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MISPERCEPTION ABOUT EPILEPSY AMONG COMMON PUBLIC IN BALOCHISTAN

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ABSTRACT

Background and Objective:

Epilepsy is a treatable chronic neurological illness that is frequently associated with supernatural activity. The objectives of this study were to determine common myths and misperception about epilepsy by analysing a comprehensive panel of variables in our local population.

Methods:

We conducted a face-to-face questionnaire interview survey in three different shopping malls. One thousand people were randomly enrolled in this cross-sectional study at Quetta, Baluchistan, during the period of 21 august 2021 to 30 august 2021.

Results:

A total of 1000 people were interviewed; among them 220(22%) were male and 780(78%) were female. Individuals between the age of 20 years and above were included in the study. Nine-hundred-eighty (98%) respondents had heard about epilepsy. Out of thousand people 419 (41.9%) thought that epilepsy was a brain disease, 488 (48.8%) responded that it was a ghost attack. Twenty-three (2.3%) believed it to be psychosis. The aspects of knowledge tested were on causes, types, and management of epilepsy. Forty-nine (4.9%) people believed that epilepsy was due to head trauma, 488 (48.8%) said it's ghost attack, 67 (6.7%) said it's because of evil eye, and 293 (29.3%) peoples believed that epilepsy was caused by black magic. Nine-hundred-twenty-eight (92.8%) people believed that home remedies such as sniffing shoes were effective in epilepsy.

Conclusion:

This study revealed a lack of awareness about epilepsy in Balochistan, as well as the prevalence of both negative and favourable attitudes about epilepsy. This result was much surprising because in this era of modern medicine and technology, still superstitious beliefs prevail among large population. The study also emphasized to increase public awareness and epilepsy education initiatives to change public opinions and promote the use of standard epileptic treatment.

Key words: Epilepsy, Attitudes, Knowledge

INTRODUCTION

Epilepsy is a non-communicable neurological condition, characterised by recurrent seizures. Bunch of nerve cells or neurons sometimes signal irregularly and cause a person to have seizure.^{1,2} People from all races and ages can developed epilepsy and many of them have no family history of seizures.³ Majority of epileptic

patients are diagnosed as idiopathic epilepsy while the rest of the cases can be caused by brain malformation, head trauma, brain carcinoma, haemorrhagic stroke, brain infections, complicated pregnancies and genetic and metabolic disease.⁴ Epileptic patients are three times more prone to die prematurely compared to the general population.⁵ Epileptic patients' lives are impacted

by discrimination, stigma, and human rights abuses.

Epilepsy is the most common central nervous system illness worldwide, affecting around 50 million people, along with approximation of 2.2 million persons in the United States.^{6,7} Yearly, around 50,000 children and adolescents under the age of eighteen are diagnosed with epilepsy. Nearly 4 billion people live in Asia and 23million of them have epilepsy,^{6,8} while the prevalence of epilepsy in Pakistan is approximately 9.99 in per 1000 population.⁹⁻¹¹ From distant history till today epilepsy remains a stigmatized disease. Despite advances in medical science, this is still true today, since the diagnosis of epilepsy can have a significant social and psychological impact on patients and their families due to a lack of other information.^{12,13} This lack of knowledge has been identified as a significant factor in the propagation of stigma.

Surveys in underdeveloped nations among several cultures show widespread views, such as that epilepsy is a communicable condition, or a kind of mental retardation, it happens due to black magic or evil spirit.^{14,15} The same sorts of misconceptions about epilepsy have been found in Pakistani studies.¹⁶ Pakistan is the fourth most populated Asian country with billions of people belonging to different caste and creed with different social and cultural background and socioeconomic classes. Here, epilepsy is still misunderstood by many in the public. People have different views, beliefs, perceptions, and knowledge about epilepsy. Poor knowledge about epilepsy is the major cause of disease remaining untreated. Epilepsy has been the cause of social shame and disability in societies of Pakistan, because of which people are stuck to false beliefs. The most common false beliefs imposed upon epileptic patients are mental illness and retardation, that affects the patient's personality. One of the major problems which are being discussed in this article is related to the knowledge, awareness, and beliefs of people regarding epilepsy.

