

STUDY OF PATHWAY TO CARE AMONG PATIENTS WITH EPILEPSY

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ABSTRACT

Objective: To assess the pathway to care among patients with epilepsy up to the tertiary care centre

Methods: It is a hospital based, cross-sectional descriptive study of 47 patients visiting BPKIHS psychiatry OPD. Written informed consent was taken from the patients and the primary caretaker. A semi structured Performa was used to record the basic sociodemographic details. Pathway Interview Schedule developed by WHO was used to collect the data.

Results

Majority (66.0%) of subjects were male. Generalized Seizures were most common (76.6%) type of seizure followed by complex-partial seizure (10.6%). More than half (51.1%) first contacted dharmi-jhakri for treatment of their illness. About sixty two percent

of patients had the first contact with the treatment provider less than 4 yrs ago. Thirty eight percent subjects sought treatment as per advice from the family members while only 2.1% sought treatment as per advice from the healthcare worker. The most common presenting complaints were sudden loss of consciousness in 89.4% of patients. In majority of patients (57.4%), problem arised \leq 4yrs back. Significant high numbers of patients (51.1%) were prescribed alternative forms of treatment like herbal medications, talisman, offerings and sacrifices and jhadphook for their presenting problem. About eighty seven percent patients had to travel \leq 12 hours for the treatment while 10.7% had to travel a distance of $>$ 24 hrs for treatment. The mean duration that one had to travel for seeking treatment was 7.95 ± 14.58 hours. It was found that the mean duration that one patient spend before coming to a hospital for modern treatment was 5.64 months.

Conclusions

People suffering from epilepsy are still using the traditional healing practices leading to delay in the patient care. These findings call for a comprehensive educational program that can remove the misconcepts regarding the illness.

INTRODUCTION

Epilepsy is a common health problem which engenders a variety of medical, social, psychological and economic burdens. The impact of the disease is

felt, noticed and experienced in all spheres of the patient's life and also to some extent in patient's family. Stereotyped assumption about people with conditions such as epilepsy are inherent in many cultures, based in old superstitions and beliefs and, often reinforced through disabling portrayal in literature and media.¹The attitude of the general public towards epilepsy has still not improved significantly. Moreover, people suffering from epilepsy are still using the traditional healing practices. This has led to delay in the patient care and social isolation of epileptic patients. Also a strong stigma is attached to this disease. This has led to psychological stress among the person suffering from epilepsy. Though there are numerous studies done on epilepsy throughout the world only few had addressed the issue of Pathway to care, making awareness; even more fewer are in Nepal. Study like this can be a first step towards the disease to be taken seriously for implementing it in the national health policy making which will help in empowering the general public with the positive knowledge regarding the disease which will reduce the various complications that a person with epilepsy and also the family has to suffer in their life.

Methods

It a hospital based cross-sectional descriptive study. All consecutive patients visiting psychiatry and other OPD's or emergency/ward were screened for potential enrolment based on the inclusion exclusion criteria. Written informed consent was

taken from the patients. A semi structured Performa developed and approved by the department of psychiatry was used to record the basic sociodemographic details. Pathway Interview Schedule developed by WHO was used to collect the data.

RESULTS

Total numbers of 47 patients were enrolled in the study after taking the consent.

Demographics

The age of the patients ranged from 16-50 years with mean age being 26 years. Male subjects were 31(66.0%) and 25(53.2%) were married. Majority of the subjects were Hindu and educated up to secondary level.

Clinical description of epilepsy:

Majority i.e. 36(76.6%) had primary generalized seizure and complex-partial seizure was found in 5(10.6%) patients and partial seizure with secondary generalization in 4(8.5%) patients. Among 47 patients, 8(17.0%) had positive family history for epilepsy.

