, M., Alarcon, F., Bimos, C., & Cascente, S. (1993). Antiepileptic drug treatment in a community health care setting in northern Ecuador: A prospective 12 month assessment. *Epilepsy Res. 14*(3):237-44.
- Reynolds, E.H. (1995). Treatment should be started as soon as possible. *BMJ* 310 (6973):176-77.
- Reynolds, E.H., Shorvon S.D. (1995). Monotherapy or polytherapy for epilepsy? *Epilepsia 22* (1):1-10 *abst.*
- Ridsdale, L., Robins, D., Cryer, C., & Williams, H. (1997). Feasibility and effects of nurse run clinics for patients with epilepsy in general practice: randomized controlled trial. *British Medical Journal 314*, 120-14.
- Sharma, V. D. (1996). Prevalent opinion of traditional healers about clients who faint or are possessed. Paper presented at International Workshop on Epilepsy, conducted jointly by EPICADEC (Epilepsy Care Developing Countries) and Department of Psychiatry, IOM.

- Shorvon, S. D., Farmer, P.J. (1988). Epilepsy in developing countries: A review of epidemiological, socio-cultural and treatment aspects. *Epilepsia, 29* (Supp. 1):S36-S54.
- Singh A., & Kaur A (1997). Epilepsy in rural Haryana -- Prevalence and treatment seeking behaviour. J Indian Med Assoc 95 (2):47.
- Zielinskii J.J. (1994). Epidemiological and medico social problems of epilepsy in Warsaw. Final report on research program No. 19-P-58325-F-01. Warsaw Psychoneurological Institute.