



12-2015

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## Recommended Citation

Mughal, Shaheen Ahmed; Lakhair, Muslim Ali; Fiaz, Muhammad Saleem; and Memon, Abdul Qayoom (2015) "Epilepsy in the rural areas of sindh: knowledge, beliefs and practices," *Pakistan Journal of Neurological Sciences (PJNS)*: Vol. 10: Iss. 4, Article 4.  
Available at: <http://ecommons.aku.edu/pjns/vol10/iss4/4>

# EPILEPSY IN THE RURAL AREAS OF SINDH: KNOWLEDGE, BELIEFS AND PRACTICES

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**Date of Submission:** July 2, 2015 **Date of Revision:** September 10, 2015 **Date of Acceptance:** October 1, 2015

## ABSTRACT

**Background:** Unfounded beliefs regarding epilepsy are still common and widespread. Visits to shrines and seeking help from faith healers goes along with these beliefs. This creates a major barrier in the timely diagnosis and treatment of epilepsy. **Objective:** To determine the knowledge, beliefs and practices relating to epilepsy in the rural areas of Sindh and how do they differ between educated and uneducated families of patients with epilepsy. **Methods:** This was an observational study conducted at the Neurology Out-Patient Department of the Peoples Medical University Hospital Nawabshah during the period 1.1.2015 to 30.6.2015. A pro forma was designed incorporating questions pertaining to knowledge, beliefs and practices regarding epilepsy among patients and accompanying family members. Each case was considered as representing the whole family. Educational background was ascertained and the comparison of study variables between educated and uneducated families was evaluated. The questions were translated into their native spoken language (Sindhi). **Results:** A total of 120 cases were included in this study. Sixty nine (57.7%) were male and 51 (42.5%) were female. Age ranged from 1 to 55 years. Eighty one (67.5%) were the residents of rural villages and 39 (32.5%) were residing in Nawabshah and adjoining towns. Of the 120 cases 80 (66.7%) families were educated and 40 (33.3%) were uneducated. Majority 76 (63.3%) believed that epilepsy is a disease whereas 44 (36.7%) considered epilepsy a “super natural force” (‘almaat’: a native term) or possession by a ‘fakir’ (Jinaat). Of the 80 educated families 56 (70.0%) had knowledge about the disease and of the 40 uneducated families 20 (50%) had no knowledge about the disease. Better awareness about the disease among families having educational background was statistically significant ( $p < 0.05$ ). Of the 80 educated families 23 (28.8%) visited shrines and of the 40 uneducated families 26 (65.0%) visited shrines. Uneducated families visiting shrines was statistically significant ( $p < 0.01$ ). Families having younger individuals (11-30 years) were more inclined towards visiting shrines. Out of 120 cases 44 (36.6%) were being treated by faith healers (dagho-phenu: a native term for this kind of practice) and 76 (63.0%) were receiving medical therapy. Of the 44 cases receiving faith healing 28 (63.6%) also visited shrines and of the 76 cases who were receiving medical therapy 21 (27.6%) visited shrines. Followers of faith healing practices significantly visited shrines compared to those who were receiving medical therapy ( $p < 0.001$ ). Those who went for faith healing at first place and did not get benefit out of it came to seek medical therapy. They also pledged for the strict compliance and that in future they will not switch over to “other” forms of therapy. **Conclusion:** Misperceptions about epilepsy are common in the rural areas of Sindh, Possession by a “supernatural force” (Almaat) was most common belief among those who did not consider epilepsy a disease. Knowledge about epilepsy was better among families having educational background. Uneducation and unawareness leads to unscientific practices like faith healing and visit to shrines. There is willingness for receiving medical therapy once the proper guidelines are provided.

**Key Words:** Epilepsy, Rural, Sindh, Beliefs

## BACKGROUND

Epilepsy is a common neurological disease. While some people consider epilepsy a medical condition, others may have false beliefs regarding this illness. These false beliefs are wide spread not only in our country but are also reported elsewhere. For example in certain ancient American and African communities people suffering from

epilepsy are considered as being possessed by an evil spirits or under the influence of some kind of black magic [1,2,3]. The community-based [4] as well as hospital-based [5,6] studies done in Pakistan has also reported similar kinds of misperceptions regarding epilepsy. It appears that over the years the unfounded beliefs regarding epilepsy are still rampant and growing. It is worrisome that when these beliefs get firmer, the affected patients and their

families instead of going to a medical doctor for treatment follow certain practices like visiting shrines or consulting faith healers for a quick remedy. This is detrimental to the well being of the patients for it would delay the diagnosis and the subsequent treatment. Previous local studies were mainly conducted at the tertiary care hospitals located in bigger urban cities [5,6]. Since epilepsy is more common in rural areas of Sindh [4], and that people living in rural areas with lower education have more negative attitudes towards epilepsy [7], it is imperative to study these aspects in those areas so that the medical intervention can be emphasized and properly guided upon. For this purpose we designed a study to determine the knowledge, beliefs and practices regarding epilepsy among the patients and their families residing in rural areas of Sindh.

