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### Abstract

*Though the standard of living is getting better worldwide but diseases and epidemics still prevail. This is not the problem of the third world, people in developed countries face such challenges. It is with the change occurring in climate and demography of the world that the healthcare providers are faced with a new challenge. Health professionals cannot generalize their practices over different communities especially in a multiethnic, multi lingual and multi-cultural country like Pakistan. The researcher used descriptive methodology. Data were gathered using survey method. This paper discusses the need for ethnographic study of diseases and sicknesses as they are often perceived differently by different communities. The study was conducted in Rawalpindi and epilepsy perspectives from both the general public and the epileptic patients were recorded. The study aims to collect views of the patients and provide them to the health care providers and professionals.*

**Key Words:** Epilepsy, Epileptic Patients, Medical Anthropology, Parallel Medical Systems, Perceptions of Diseases and Disorders.

### Introduction

Disease and illness are a global phenomenon, but their perceptions and remedies vary culturally across the continents. How people are infected and in turn how they affect their surrounding and how their surrounding affects them comes under the investigation of medical anthropology. The social constructions of diseases and their cures also come in the sphere of investigation. The medical dimension of human experiences faces different conditions, these being, diseased, illness and sickness. These terminologies are often used interchangeably but considering cultural variations, disease is an attack of a pathogen on the body while illness and sickness may be the imbalance in spiritual or psychological state of the patient. These cultural perceptions of disease or illness are important to understand for any medical practitioners and the society.

[Andermann \(2000\)](#) discusses in her paper how important ethnographic perspectives can be when dealing with issues that are present across cultures. People from different cultural backgrounds often have different experiences of diseases and illnesses. These experiences need to be explored through anthropological tools; as these tools provide an understanding of diseases by the patient. Patient's understanding can be immensely benefitting the medical practitioner and the patient's treatment.

The subject case for this study was Epilepsy. [Cunha \(2016\)](#) explained that 'epilepsy is a neurological disorder which happens due to the unusual electrical movements in the brain'. Epileptic seizures are episodes that can range from short and almost undetectable to long periods of vigorous shaking. [Mehta, et al., \(2014\)](#) described that 'epilepsy is basically a neurological disorder but with that, it takes up with him these three consequences. These are; physical, psychological and social consequences.

A revelation of epilepsy is usually terrified for people. Epilepsy comes with 'psychological stigma, societal stigma, mental illness and fear of repeated seizures that likely to last for a decade' [[Krishnamoorthy, et al., 2017](#)]. But stigma still prevails in underdeveloped countries, particularly in Pakistan, due to a lack of information. The researcher observed that people were afraid to share this illness. People who felt the threat from the community; those people were sieged in stigma. Stigma and omission are the basic features of epilepsy. Stigma and omission are 'interlinked to each other. This also puts a huge burden on the development of society. Stigma socially excludes the person from society. So automatically it meant that it stopped the person's growth towards the quality of life' [[Boer, 2010](#)].

Epileptic and general people both took it as an activity of unusual facts. Some of them concluded that 'epilepsy is a result of possession by a spirit or the wrongdoings of ancestors' (Tin, 2015). This elevates the stigma in patients which becomes a reason for their boycott from the society. Chomba, et al., (2006) mentioned that 'most of the epileptic persons feared that they might be rejected by their families'. Because of this fear, they become introverts. A society and culture put a strong effect on a human's mental health. While a good environment can grow him, a bad behavior or response could break him too.

People with epileptic disorder need more attention and support from their family and friends to come back to life. Such patients need moral support from their bystanders to be rescued and continue their daily routine life as other normal people. Anne Fadiman mentioned epilepsy in one of her books. She even described the belief system of the Hmong family and the conflicts they had between biomedicine and non-biomedicine. Daughter of Hmong family 'diagnosed with the symptoms of epilepsy. In their culture, it is considered as spirit possession. The family carried out practices for the well-being of their daughter' (Mitchell, 2016).

Noble cited Goffman's theory about stigma and said, "Goffman mentioned stigma as a loss of position that can be developed from undesirable characteristics" (Noble, et al., 2016). Similar is the case of epilepsy. Society sees the sufferers of epilepsy as people of lower standard because the victims cannot perform well or as good as others in everyday life. Just like Noble and his colleagues describe that "patients are not considered human in the eyes of the society" (ibid). As a result, patients lose their position and importance in society.

