ORIGINAL ARTICLE

Perception about Epilepsy among Epileptic Sufferers

NAZEEFA JAVED, ATIQ UR REHMAN, KASHIF SALEEM, *M. ARSLAN SIDDIQUI, SALAMAT GILL*

ABSTRACT

Objective: To find the views of epileptic patients about epilepsy and its effects on their living.
Study design: based on a predesigned questionnaire, cross sectional, observational study.
Place and duration of study: OPD of Neurology, Fatima Memorial Hospital Lahore.
Materials and methods: The study was conducted on 206 patients divided into pediatric and adult age group. Only epilepsy sufferers were included. The questions were answered by the parents in pediatric age group to record the response and views of family about this particular problem. The inclusion and exclusion criteria were followed and impact of epilepsy on patients lives was seen.
Results this study represents better awareness and concepts of epileptic patients regarding epilepsy. 71% acknowledged to be suffering from fits, and a similar percentage of patients had their diagnosis done by a doctor.78% considered it to be medical disorder rather than to be a state of possession which was thought to be by 10.2%. While 4.9% of our patients were of the view fits were contagious and 6.3% believed their arrest with shoe sniffing. 52.4% considered fits to be a cause of shame which signifies fits to be cause of social stigma which was also observed for getting married, 37.9% thought fits were a major hurdle in getting married. Similarly 71.4% considered epilepsy to be a major hurdle in completing their daily task. A majority 93.2% agreed to take medication from physician and minority 24.3% were willing it to be treated by non medical doctors. 58.75 were tired of their underlying condition. Despite of this 76.2% considered themselves to be a useful member of society.
Conclusion: Epilepsy is both a medical and a social issue for patients and their families, who have many myths and misconceptions despite advancement in the available tools for its diagnosis and management. Therefore public education and awareness on a mass scale will help to reassure the patients as well as their care givers and help them to seek appropriate medical and psychological help on time.
Key words: epilepsy, fits, seizures, social stigma, shoe sniffing

INTRODUCTION

Epilepsy is an important neurological disorder which has a significant impact on daily living of sufferers and also leaves a social stigma. Studies have been done in Pakistan to overview the perception among epileptics indicating patients having better understanding of the disease rather than it to be a possession by some supernatural power. As Pakistan has higher prevalence (9.85) of epilepsy more work is needed to be done to create awareness and better understanding of this disease[1]. To achieve this target the first and foremost thing needed is to know what the patients themselves think about epilepsy. This will reduce wrong self management modalities and will definitely reduce the negative social impacts imposed by others. Patients will be better adherent to their management and will have a better follow up with their attending physician. This study is also an effort to know the views of epileptic patients whether they consider it to be truly a disease process which can be treated with medications and questions pertaining to marriage.

Department of Neurology, Fatima Memorial Hospital, Lahore
Correspondence to Dr. Nazeefa Javed, Assistant Professor
Email: nazeefajaved@yahoo.com

METHODS

A total of 206 epilepsy patients were included in the study. An Urdu questionnaire formatted on 15 basic questions was given to the patients and the response was recorded as “yes”, “no” and “do not know”. The proformas of pediatric patients were filled out by their adult caregivers regardless of their educational status. Only outpatients were included. Patients who were willing to fill the questionnaire were included. Relatives of epileptics were included in the study. Non epileptic patients were excluded from the study. This study had its limitations as all the aspects were not studied pertaining to social impact of epilepsy.

Out of 206 patients 51 patients belonged to pediatric age group (newborns to 12 years of age) and the remainder 155 patients belonged to adult age group (12 years of age and above). The gender distribution in our study showed male predominance; 114 males and 92 females answered the questionnaire. As far as the area to which patients

belonged to is concerned majority (179) patients were residents of Lahore and the remainder belonged to other cities. Their distribution is shown in the table.

RESULTS

The questionnaire was filled by the patients and by the immediate attendants of the pediatric age group just as to see the response of patients and the family members, and to find out their views regarding epilepsy and its impact of epilepsy on their lives. The response to different questions was as follows;

1. **Do I suffer from fits?** 148 patients responded yes to this question and 38 denied their primary diagnosis while 20 patients did know about their problem.