The goal of this study was to investigate common public perceptions of epilepsy in the Quetta city, as well as that how these social ties alter the significance linked to epilepsy. To our knowledge, no research on this topic has ever been published from Baluchistan. The following research questions were explored.

- How do common people perceive epilepsy?
- To what extent is epilepsy accepted socially?
- To what extent do people know about epilepsy?

METHODS

Study Design:

Prospective cross-sectional survey.

Place and duration of study: Three of the biggest shopping malls located in Quetta from 21 August 2021 to 30 august 2021.

Sampling size:

One thousand individuals above the age of 20 years were included in the study.

Sampling technique:

Non probability, consecutive sampling.

Data collection:

It was a questionnaire based study; a standard questionnaire was established according to norms and culture of the province. The questionnaire was translated into Urdu language. The study was made clear to participants in the interview. The research objective was discussed in detail in order to make it more understandable. All the information collected from respondents during fieldwork was kept confidential and remained anonymous. The address and their real names were kept confidential. Any kind of harm to the privacy of the respondent was eliminated. Research participants were informed about the purposes of the study, the duration of interview, the risks and benefits of participation, and their rights to refuse participation or terminate interview session.

We developed standard questionnaire containing 17questions on attitudes and knowledge towards epilepsy misperception.We sought information on basic demographics, myths, beliefs about epilepsy, and ethical positions. The questionnaire was translated into Urdu at department of languages university of Baluchistan. The survey and data collecting technique were taught to the research assistants who assisted with data gathering. Health-related people, having a current or past history of seizure, and refusing to participate in the study were excluded from study.

Data analysis:

The results were analyzed by using SPSS version 20.

RESULT:

Demographic data of the participants:

A total of 1000 people were interviewed among them 220(22%) were male and 780(78%) were female. People of all age group were included in the study.

Table no1 contains these results.

Table 1: Age and Sex distribution (n=1000)

SEX	NO	PERCENT
Male	220	22%
Female	780	78%
AGE DISTRIBUTION		
SEX	NO	PERCENT
20-40	450	45%
40-60	396	39.6%
Older than 60	154	15.4%

People with different educational background, 242(24.2%) people had matriculation, 158 (15.8%) had graduation degree and only 78 (7.8%) people had masters while 522 (52.2%) were illiterate which indicates the higher rate of illiteracy in Balochistan. Table 2 contains these results.

Table 2: Educational Background of the participants (n=1000)

Education	Number	Percentage
Matriculation	242	24.2%
Graduation	158	15.8%
Masters	78	7.8%
Illiterate	522	52.2%

People belonged from different occupational classes. Table number three shows these results and monthly income data.

Table 3: Occupation and monthly income

Occupation	N %
Govt. Sector	117 (11.7%)
Business	88 (8.8%)
Farmer	8 (0.8%)
Housewife	613 (61.3%)
Student	56 (5.6%)
Unemployed	118 (11.8%)
Monthly Income	
Monthly Income	N (%)
Low Income	722 (72.2%)
Average	267 (26.7%)
High Income	11 (1.1%)

FAMILIARITY WITH EPILEPSY:

Out of thousand people, four hundred nineteen (41.9%) participants correctly thought that epilepsy was a brain disease, 488 (48.8%) believed epilepsy to be a jinn possession, 23(2.3%) marked it psychosis and 70 (7.0%) responded with other reason. Around 980 (98%) respondents had heard about epilepsy and 20 (2%) participants never heard about epilepsy.

Three-hundred forty-nine (34.9%) people knew a person with epilepsy and 433 (43.3%) had seen some one with epileptic seizures. Table 4 shows these results.