People call epileptic people with different names such as mentally disturbed, mad, psychotic, lunatic, etc. Community people consider epileptic patients as mentally retarded persons. Local community people of African Cameroon still believe that people are under the shadow of the devil. In Liberia, people still think that someone does witchcraft on them' (Boer, 2010). Noble and his colleagues also explain that 'epilepsy affects a sufferer's mind severely and they even lose their social recognition overtime. Theory of mind describes the model and explains different questions as to why people face a lack of social recognition once they become sufferers of epilepsy' (ibid).

The patients' families need to make sure that the patients are safe from humiliation, cruel words, and harm to society. Every patient passes through the following five phases: 'denial, anger, bargaining, depression, and acceptance. These five stages are mentioned in the grief model, which talks about people's views about this disease and how they cope up and understand the problem. It also gives a clear idea about people's behavior regarding health' (Gregory, 2018).

The patients and their respective families get into the stage of denial and anger about their epileptic patients and do not easily accept the crude reality. The families still saw epilepsy as a supernatural disease that was not in their control. Patients also hated epilepsy because they were convinced that from now onwards, they would not be able to spend their life like a normal person. They would not do their carry out life activities and cannot give focus on other work. People with epilepsy may suffer from mental issues like sadness, anxiety and psychosis. The patients also feel fear and shame because of epilepsy. Consequently, living with a person with epilepsy is a challenging task especially at home. Patients of epilepsy are not in an ideal position to perform any social activity due to the shame that hangs from their neck.

They face difficulty doing normal things like house chores and jobs. The patients have their own reasons for not doing normal routine work. The epileptic patients have a lack of energy since they expend a lot of strength in thinking negatively about the social response. They feel self-stigma and also social stigma in their place of work. The core questions guiding the research were how these disorders affected the lives of those who were suffering? How the knowledge about such disorders affect health practices? How is life experience by the patients? And the positive and negative believes of patients and general public.

## **Literature Review**

Every disease has some misconceptions linked to it and so is the case with epilepsy. Thomas & Nair (2011) identified Goffman's theory on stigma as something which 'excludes the person from society. If a person has developed certain characteristics that make them look different compared to the rest, he is considered a source of disgrace and shame in society and is considered abnormal. Due to such harsh behavior, the sufferer also feels ashamed of being who he is'. Goffman also pointed out that 'stigma projects a dark shadow on those who are associated with stigmatized subgroups, including family members and mates. One of the first straightforward statement of a stigma theory emerged from the sociologist Erving Goffman' (ibid).

This humiliating behavior also leads to anxiety, depression, and violence, criminal and sexual activities. Psychiatric problems in epileptic patients include 'personality defects, rage and violent reactions, depression, suicidal reactions, and psychotic disorders' (Svoboda, 2004). Singer (2009) mentioned about an anthropologist, Evans Pritchard, who worked and studied the beliefs of Azande. After the study, he explained that 'every community or society have their own set of beliefs and so do Azande. Azande's community believes that whatever is happening with them is because of witchcraft and magic. Researchers work to put forward mutual beliefs of every community to promote like mentality and to reduce differences its beliefs and practices'.

The term epilepsy came from the ancient times. Magiorkinis, et al., (2011) describe that "one of the first descriptions of epileptic seizures can be traced back to 2,000 B.C. in ancient Akkadian texts, a language widely used in the region of Mesopotamia". A Concise Dictionary of Akkadian also mentions epilepsy as "antasubbu as fallen sickness, epilepsy" (Black, et al., 2000). Local people link this disease with supernormal activities and oracles. Kahissay, et al., (2017) state that people believe that 'illness either is a punishment from God or related to spiritual activity'.

Adanir & Cihan (2018) illustrates 'like other diseases in ancient times, epilepsy was considered a supernatural disease and perceived as a punishment of God'. Lynch & Medin (2006) used 'Murdock's health theoretical model to explain the causes of illness in a psychological and physical context'. Through this model, 'specialists understand the causes of illness and people's perceptions about the disease. In the United States, people think that one gets ill if s/he cuts off from society' (ibid). According to Murdock, supernatural causes include "theories of mystical causation (i.e., fate, ominous sensation, contagion, and mystical retribution); theories of animistic causation (i.e., soul loss, and spirit aggression); and theories of magical causation (i.e., sorcery and witchcraft)".

