Pakistan Journal of Neurological Sciences (PJNS)

Volume 10 | Issue 3 Article 3

12-2015

Misconceptional views about epilepsy exist across social class system of society

Shoaib Rao
Aga Khan University

Bakhtyar Ali Shah
Khyber Medical University, Peshawar, Pakistan

Nimra Altaf
Aga Khan University

Fazal M. Arain
Aga Khan University

MISCONCEPTIONAL VIEWS ABOUT EPILEPSY EXIST ACROSS SOCIAL CLASS SYSTEM OF SOCIETY

Shoaib Rao[1], Bakhtyar Ali Shah[2], Nimra Altaf[1], Fazal M. Arain[1]
[1] Department of Biological and Biomedical Sciences,The Aga Khan University
[2] Institute of Nursing Sciences, Khyber Medical University, Peshawar, Pakistan

Corresponding Author: *Fazal M. Arain, Department of Biological and Biomedical Sciences, The Aga Khan University. P.O. Box 3500 Stadium Road Karachi 74800, Pakistan Tel: (021) 3493 0051 ext 4523 Email: fazal.arain@aku.edu*

Abstract

Introduction:
Epilepsy affects over 1% of population worldwide. Studies have shown that although our understanding about epilepsy has come a long way, misconceptions about its etiology and treatment exist in rural slums. However, no study has been conducted to see whether such misconceptions exist in middle and upper socio-economic class. This study aims to explore the existence of misconceptions and social stigma in the middle and upper socio-economic class. **Materials and Methods:** We conducted a survey-based study about epilepsy on 227 participants, belonging to middle and upper socio-economic class. **Results:** The symptoms of generalized tonic-clonic seizures were correctly described by participants. However, magic, superstition and 'jin' were considered as the etiology by some. Incorrect treatment options, like shoe sniffing and 'taweez' etc., were also mentioned. Social stigmas regarding sharing information about epilepsy and marrying epileptics also existed. **Discussion:** Our study shows that although the general understanding about epilepsy was correct in majority of participants belonging to the middle upper socio-economic class, it was restricted to generalized tonic clonic seizures. Key misconceptions regarding the etiology and treatment of epilepsy and social stigma associated with it did exist. These findings emphasize the need to educate all segments of the society about epilepsy.

MESH WORDS: Epilepsy, Misconceptions, Stigma, Socio-economic class

INTRODUCTION

Epilepsy is a common neurological disorder affecting approximately 1% of the worldwide population[1]. It is defined by the occurrence of two or more unprovoked seizures. Epilepsy has been classified into three etiological categories: 1) Genetic, 2) Structural/ metabolic and 3) Unknown (this includes conditions in which the underlying cause is "as yet unknown")[2]. Although significant progress has been made in understanding the etiology and treatment of epilepsy, the ideas of demonic possession or a punishment by supernatural spirits as the primary cause, exists in many developing societies as a common belief[3]. A study conducted in a slum area of Karachi, showed that 25% of the studied population believed that epilepsy was caused by evil spirits, black magic and envy by others[4]. Studies have also shown that such misunderstanding are not restricted to the etiology of epilepsy but also exists about the treatment of epilepsy in such a population class[5]. This is why 90% of patients with epilepsy in developing societies do not receive appropriate treatment[6]. Although it is known that 70-80% of epileptics can live normal lives if patients with epilepsy comply with the treatments[7], this does not occur in such societies. All of these factors add to the fact that epilepsy has serious physical, psychological, social and economic consequences[8]. Although it is understandable that such misconceptions regarding epilepsy exists among people belonging to lower socio-economic classes, whether or not such misconceptions also exist among the privileged and well-informed society of Pakistan is not known. Therefore, this study is designed to evaluate the conceptual status of epilepsy of the middle- and upper-class communities.