2. **Are these fits diagnosed by a doctor?** 148 patients acknowledged their problem to be diagnosed by a doctor, 49 patients responded NO to this question and 7 patients did not know about it. The remainder two questionnaires were unfilled.

3. **Do I consider fits to be a medical illness?** 161 patients said yes to it while 32 did not consider it to be medical problem and 13 did not know it to be an illness.

4. **Are these fits treatable?** 163 patients considered their disease to be a treatable condition, 16 denied it and 27 did not know about it.

5. **Is it a state of being possessed?** 21 patients considered their disease to be a a state of possession and 158 patients did not consider it to be so and 26 patients responded that they did not know if it was a state of being possessed.

6. **Are these fits contagious?** only 10 patients thought fits to be a contagious process and 170 patients said NO to it however 26 patients did not know about its contagious nature.

7. **Do the Fits arrest with shoe sniffing?** 13 patients agreed to it,152 patients did not agree with shoe sniffing remedy and 36 patients did not know about it. Five subjects omitted filling response to it.

8. **Are these fits cause of shame?** 108 patients considered it to be a shameful process,77 said NO to this question and 19 patients did not know answer to it. The rest two performas were not filled for this question.

9. **Are these fits a hurdle in patient's marriage?** the response was equal to yes(78)and no (74)and 50 patients did not know about it. Four subjects did not recorded their response for this question.

10. **Is marriage a solution to it?** 18 patients said yes to it and 105 patients did not consider it to be the solution to it however 79 patients did not know about it. Four questionnaires were not filled in for this particular question.

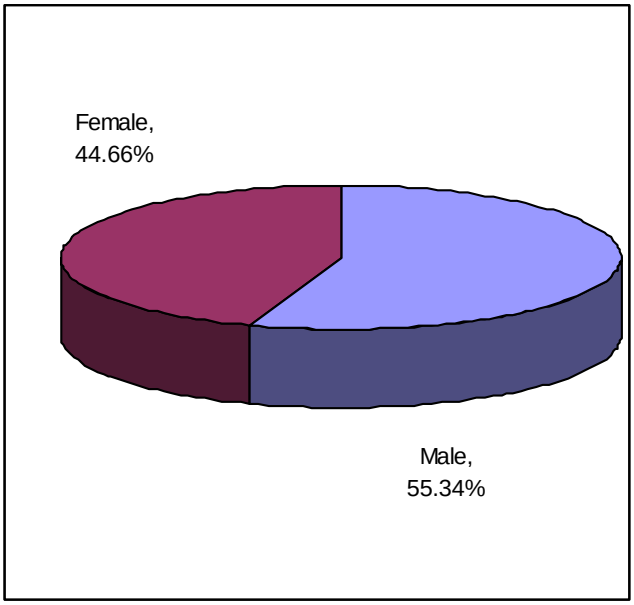
11. **Fits being an obstacle to daily living?** 147 patients considered fits to be a major obstacle while 39 did not and 17 patients said they did not know about it. The remaining three did not answer this particular question.