People gave the name of illness according to their surroundings and the knowledge. Lack of knowledge restricts their ideas about the illness. Epileptic patients and their families also take advice from the close family members, relatives or friends. This enhances the idea of popular culture which revolves around the thoughts and beliefs of community about certain things. Noble, et al., (2016) once said that 'every individual can understand the behavior, thoughts, and beliefs of other human beings. This ability makes it possible for everyone to connect and live with other human beings. This is referred to as cognitive functioning, which is also called the Theory of mind (TOM)'.

However, 'cognitive functioning is not found in epileptic patients as they face difficulty in communicating with people, maintaining relationships, finding jobs and even seeking admission for education. It can also be deduced from different studies that adults with frontal lobe epilepsy and children with generalized epilepsy do not have a very good social life due to lack of recognition' (ibid). Patients resign from their jobs after epilepsy. Jennum, et al., (2011) state 'epilepsy is associated with substantially higher health and social transmission costs, and lower jobs and income rates. Because of epilepsy, patients lose their jobs and education along with their status in the society.

Sinha & Bhaumik (2014) describe 'the children with epilepsy frequently lag in education because they find it difficult to get work. Employers wouldn't want to employ an epileptic'. Major, et al., (2013) state 'the system justification model of Jost says that people depend on their surroundings and justify their behavior with invalid and improper reasoning. Such justifications eventually become labels e.g. government gives different excuses for not providing adequate healthcare services. Grete & Bell (2016) state 'another aspect of material deprivation is poverty. People living below the poverty line do not have enough resources to fulfill their necessities such as food, water, shelter, and clothing'.

In such a situation, 'it becomes next to impossible for people to pay for their hospital and medical bills. Due to a lack of resources, people often go in depression, stress and get additional health problems' (ibid). Cherry (2018) states 'behavior explains the person's act or attitude toward some task. These are may be negative or positive. Basically, any individual learns anything from their surroundings. According to behaviorists, our surroundings made our behaviors. It's all started with the article by John Watson. In the article John cited that person learn anything from their surroundings in which he lives. He also said that if some babies gave him, he molds their behavior according to any type'.

## Methodology

Researcher used descriptive methodology to collect data. Descriptive methodology is the type of research methodology. Descriptive methodology is 'consisted of current observations. It provides a solution to current

problems' ([Wallace & Van Fleet, 2012](#)). Any researcher used this methodology when he/she wanted to address questions of how, what and when. The purpose of descriptive methodology is to explain current situations in a more depth manner along with highlights the important issues. According to [Singh \(2010\)](#) illustrated 'descriptive research is concerned about present and endeavors to establish the type of phenomenon under inquiry'. Descriptive methodology is a general process for accomplishing research in many disciplines like anthropology, psychology and social sciences.

Before going into the field, every researcher's brain is like an empty slate. Researchers have to go through the literature of review to know about his/her research topic. From review of literature, researchers get introduced to the different authors' work. It also indicates about problems to be addressed. [Ridley \(2008\)](#) described that 'researcher likewise can pick literature to help find out errors for research and to delineate that there is a hole in past research which should be filled out'. Review of literature helps the researchers to develop a better understanding about research topic. According to [Mligo \(2013\)](#) 'with a review of the literature, we can contrast our and other's work so our information becomes analytically solid and we can make a detailed study in field territory'.

In descriptive research, it is necessary that the researcher must have an idea about the errors of address. Every research has consisted of some specific phenomenon that needs to be addressed. When a researcher has to study about research problem, he/she have to take a help from methodology. According to [Jefferson \(2004\)](#) defined that 'descriptive research entails data collection process which helps to accept or reject hypothesis relating to present situations. A descriptive study is held when a researcher wants to develop an enhanced insight towards his/her topic. The descriptive study does not only describes the current situation but also interprets what is going on. Descriptive study has no concern with question of why but it illustrates how things are happening in the field.

The locale of the study was Rawalpindi. Rawalpindi is situated in the north west corner of Punjab. It's 'North latitude is 33 to 34, and it's East longitude is 72 to 74. Hazara district is in North of Rawalpindi. In its East it has Poonch while Jehlum is in South and Attock is in West' ([Zafar, et al., 2007](#)). In today's era, Rawalpindi is considered a part of Islamabad. Moreover, Islamabad is the capital of Pakistan. Before that, 'the sewere considered two different cities but later, Islamabad was merged with Rawalpindi and was considered on large city' ([Doxiadis, 1965](#)).