METHODOLOGY AND RESULTS:

A survey was carried out in a shopping mall in Karachi, which is mostly visited by individuals belonging to the middle and upper socio-economic class. The participants were asked pre-designed questions about their understanding and beliefs regarding epilepsy. The

questionnaire consisted of 4 major segments: 1) basic demographic data, which included age, sex, occupation and education of the participant; 2) understanding and beliefs about epilepsy, including the etiology of disease, symptoms, mode of transmission and reprecussions; 3) social stigma regarding epilepsy, including opinion regarding marriage and employment of epileptics; 4) source of knowledge about epilepsy. The study was carried out from May till September 2014, after receiving approval from Aga Khan University Ethic Review Committee. A total of 227 subjects were interviewed. Data was entered into SPSS version 19 for coding, cleaning and analysis. Comparison of all the variables across gender was made and difference in proportions across gender was measured by pearson chi square test. Two sided p values less than or equal to 0.05 was considered significant. Among the 227 participants, 115(51%) were included in the age group of 17 to <30 years followed by the age group of 30 to < 40 years 105(46%) and 40 to 53 years 07 (3%). 119 (52%) of the participants were male, while 108(48%) were female. 79 (35%) of our participants had masters or greater qualification, 126 (56%) had a bachelor degree and 22 (10%) had high school or less education. Occupation of the participants included students 51 (23%), accounting related jobs like clerk, bank manager and sales manager 37 (16%),house wives 29 (13%), teachers 18 (8%), engineers 16 (7%), businessmen 17 (8%), health professionals7 (3%) and 52 (23%)were from different fields including librarian, textile designers, landlords, human resource and government employees. This data has been summarized in figure 1. The response to the question regarding the symptoms of epilepsy was variable and included a variety of answers including body shakes, frothing and loss of consciousness as isolated symptoms or combination of these symptoms. However, majority of participants had a correct general understanding of the symptoms of epilepsy. The participants described stress, neurochemical imbalance, genetics, accident, brain tumors, lack of sleep, drugs, diet, magic, superstition and 'jins' (evils), as major causes of epilepsy (table 1). All except one participant correctly said that epilepsy is not infectious. Regarding the repercussions of epilepsy 58% of the participants said that it causes mental retardation, 52% said that it also causes memory loss and 52% said it also causes other neuro-psychiatric disorders. Quran, 'dum', 'taweez', yoga, psychotherapy, shoe sniffing, physical therapy, smelling any pungent odor along with holding iron object in hand and spiritual healing etc. were described as valid treatment options for epilepsy, along with anti-epileptic drugs (AEDs) (table 2). This study also revealed some strong social stigmas regarding epilepsy in our target population. For example, 69% participants said that if they had epilepsy they would be comfortable sharing this information with people who are not first degree relative. However 31% participants were not comfortable with sharing this information. Among the female participant, 56% said that they will marry a man diagnosed with epilepsy, while 45% said no. However, 89% of the male participant said that they would marry a woman diagnosed with epilepsy, which is significantly more than women who were willing to accept an epileptic life partner ($p = 0.038$). The participants said that they learned about epilepsy either from their relatives diagnosed with epilepsy or observing a patient having seizure or on media.

Table 1: Common causes of epilepsy identified by the participants. The participants usually mentioned more than one cause of epilepsy. Some of the identified causes of epilepsy, such as neurochemical imbalance and genetics, were correctly identified but incorrect causes, such as Jin and magic, were also mentioned.

Causes of Epilepsy	Number of Participants
Neurochemical Imbalance, Stress, Genetics, Accident, Diet, Jin	37 (16%)
Neurochemical Imbalance, Genetics, Accident	35 (15%)
Neurochemical Imbalance, Genetics, Accident, Brain Tumor	6 (3%)
Neurochemical Imbalance, Genetics, Jin, Magic, Fever, Superstition	11 (5%)
Genetics	5 (2%)
Neurochemical Imbalance, Stress	19 (8%)
Other	114 (50%)

DISCUSSION

We conducted a study targeting the middle and upper class population of the largest city of Pakistan, i.e. Karachi. As can be seen by the presented data, our participants were mostly young, well educated (91% had a Bachelor's degree or higher) and were well settled in their jobs or businesses. Both genders were equally represented. All of these factors indicate that we were able to include the middle and upper socio-economic class population in our study and our data could be considered a valid representative of this segment of the society. Majority of our participants correctly identified the symptoms of epilepsy and most of the factors that induce seizures. However, a significant proportion of them still believed that factors like magic, superstition and 'Jin' can be the etiology of

this disease. Similarly, even though many participants identified anti-epileptic medications as treatment for epilepsy, a significant proportion still believed that shoe sniffing, holding iron object and spiritual healing are best treatment options. These factors indicate that even though our participants were well educated, their misconceptions about epilepsy seem to be well grained.