Table 4: Familiarity with Epilepsy

Variables	N (%)
What Is Epilepsy?	
Brain Disease	419 (41.9%)
Jinn Possession	488 (48.8%)
Psychosis	23 (2.3%)
Others	70 (7.0%)
Did you Ever Hear About Epilepsy?	
Yes	980 (98%)
No	20 (2%)
Do you know someone having Epilepsy?	
Yes	349 (34.9%)
No	651 (65.1%)
Did you see someone with Epileptic Seizures?	
Yes	433 (43.3%)
No	567 (56.7%)

Knowledge of Epilepsy:

A set of few questions in the questionnaire were formulated to test the knowledge of the common people about epilepsy. The aspects of knowledge tested were on causes, types, and management of epilepsy. Forty-nine (4.9%) people believed that epilepsy was due to head trauma, 6 (0.6%) believed it was due to depression, 53 people (5.3%) thought that epilepsy was a hereditary disorder, no one (0%) believed that it was due to high temperature, 41(4.1%) responders thought that epilepsy was caused by medicine, four hundred eighty eight people had false notion that epilepsy (48.8%) was caused by jinn possession, 67 (6.7%) considered that epilepsy was caused by an evil eye, only 3 (0.3%) individuals thought that it was due to sins punishment and 293 (29.3%) people believed that epilepsy was caused by black magic. Table no5 summarises these results.

Table 5: The Cause of Epilepsy

CAUSE OF EPILEPSY?	N (%)
Head trauma	49 (4.9%)
Depression	6 (0.6%)
Hereditary	53 (5.3%)
High Temperature	0 (0%)
Medicinal	41 (4.1%)
Jinn Possession	488 (48.8%)
Evil Eye	67 (6.7%)
Sins Punishment	3 (0.3%)
Black Magic	293 (29.3%)

Table no 6 summarises knowledge about epilepsy. Five hundred seventy-one (57.1%) participants believed that epilepsy was a treatable disease. Seventy-five (7.5%) participants thought epilepsy was a communicable disease, and 23 (2.3%) people considered it a Psychiatric disorder. Table no 6 contains these results.

Table 6: Knowledge of Epilepsy

VARIABLES	N %
Is Epilepsy a Treatable Disease?	
Yes	571 (57.1%)
No	429 (42.9%)
Is a Epilepsy Communicable Disease?	
Yes	75 (7.5%)
No	925 (92.5%)
Is Epilepsy a Psychotic Illness?	
Yes	23 (2.3%)
No	977 (97.7%)

Treatment of Epilepsy:

We came to know about various treatment methods adopted by different people. Majority of individuals 928 (92.8%) believed on home remedies such as sniffing shoes were effective in epilepsy. Around 69 (6.9%) participants believed that recitation of the holy Quran is the treatment of epilepsy, 480 (48.8%) individuals believed in medicine, 53 (5.3%) participants picked herbal Medicine as a treatment of epilepsy, while 13(1.3%) believed in prayers and 15 (1.5%) people in other things. Table no 7 contains these results.

Table 7: The Treatment of Epilepsy.

VARIABLES	N (%)
Is shoe sniffing an effective act in epilepsy?	
Yes	928 (92.8%)
No	72 (7.2%)
What is the treatment of epilepsy?	
Recitation of Quran	69 (6.9%)
Medicine	480 (48%)
Herbal medicine	53 (5.3%)
Prayers	13 (1.3%)
Other	15 (1.5%)

Attitudes towards epilepsy:

Table 8 summarise various attitudes towards epilepsy. A set of few questions in the questionnaire which was to be answered in simple yes or no was formulated to check the attitude of the common people about epilepsy. Around Two hundred twenty (22%) people said yes that they would consider marrying an epileptic patient while 780 (78%) individuals were reluctant for possibility of marriage to an epileptic. Only 30% peoples said yes that they would hire domestic help with known epilepsy. Twenty-one (2.1%) participants thought that epileptic patient should be separated from other members of the family while majority of the individuals 979 (97.9%) did not feel so. Nine-hundred-ninety-two (92.2%) people believed that epileptic children should be allowed to take admission in school, remaining 8 (0.8%) did not feel so.

Table 8: Attitude of people towards Epilepsy.