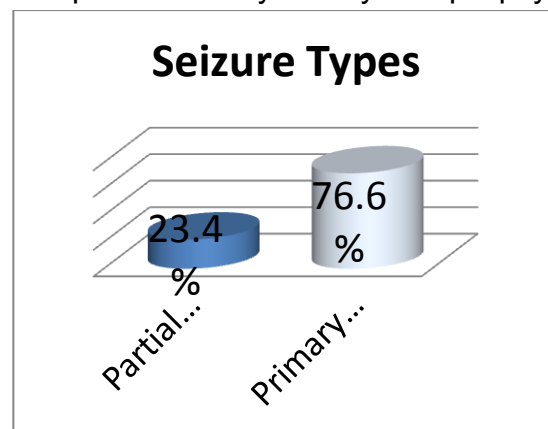


Fig 1. Seizure Types

Pathway to care:

Among 47 patients in the study more than half i.e. 24(51.1%) first contacted the dhami-jhakri for treatment of their illness. Remaining 23(48.9%) directly visited to a doctor for the treatment of their illness.

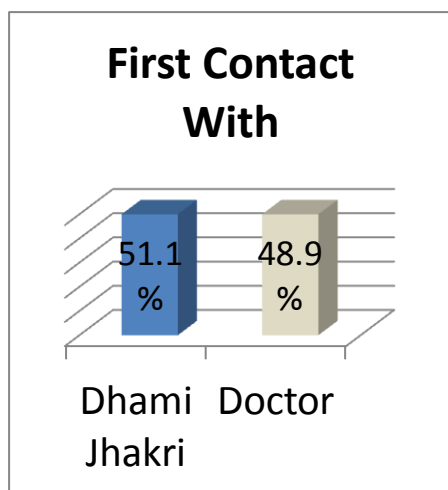


Fig 2. First contact of patient with treatment provider.

Among the 47, Majority of them i.e. 29(61.7%) had the first contact with the treatment provider less than 4 yrs ago while 8(17.0%) had first contact 5-9 yrs back. Seven(14.9%) visited the treatment provider about 10-14 yrs back. Remaining 3(6.4%) had first contact more than 15 yrs back. The mean duration was 5.33 ± 5.29 years.

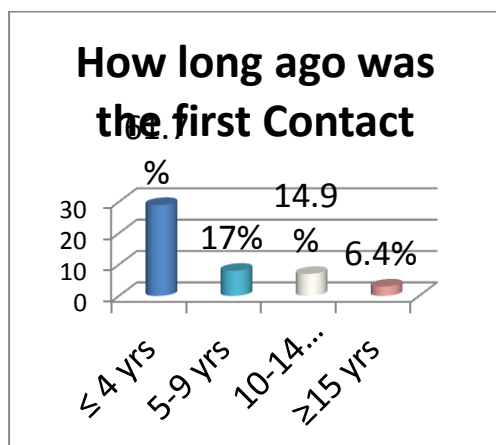


Fig 3. How long was the first contact with the treatment provider

On asking who suggested for the care, Among 47 patients, 18(38.3%) said that it was as per advice from the family members. 3(6.4%) sought treatment as per advice from their friends. 14(29.8%) patients came for treatment as per suggestion from the villagers, while 11(23.4%) patients said they sought treatment by their own. Only 1(2.1%) sought treatment as per advice from the healthcare worker.

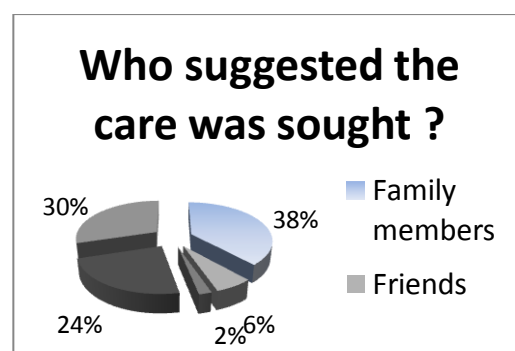


Figure 4. Who suggested to seek for treatment

Among 47 patients, majority i.e. 42 (89.4%) of patients presented with the complaint of sudden loss of consciousness. 2(4.3%) patients presented with abnormal behaviour, 1(2.1%) patient each presented with complain of headache, vomiting and difficulty to speak and movement of right fingers.