Table 2: Treatment options for Epilepsy. Most of the participants knew that antiepileptic drugs were the correct treatment options. However, a significant proportion believed that Quran and spiritual treatment were the best cure for this disease.

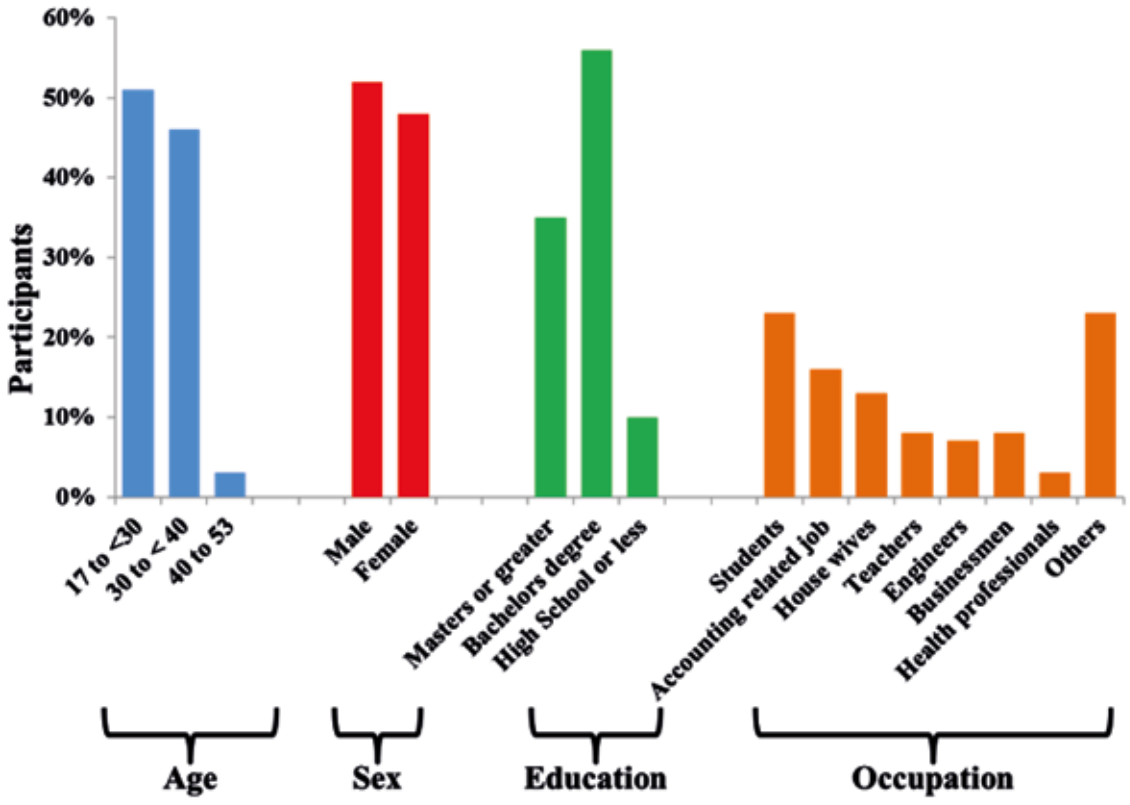
Treatment of Epilepsy	Number of Participants
Antiepileptic Drugs	14 (6%)
Antiepileptic Drugs and Quran	52 (23%)
Antiepileptic Drugs, Quran, Spiritual	19 (8%)
Antiepileptic Drugs, Quran, Diet	21 (9%)
Antiepileptic Drugs, Quran, Surgery	11 (5%)
Quran, Spiritual, Diet	8 (4%)
Cannot be Treated	17 (7%)
Don't Know	9 (4%)
Other	76 (34%)