**Table 1:** (n=120)

Variables	Number	Percent
<b>GENDER</b>		
Male	69	57.5
Female	51	42.5
<b>AGE in years</b>		
Up to 10	25	20.8
11 – 20	45	37.5
21 – 30	36	30.0
> 30	14	11.7
<b>EDUCATION</b>		
None	37	30.8
Primary	25	20.8
Secondary	28	23.3
Inter	19	15.8
Graduate	11	9.2
<b>FAMILY</b>		
Educated	80	66.7
Uneducated	40	33.3
<b>Epilepsy a disease?</b>		
Yes	76	63.3
No	44	36.7
<b>Families visiting Shrine</b>		
Yes	49	40.8
No	71	59.2

## METHODS

This was an observational study conducted at the Neurology Out-Patient Department of Peoples Medical University Hospital Nawabshah during the period 1.1.15 to June 30.6.15. A pro forma was designed incorporating questions relating to knowledge, beliefs and practices relating to epilepsy. After taking verbal consent the questions were asked in their native language (Sindhi). Each case was considered as representing the whole family since the views of the family are generally the same as that of patients. Thus the cases also mean the families. The answers were documented in the pro

forma for each patient separately. Demographic details like age, sex, place of residence, and level of education was recorded. Questions were asked pertaining to their perception out epilepsy. Questions included were whether they consider epilepsy a disease or not. If not then what do they think it was. They were giving some examples to pick the one they firmly believed in such as possession by evil spirits, black magic, curse, or God's will. The treatment options were given and they were asked which one they usually prefer including medical, homeopathic, herbal, faith healing. They were specifically asked whether or not they visit shrines (Darghas) and what purpose it serves. An attempt was made to distinguish between educated and uneducated families with respect to knowledge about epilepsy, following practices like faith healing and visiting shrines. Considering the therapeutic uncertainty and noncompliance, enquiry was made whether they will stick to the medical treatment or switch over to other forms of therapy in the event seizures recurred during the course of treatment. Clinical characteristics were summarized in terms of frequencies and percentages for qualitative variables i.e. gender, residence, age groups, education, beliefs about epilepsy etc. Statistical comparison and visit to shrines with educated/non educated families was performed by using Chi-square test. In all statistical analysis p-value <0.05 was considered significant.

## RESULTS

A total of 120 cases were included in this study. Sixty nine (57.7%) were male and 51 (42.5%) were female. Age ranged from 1 to 55 years. Eighty one (67.5%) were the residents of rural villages and 39 (32.5%) were residing in Nawabshah and adjoining towns. Of the 120 cases 80 (66.7%) families were educated and 40 (33.3%) were uneducated. Majority 76 (63.3%) believed that epilepsy is a disease whereas 44 (36.7%) considered epilepsy a "super natural force" ('alamaat': a native term) or possession by a 'fakir' (Jinaat). Of the 80 educated families 56 (70.0%) had knowledge about the disease and of the 40 uneducated families 20 (50%) had no knowledge about the disease. Better awareness about the disease among families having educational background was statistically significant (p<0.05). Of the 80 educated families 23 (28.8%) visited shrines and of the 40 uneducated families 26 (65.0%) visited shrines. Uneducated families visiting shrines was statistically significant (p<0.01). Families having younger individuals (11 -30 years) were more inclined towards visiting shrines. Out of 120 cases 44 (36.6%) were being treated by faith healers (dagho- phenu: a native term for this kind of practice) and 76 (63.3%) were receiving medical therapy. Of the 44 cases receiving faith healing 28 (63.6%) also visited shrines and of the 76 who were on

medical treatment only 21(27.6%) visited shrines. Followers of faith healing practices significantly visited shrines compared to those who were receiving medical therapy ( $p < 0.001$ ). Those who went for faith healing at first place and did not get benefit out of it tend to seek medical therapy on the advice of their friends/relative who already knew about the illness and also had prior good experience of getting satisfactory results from the medical treatment. All the cases who came for medical treatment pledged that they will follow the treatment regime as prescribed by the physician and that they will not switch over to "other" forms of therapy.