Variables	No, N (%)	Yes, N (%)
Will you consider marrying an epileptic patient?	220(22%)	780(78%)
Will you hire domestic help with known epilepsy?	300(30%)	700(70%)
Should patients with epilepsy be separated from the rest of the house members?	21(2.1%)	979(97.9%)
Should a patient with epilepsy attend school?	992(99.2%)	8(0.8%)

DISCUSSION:

The current study revealed that majority of the participants had misperception and poor knowledge

about epilepsy, which is similar to the trends reported in other studies conducted before. With the advancement in medical sciences epilepsy is no longer a life-threatening disorder, yet it is still considered untreatable condition by most of our population. Unfortunately, being a developing country people of Pakistan still chose spiritual, sacrificial and religious rituals presided over by priests to treat epilepsy.^{17,18} People are deprived of medical care and drown in a swamp of superstition due to a lack of knowledge and awareness. Superstitions are especially common among epileptic patients in rural regions, where people seek spiritual healers and sainting known as Peer in Pakistani societies to solve their problems.

In this study, 1000 people who visited the shopping malls were asked about their knowledge, attitudes, and experiences with epilepsy. We found the nearly same results with Shahen Ahmed et al.¹⁹ The sporadic knowledge and incidence of misconceptions and misbeliefs were more in line with findings of study conducted previously in Lahore.²⁰ To our knowledge no study has been published on misperception of epilepsy in Balochistan province Although there is a significant literature on misconceptions, negative attitudes, and stigma surrounding epilepsy from Pakistan, there is a relative deficiency of recent data from Pakistan, as well as a very limited literature on stigma-reduction strategies in our population. The majority of the participants in this survey were un-aware; 48.8% participants said its ghost attack, only few correctly identified the origin of the disorder. These findings confirm earlier data on epilepsy derived from community surveys in Asian nations such as India.^{21,22} Less than half of the population (43.3%) in this research said they had observed a seizure in front of them at least once in their lives. This is close comparable to study in Saudi Arabia where 42.7% had seen or witnessed someone having a seizure.²³ Historically Epilepsy has been thought to be a condition

caused by evil spirits or supernatural forces in many cultures and for many centuries.^{24,25} Majority of the participants in this study believed that epilepsy was caused by ghost attack (48.8%) and black magic (29.3%); these are nearly close to the figures reported by Iranian and Bulgarian study.^{14,26} Many of the respondents believed that epileptic seizure could be relieved by sniffing shoes. In addition, some positive attitudes were encouraging; almost all (99.2%) participants believed that epileptic child could take admission in school. The majority of survey participants agreed that their knowledge about epilepsy is inadequate, and they all expressed a wish to learn more. These positive feelings may signal that if more effort is placed into sharing correct epilepsy knowledge in Balochistan, unfavourable attitudes can be changed over time.

There are two major limitations in this study that could be addressed in future research. First, insufficient sample size, the larger the sample size, the more precise results will be. Second limitation is lack of previous studies on topic.

It is recommended to use native advertising through direct media, electronic media, social media to raise general awareness about epilepsy. Awareness sessions and events should be conducted in schools, colleges, and community centres.

CONCLUSION

Epilepsy is still a poorly known disease in underdeveloped nations, and false local attitudes and cultural beliefs may play a role in people with epilepsy not receiving quick and proper treatment. This study revealed a lack of awareness about epilepsy in Baluchistan, as well as the prevalence of both negative and favourable attitudes about Epilepsy. The study also emphasized to increase public awareness and epilepsy education initiatives to change public opinions and promote the use of standard epileptic treatment.

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Muhammad Essa; data collection, data analysis, manuscript writing, manuscript review
 Gulandam; data collection, data analysis, manuscript writing, manuscript review

Saleem Barech; concept, data analysis, manuscript review

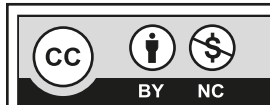
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Suhail Mari; concept, data analysis, manuscript review

Muhammad Dawood; concept, data collection, manuscript writing

Tahir Shah; concept, data collection, manuscript writing



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