The social stigma regarding epilepsy also persisted in this segment of the society. Our participants were clearly not comfortable with sharing information with other people who were not immediate family members, if they were diagnosed with epilepsy. In other words they would feel ashamed if they were diagnosed with epilepsy, as if it is a disgrace to be an epileptic. A significant proportion of our participants also said that they will not accept an epileptic as their life partner. Female participants were particularly strong about this opinion. The possible reason for this could be that they felt that their husbands would not be able to earn enough money to run their household or that they would not want to continuously worry about hiding the fact that their husbands were epileptic from non-family members.

CONCLUSION

The data of the present study shows that misconceptions regarding epilepsy still exist across all three classes: lower, middle and upper. The understanding of the etiology and treatment of epilepsy were in particular very poor. The social stigma that

Figure 1: Distribution of participants. The participants were divided on the bases of age, sex, educational background and occupation.



these misconceptions are causing is very disturbing. How might these misconceptions be removed from a treatable disease is indeed a challenge. It requires effective health and educational policies of a state to aid shedding off socio-religious stigma of epilepsy associated with common practice of consanguinity and apartheid.

ACKNOWLEDGEMENTS

The critical review of this manuscript by Dr. HR Ahmad and Dr. Najeeha Iqbal from Department of Biological and Biomedical Sciences Aga Khan University is gratefully acknowledged by authors.

REFERENCES

1: Banerjee PN, Filippi D, Allen HW. The descriptive epidemiology of epilepsy-a review. Epilepsy Res. 2009;85(1):31-45. DOI: 10.1016/j.eplepsyres. 2009. 03.003.

2: Berg AT, Berkovic SF, Brodie MJ, Buchhalter J, Cross H, van Emde Boas W, et al. Revised terminology and concepts for organization of seizures and epilepsies: report of the ILAE Commission on Classification and Terminology, 2005-2009. Epilepsia. 2010;51(4):676-685. DOI: 10.1111/j.1528-1167.2010.02522.x.

3: Eadie M. Epilepsy-from the Sakikku to hughlings Jackson. J Clin Neurosci.1995;2(2):156-162.

4: Shafiq M, Tanwir M, Tariq A, Saleem A, Zafar M, Khuwaja AK. Myths and fallacies about epilepsy among residents of a Karachi slum area. Trop. Doct. 2008;38(1):32-3. DOI: 10.1258/td. 2006.006311.

5: Shafiq M, Tanwir M, Tariq A, Kasi PM, Zafar M, Saleem A, et al. Epilepsy: public knowledge and attitude in a slum area of Karachi, Pakistan. Seizure. 2007;16 (4):330-337.

6: Meinardi H, Scott RA, Reis R, Sander JW. The International League Against Epilepsy Commission on the Developing World. The treatment gap in epilepsy: the current situation and ways forward. Epilepsia. 2001;42(1):136-49.

7: Osungbade KO, Siyanbade SL. Myths, misconceptions, and misunderstandings about epilepsy in a Nigerian rural community: implications for community health interventions. Epilepsy & Behav. 2011;21(4):425-429. DOI: 10.1016/j.yebeh.2011.05.014.

8: McHugh JC, Delanty N. Epidemiology and classification of epilepsy: gender comparisons. Int. Rev. Neurobiol. 2008;83:11-26. DOI: 10.1016/ S0074-7742(08)00002-0.

Conflict of Interest: Author declares no conflict of interest.

Funding Disclosure: Nil

Author's contribution:

Shoaib Rao: Study concept and design, protocol writing, data collection, data analysis, manuscript writing, manuscript review

Bakhtiar Ali Shah: Study concept and design, protocol writing, data collection, data analysis, manuscript writing, manuscript review

Nimra Altaf: Data collection, data analysis, manuscript writing, manuscript review

Dr. Fazal M Arain: Data collection, data analysis, manuscript writing, manuscript review