**Table 2:** Association of Gender, Age, Treatment v/s Visit to Shrine (n=120)

Variables	No. of subject	Visit to Shrine		P-value
		Yes	No	
<b>Gender</b>				
Male	69	26 (37.7%)	43 (62.3%)	0.423
Female	51	23 (45.1%)	28 (54.9%)	
<b>Age in Years</b>				
Up to 10	25	6 (24.0%)	19 (76.0%)	0.165
11 – 20	45	18 (40.0%)	27 (60.0%)	
21 – 30	36	17 (47.2%)	19 (52.8%)	
> 30	14	8 (57.1%)	6 (42.9%)	
<b>Treatment Choice</b>				
Medical	76	21 (27.6%)	55 (72.4%)	0.001*
Faith healer	44	28 (63.6%)	16 (36.4%)	

\* Faith healer's visit to shrine (63.6%) were significantly more compared to those receiving medical treatment (27.6%)  $p < 0.001$

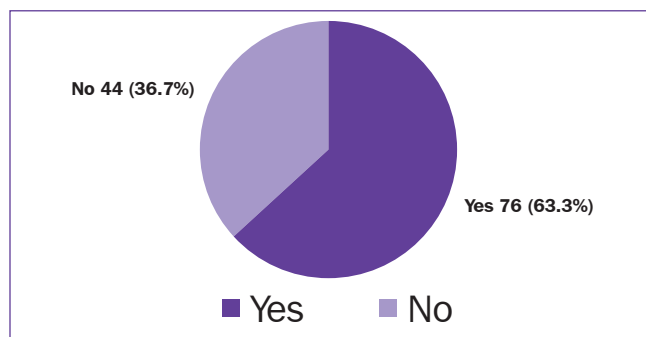
## DISCUSSION

Epilepsy is common in rural areas of Sindh. People living there have different life styles and living standards. They follow certain sets of cultural values and traditions which are passed on to newer generations. In addition, certain myths and beliefs are also carried over. Those include misperceptions about epilepsy. Some families that we studied were the settlers of small villages situated along the banks of river Indus popularly known as the 'kutch areas'. The hallmark of rural dwellers is their lack of education and unawareness about various diseases. In case of epilepsy, the outlook of a grand mal seizure is so frightening that the onlookers remain perplexed as to what is going on with their dear one. The thought more often comes to their mind is that of some kind of 'supernatural force' is in action. Not having a medical facility around they rush for help and the only help they get is that of a prayer leader (Imam of mosque) or a traditional faith healer who provide spiritual remedies and this practice is referred to as 'DaghoPhinu' in their native language. Such practices are being passed on from generation to

generation. A study that could provide some data highlighting such beliefs and practices particularly in the rural areas has been lacking. Our study focuses on these aspects and attempts to scrutinize them. This study provides evidence that 36.7% of the participants considered an epileptic seizure as a 'Alamaat' which is a native term used for 'supernatural' power or possession by evil spirits (fakir). Looking at the previous studies done in different settings, similar kinds of misperceptions about epilepsy were present in 3% of rural communities residing 80 kilometers from Karachi along the coasts of Arabian sea<sup>[4]</sup>, 60% among patients residing in Karachi<sup>[5]</sup> and 50% in those residing in Lahore<sup>[6]</sup>. It appears that misperceptions regarding epilepsy may vary from one region to another. Such variations are not unique to our region. In fact, these may vary in different geographical regions across the continent and the reason for this variability is likely multifactorial<sup>[7]</sup>. Given the figures, it is intriguing to note that their misunderstanding and unawareness about epilepsy are not only prevalent in the rural areas they are also reported among people living in the big urban cities like Karachi<sup>[5]</sup> and Lahore<sup>[6]</sup>. This negates a general impression that lack of knowledge regarding epilepsy are more common in the rural areas than the urban. Such rural/urban generalization of public views about epilepsy is surprising but at the same time understandable. There are a growing number of 'kutchi abadis' (slum areas) being developed around the big urban cities. We believe, the people living in these places having rural-derived roots are the 'carriers' of the ancestral beliefs towards epilepsy. The same people usually visit major public sector hospitals and narrate their views and experiences when specific questions are asked from them. The net result is the projection of misconceptions about epilepsy among rural and urban dwellers alike. There can be no doubt that lack of awareness is a driving force towards cultivating unscientific practices like faith healing and visits to shrines. In our study 70% of the families having educational background at a primary/secondary level were aware that epilepsy is a disease and require long term treatment. This is close to 86% of the school teachers who had knowledge about the illness and only 14% thought epilepsy is not a disease [8]. In contrast, 50% of uneducated families in our study did not consider epilepsy a disease. Uneducation and unawareness about the illness promotes faith healing and this is followed by visits to shrines. This is evident in our data. Mostly those who were uneducated went for faith healing and also visited shrines more often. Interestingly, the number of faith healing practices in our study is low (36.6%) compared to 80% reported by Syed et al<sup>[5]</sup>. The reason for this discrepancy is not clear. It is conceivable that some families who went for medical therapy may have also gone for faith healing but did not disclose it because