Data was collected by a total of 40 individuals. 20 of them were patients of epilepsy and 20 were general public. That sample was divided into male and females. 10 of the patients were male and 10 were female. The researcher had no restriction on the level of education and which background they were coming from in order to generate diverse views and results. Semi structured interviews were conducted with both the patients and general public. An interview guide was constructed and administered to both the patients and public. The views that were generated are discussed in the next section.

## **Discussion**

To understand the perceptions about epilepsy, data was collected from both the patients and public. Data collected from patients generated the following results, their views on epilepsy varied dramatically. This could be because of them coming from different socio-economic classes and different backgrounds. Their views however did start to converge once their treatment started in the hospital.

## **Paranormal Activity**

Most of them prior to their medication held the view that epilepsy was caused due to some sort of paranormal activity. From the patients only one individual had prior knowledge of epilepsy. To the individual, epilepsy was an inherent disease. This was caused due to head injuries, accident, beating and views like paranormal activity also existed. There existed a view among the patients that paranormal beings like *jinn* were the cause of epilepsy. When human body was possessed by such spirit or being, the body experienced violent shocks and uncontrolled muscle movement. This was seen by most of the people as inhuman experiences and hence referred to as paranormal or spiritual possession. Pertaining to the supernatural world views there also is a view of epilepsy being passed on from patient to someone else even if they are not related. The researcher interviewed a patient and found out that his neighbor, who was not epileptic now, experienced epileptic attacks because 'he used to make fun of the patient's epilepsy'. View of epilepsy as spirit possession comes from the belief in spiritual beings which is strengthened by the religious belief of the people that "spirits are stated in the Quran".

### **General Public's View**

Among the general public were 11 females and 9 males. Females had the view that an epileptic patient was not to go near fire. This was because of the shocks that the patients experienced in a state of epileptic attack. This was agreed among the general public that this is a mental illness. To the public, the causes of epilepsy are social and psychological pressure, mental weakness, having a fall during earthquake. It was also found that among the public it was a widely held believe that epilepsy could be triggered by eating certain food like, green chilies.

### **An Insight**

Epileptic patients suffer a troublesome life. They have a difficult time finding jobs as employees are shy or straight up refuse to employ individuals with such disabilities. An epileptic patient suffers loneliness as people who hold the view of not meeting with epilepsy patients ignore interaction with them. Because of the range of views about epilepsy their social life is haphazard. People around them perform their functions in effect of epilepsy. Hence their functions are not normal and this "shared disease" makes it difficult for people with epilepsy to get around. From food they eat to where they can and cannot go, everything is affected in the patient's life and those of his contemporaries. This is also a problem for children who suffer from epilepsy. Often people don't allow their children to play with epileptic children. This creates a hollow sphere in their life of lack of companionship.

### **Cure**

Patients tried both modern day medical system and parallel [local] medical systems to cure their epilepsy. Epilepsy to the public can be caused by various factors as stated above. To the people it has varying remedies, to some it is cured by modern medicines and to some it requires both modern and traditional medical treatment. For such people epilepsy is has a paranormal root and is effective on the physical being of humans. For its cure one needs to address both spiritual and physical needs of the epileptic patients.

### **Conclusion**

To conclude we can say that epilepsy is a worldwide disorder. People of all ages and gender suffer from epilepsy and people of different ethnic backgrounds understand diseases differently. Believes of them are affected highly by their cultural institutions like religion and by their social groups like friends and peers.

In Pakistan, most people have the view that epilepsy is caused due to spirit possession. Some believe that this is a mental illness and requires modern medical treatment. Along with spirit possession people also hold the view that epilepsy is caused because of eating green chilies or maintaining contact with someone who already has epilepsy.

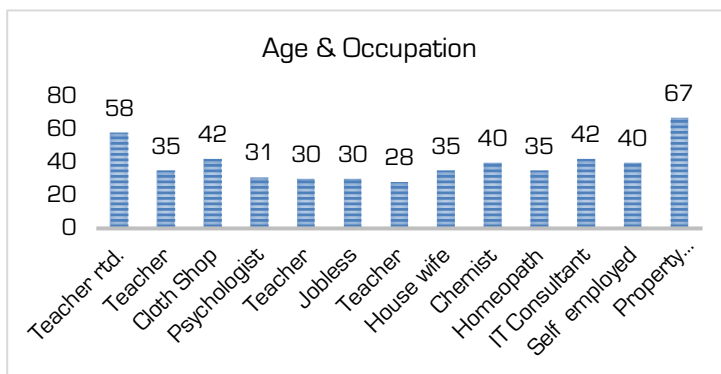
This brings us to the point of social seclusion. The patient very so often suffers social seclusion and is ignored by his or her contemporaries. Lack of support due to avoidance by friends or family members is faced by the patient. Epileptic patients also have difficulty finding jobs and running their life circle.