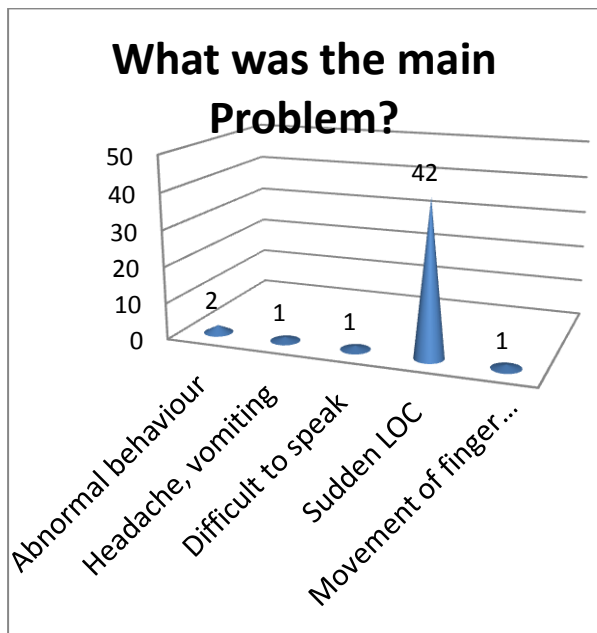


Figure 5. presenting complaints

In majority of patients i.e. 27(57.4%) problem arised \leq 4yrs back. In 11(23.4%) patients problem arised 5-9 yrs back. Five(10.7%) patients had the problem 10-14 yrs back and 1(2.1%) patients had the problem since 15-19 yrs while 3(6.4%) patient had the problem arise from >19 yrs. The mean duration was 5.8 ± 5.7 years.

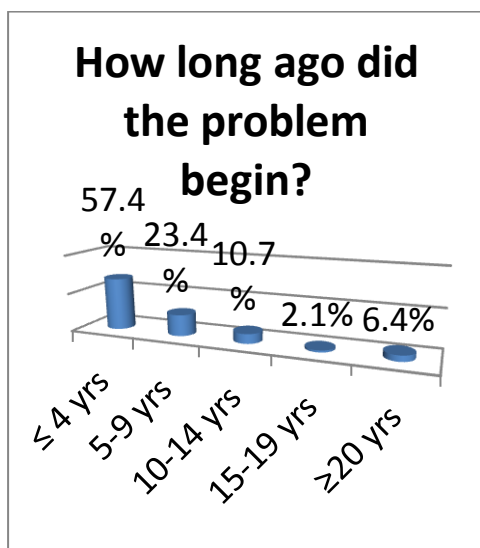


Figure 6. Duration of the problem

Among the 47 patients in the study, 23(48.9%) were prescribed medications, 8(17%) were prescribed herbal medications, 8(17.0%) were prescribed talisman as treatment. 5(10.7%) were treated with offerings and sacrifices and remaining patients i.e. 3(6.4%) were treated with jhadphook for their presenting problem

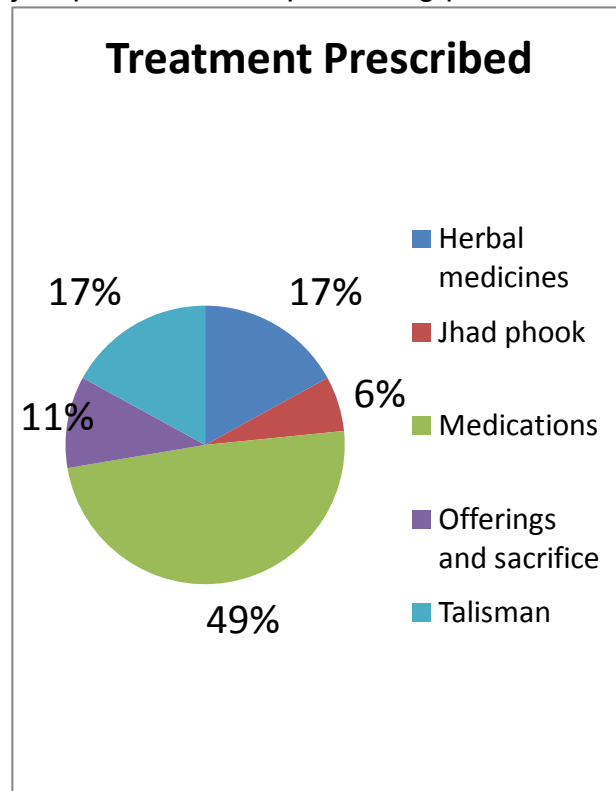


Figure 7. Treatment prescribed by the treatment provider

Among 47 patients, high majority i.e. 41(87.2%) patients had to travel \leq 12 hours for the treatment. Only 1(2.1%) patient had to travel 13-24 hrs for treatment and remaining i.e. 5(10.7%) had to travel a distance of >24 hrs for treatment. The mean duration that one had to travel for seeking treatment was 7.95 ± 14.58 hours. It was found that the mean duration that one patient spend

before coming to a hospital for modern treatment was 5.64 months.