of stigma attached to it. The pattern of uneducation, unawareness, faith healing and visits to shrines culminates into unscientific practices and improper behaviors and attitudes. Our views are supported by Lim et al [7] in a review article where people living in rural areas and having low educational background tend to have more negative attitudes towards epilepsy. Practice of visiting shrine is a sort of religious ritual in rural Sindh where individuals as well as families seek help from Divine forces using the resting places of Saints (Dargah) as a facilitator for fulfillment of their prayers and wishes. A local study done in this context suggests that the visits to shrine provides a relief from psychosocial stress [9]. This probably explains why families with younger individuals with epilepsy visits shrines in greater number and without gender distinction. The epileptic issues particularly at young age are understandably more stressful. On a positive note, it is comforting to observe that people not having any educational background and not knowing the nature of the disease were willing to go for the medical treatment when proper information about epilepsy were communicated to them. However, in certain proportion of cases a sense of uncertainty remains. That happens when the seizures recur despite of being on the anticonvulsants. The recurrent seizures either due to noncompliance [8,9] or inadequate dose is mistakenly taken as a treatment 'failure' and it is assumed that since drugs are not working it cannot be a disease. That in turn reinforces their false beliefs. These kind of cases are the proponents and 'flag-bearers' for the continuing misperception about epilepsy. The authors believe that the overall picture regarding epilepsy in our region is unlikely to change as long as the 'carriers' and the 'flag-bearers' of misunderstandings pertaining to epilepsy continue to preach and persist in our society.

**Figure 1:** Whether Epilepsy a disease? (n=120)

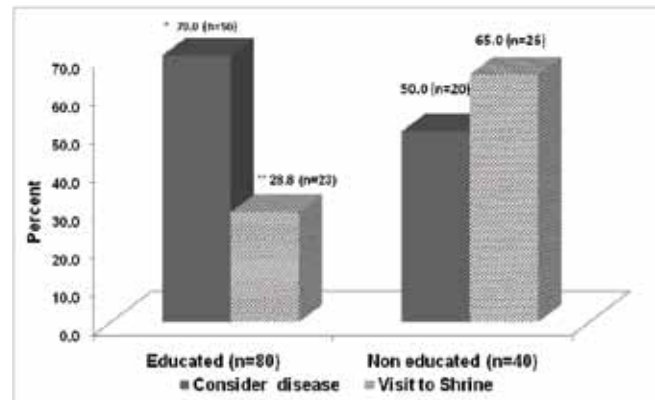


## CONCLUSIONS

Misperceptions about epilepsy are common in the rural areas of Sindh, Possession by a "supernatural force" (Alamaat) was most common belief among those who did

not consider epilepsy a disease. Knowledge about epilepsy was better among families having educational background. Uneducation and unawareness leads to unscientific practices like faith healing and visit to shrines. There is a willingness for receiving medical therapy once the proper guidelines are provided. True picture of epilepsy need to be highlighted in this segment of population.

**Figure 2:** Association of Education, Beliefs and visit to Shrine (n=120)



\* 56 (70.0%) educated families considering epilepsy a disease were significantly high compared to 20 (50%) uneducated families ( $p < 0.05$ ).

\* 23 (28.8%) educated families visiting shrines was significantly low compared to 26 (65.0%) uneducated families ( $p < 0.01$ ).

## RECOMMENDATION

A mass awareness campaign may be initiated with the help of mobile phone operators through short message services (SMS). This would help in dissemination of public knowledge about various neurological diseases including epilepsy across the country.

## ACKNOWLEDGEMENT

We thank Mr. Ejaz Alam of Pakistan Medical and Research Council (JPMC Cell) for the help in statistical analysis.

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**Conflict of Interest:** Author declares no conflict of interest.

**Funding Disclosure:** Nil

**Author's Contribution:**

**Dr. Shaheen A Mughal:** Study concept and design, protocol writing, data collection, data analysis, manuscript writing, manuscript review

**Dr. Musliam A Lakhair:** Data collection, data analysis, manuscript writing, manuscript review

**Dr. Muhammad Saleem Fiaz:** Data collection, data analysis, manuscript writing, manuscript review

**Dr. Abdul Qayyum Memon:** Data collection, data analysis, manuscript writing, manuscript review