All in all, the life of an epileptic patient is a troubled one. Their epilepsy is viewed defiantly by different people and it is important for health care professionals to keep in mind these perspectives while curing their disorder. This is necessary as the practitioner is not only curing the patient rather the social construction of the disease.

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**APPENDIX**

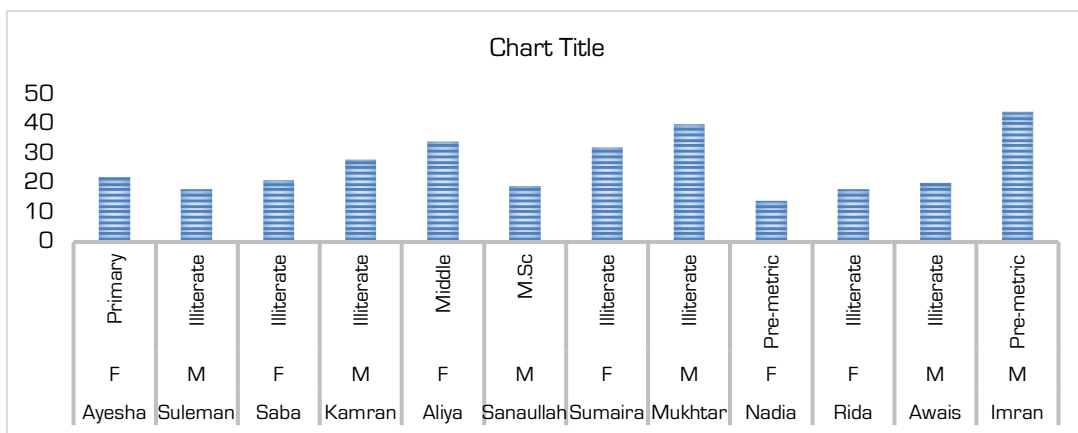


**Graph 1:** The Chart above Represents the Age and Occupation of Respondent among the General Public from whom data was Collected.

**Table 1**

S. No	Name	Gender	Education	Occupation	Age
1	Asiya	F	M.A	Teacher rtd.	58
2	Noreen	F	B. A	Teacher	35
3	M. Munir	M	B. A	Cloth Shop	42
4	Amna	F	M.A	Psychologist	31
5	Anum	F	B.Sc	Teacher	30
6	Fauzia	F	F. A		30
7	Zulqrnain	M	B.Sc	Teacher	28
8	Isma	F	M.BA	House wife	35
9	Abdul Hafiz	M	B. A	Chemist	40
10	Mazhar	M	B. A	Homeopath	35
11	Naveed	M	B. S	IT Consultant	42
12	Banaras	M	Metric	Self employed	40
13	Abdul Sattar	M	F. A	Property Dealer	67

Table above represents bio-statistics of respondents from whom data regarding epilepsy was collected.



**Graph 2:** The Chart above Represents Age and Education of the Patients from whom data was Collected.

**Table 2**

<b>S. No</b>	<b>Names</b>	<b>Gender</b>	<b>Education</b>	<b>Occupation</b>	<b>Age</b>
1	Ayesha	F	Primary	Jobless	22
2	Suleman	M	Illiterate	Jobless	18
3	Saba	F	Illiterate	Jobless	21
4	Kamran	M	Illiterate	Servant	28
5	Aliya	F	Middle	Teacher	34
6	Sanallah	M	M.Sc	Mechanic	19
7	Sumaira	F	Illiterate	Jobless	32
8	Mukhtar	M	Illiterate	Jobless	40
9	Nadia	F	Pre-metric	Jobless	14
10	Rida	F	Illiterate	Jobless	18
11	Awais	M	Illiterate	Jobless	20
12	Imran	M	Pre-metric	Optical technician	44

Table above represents bio-statistics of epileptic patients from whom data was collected. Irregularity in age and joblessness is clearly visible.