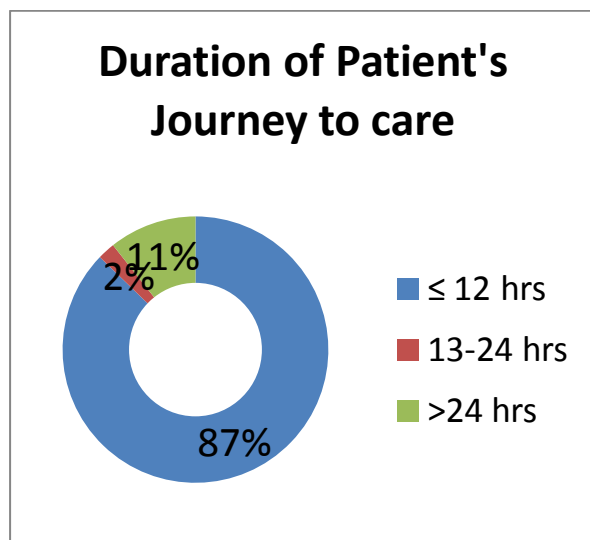


Figure 8. Duration of patient's journey to the treatment provider

DISCUSSION

The pathways which patients take to reach mental health care have rarely been examined in a systemic way. The model put forward by Goldberg and Huxley (1980) assumed that most patients start by consulting their general practitioner, but it was appreciated that other pathways may be used. The pathways which patients take are likely to be influenced by conventions governing referral, by relationships which exist between mental health services and other sources of help and by availability/accessibility of mental health and other helping agencies. It is necessary for the inclusion of mental health care into general health care so as to be able to train health staff and make other arrangements necessary to provide appropriate help as soon as

possible after the beginning of patients contact with services. Persons with epilepsy with diverse ethnic groups believe the Hindu philosophy of Karma and they are influenced by Hindu religious practice. They believe that the present life is determined by past deed. Many believe the epilepsy is due to the evil spirit to the sinner from past life as a punishment of god. The evil spirit will remain on the victim until the termination of its imposed punishment.² Most of the ethnic groups adopt various traditional approaches to get rid of epilepsy. They prefer seeking help from traditional faith healer. Thus, most of the persons with epilepsy reach to proper facility very late with neuron-psychiatric and psychosocial complications. Such delay is also associated with social stigma.

In our study, 51.1% patients had first contact with the faith healers like DharmiJhakri. Nepal *et al* reported in their survey that among 34 patients with epilepsy, 9% were treated by traditional healers and another 29% had previously been treated by traditional healers.³ Thus, the patients were just as likely to seek treatment from traditional healers as modern medicine. Another survey done in a village health post in Kaski district in Nepal reported that it was more convenient to visit a traditional healer (Jhankri) than to come to the village health post.⁴ P.Rajapakse *et al*. reported in their study that significant percentage still resort to alternative modes of treatment. This reflects the traditional thinking and beliefs in the society.

The help seeking behaviour of the epileptic cases is hindered by various means. While they seek help, many i.e. 38.3% do so as per suggestions from the family members followed by suggestions from villagers (29.8%). The reason for seeking help in high majority of cases (89.4%) was sudden loss of consciousness. The mean duration lost before the first contact with a medical practitioner for modern treatment was 5.64 months.

CONCLUSIONS

In this study, it was found that majority of the patients with epilepsy seek alternate methods of treatment than visiting to a doctor. A significant period of time elapse before the patient reaches to the medical practitioner for proper treatment and care. These findings call for a comprehensive educational program and psychological interventions aimed at improving the knowledge about epilepsy and reducing the stigma in the population at large. Such an educational program must take into account the belief and value system of the community. It is hoped that with increasing knowledge and awareness, long-held erroneous notions and perceptions associated with epilepsy will be eradicated.

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