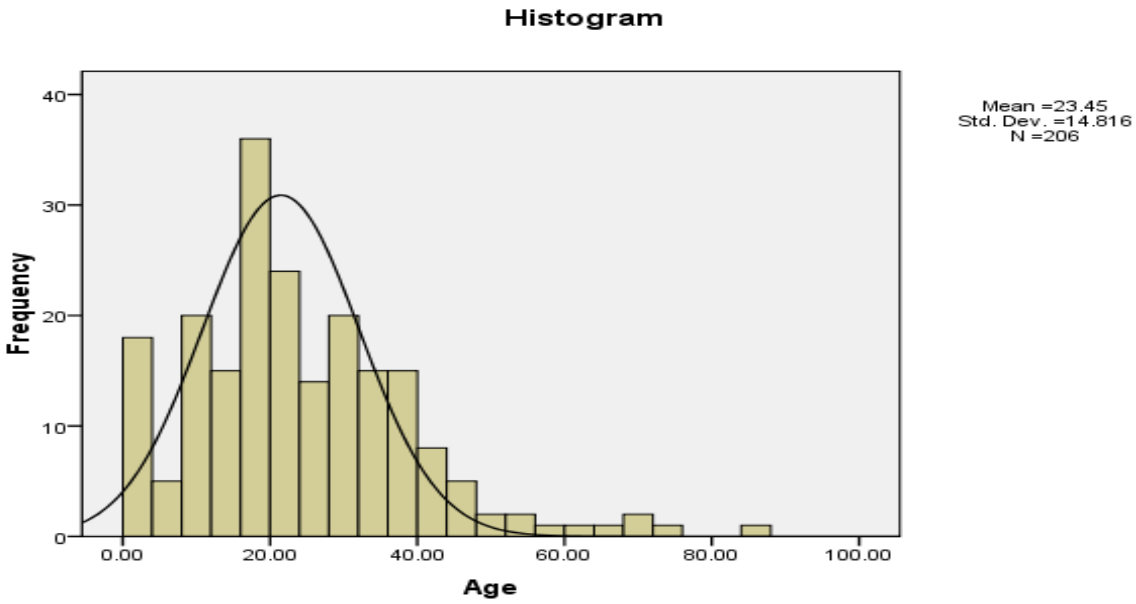
12. **Should medications be taken from a qualified doctor?** 192 patients responded yes to it, 8 patients said no to it and 5 patients said they did not know about it. Only one person did not answer this question.

13. **Fits treated with homeopathic, hakeem and ayuverdic medication**? 50 patients said yes to it, 107 patients said no to it and 49 patients did not know about it.

14. **Being fed up with fits?** a large number (121) said yes to it and 75 said no to it and 8 patients did not know about it. The remainder two did not answer this question.

15.**Can I be a useful person of society despite fits?** 157 patients agreed to it, 27 patients did not agree with it and 20 did not know. Two subjects did not register their response.





DISCUSSION

Epilepsy is a neurological disorder associated with myths, social discrimination physical and emotional trauma. Studies have been conducted around the world regarding awareness knowledge and attitudes towards epilepsy. As far as our study is concerned which was conducted at a local private tertiary care set up it shows the awareness among not only the patients but their family members also.

Studies have been done in various countries for the assessment of awareness and attitude of people about epilepsy. In one study done in India awareness was assessed among school teachers which were reported to be 97%[2]. In contrast to this awareness was restricted to 57.8% among school teachers in Thailand[3]. The school teachers from Sudan had a low level of (47%) awareness and understanding of this neurological disorder among school teachers compared to 64% in secondary schools[4].

66 studies have been mentioned in literature which was conducted between 1993 and 2010 in different countries across the world but only one was considered to be interventional[5].

A study conducted in Bandung Indonesia shows a high level of awareness among general public but there was also a lot of misunderstanding about epilepsy[6]. There was wrong concept about epilepsy identification as mental retardation or psychiatric illness and triggered by seeing water or fire. Twelve percent of the respondents believed epilepsy to be transmitted by saliva and was a contagious disorder. However 85% of respondents agreed to regular antiepileptic intake while 82% agreed that it was a curable disorder[7].

The contagious nature of epilepsy was also reported from Nigerian study even among medical students[8]. In Africa epilepsy was considered equally contagious and hereditary. In Afghanistan it was considered to be a possession by jinn among rural residents[9].

A research done in Pakistan and Turkey in 1987 showing cross cultural comparison showed that Pakistani population had a positive attitude towards epilepsy and had a better approach towards treatment seeking behavior. The results of interim report by Epilepsy Control Programme about knowledge and attitude were also similar. It was conducted among school teachers. No significant difference was reported for age, gender and educational status of patient.

CONCLUSION

Epilepsy is a disorder which was considered to be a state of possession for a long time and treatment was bromide for half a century before antiepileptic drug therapy was launched. Treatment has been revolutionized by advent of newer antiepileptic drugs with fewer side effects and minimal drug to drug interactions. Surgical treatment and vagus nerve stimulation are options for intractable seizures. But inspite of all these advancements still many myths and misconceptions exist in the minds of people. Our population has more positive ideas for this disorder but public education and awareness is needed to

assure that it is a non contagious unpredictable disorder which can be well controlled with appropriate medications with a good quality of life.

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