

Research Article

Nature and extent of perceived stigma among epileptics in Pakistan

Rehana Khalil^{1*}, Saadia Gul², Zahid Naeem¹

¹Department of Family and Community Medicine, Unaizah College of Medicine, Qassim University, Saudi Arabia

²Department of Community Medicine, Baqai Medical University, Karachi, Pakistan

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***Correspondence:**

Dr. Rehana Khalil,

E-mail: rehana.noman@ucm.edu.sa

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ABSTRACT

Background: Epilepsy is one of the oldest disorders known to mankind. Often the social stigma (whether a “felt” stigma or an “enacted” stigma) attached to epilepsy is a greater handicap to the person with epilepsy compared to the disability associated with seizures or the side-effects from medications. The aim of this study was to explore the perceived stigma and discrimination among epileptics of Karachi, Pakistan.

Methods: A descriptive cross sectional study was conducted in Karachi, Pakistan in the year 2016. A standardized pretested semi-structured questionnaire was completed by 120 epilepsy patients selected through purposive sampling from Department of Neurology, Jinnah Postgraduate Medical Centre. Informed verbal consent was obtained prior to the interview. The data were analysed using IBM SPSS Statistics version 22 and Microsoft excel.

Results: The average age of the sample participants was 18-50 years. Almost two third (68%) of the respondents were male. More than half (55%) of the sample was educated up to matriculation. Among them 28.5% were married. Three fifth (60%) of participants were unemployed. More than half (60%) of the respondents reported discrimination in educational opportunities and three fourth (78.5%) in job opportunities. Results indicated that (75%) participants encountered social problem like being discriminated (30%), or segregated (11%) in performance of daily tasks and were avoided (58.8%) to get marry more often with the belief that people with epilepsy are infectious.

Conclusions: The study concludes that there is significant perceived stigma among epileptics living in a big metropolitan city of a developing country. The nature of stigma includes discrimination in education, marriage and job opportunities. There is a need for public awareness programmes to address this ignored facet of epilepsy, since it has both medical as well as social implications.

Keywords: Perceived stigma, Epileptics, Epilepsy

INTRODUCTION

Epilepsy is a stigmatising disorder, and epilepsy per se can and does have a significant impact on the day-to-day functioning of those with the condition. It is as common as 1% in the general Pakistani population, with the majority of epileptics being under 19 years of age. The age specific prevalence rates are 14.8 per 1000 in rural and 7.4 per 1000 in urban areas.¹

According to Scambler and Hopkins, “stigma” may be of two kinds; a “felt” stigma (felt from within by the person), and an “enacted” stigma (from the outside, done

by society).² The person with epilepsy appears to have a “world view” about epilepsy, often leading to the expectation of stigmatization. It may be the expectation, then, rather than the experienced stigmatization, that makes epilepsy such a burden to some patients. It is hard to quantify the role of society in the stigmatization of persons with epilepsy.²

There is growing awareness of the psychosocial implications of epilepsy and of the behavioral patterns of the patients who seek treatment. The high prevalence of negative attitudes towards epilepsy has been highlighted by several recent studies, carried out in diverse

communities including Ethiopia, Hong Kong and the United States.³⁻⁵ Most of the evidence for the psychosocial problems associated with epilepsy has been drawn from studies in developed countries; in comparison, relatively little is known about the situation of people with epilepsy in developing countries.⁶⁻¹⁴ In a Britain-based study, epileptic adolescents were shown to have higher levels of depression and social anxiety and higher numbers of obsessive symptoms than adolescents without epilepsy.¹⁵

Even though very few relatively small studies conducted in developing countries including Africa, South America, India, and Pakistan but it is reasonable to assume that uncontrolled seizures and stigma may result in similar psychological repercussions as those for people with epilepsy in developed countries and has a disruptive impact on daily lives of those with the condition.¹⁶⁻¹⁸ A study carried out in Pakistan reveals that epileptics have considerable problems in getting educated, performing daily tasks and getting married.¹⁸

It has been shown that often, the social stigma attached to epilepsy is a greater handicap to persons with epilepsy compared with the disability associated with seizures or the side-effects from medications. Viewing from the general public perspective, various studies have assessed the knowledge and attitude of communities regarding epilepsy.

It is conceivable that negative attitudes displayed by the public towards epilepsy may stem from deficient or incorrect information about epilepsy. In another study, conducted on patients visiting a family medicine centre in Pakistan, assessing the prevalence of myths and fallacies relating to various health related issues reported 13% believed evil spirits could cause epilepsy, while 73% thought that epilepsy could be caused by psychological stress.¹⁹

People with the condition report a significant impact of epilepsy and its management in terms of family dysfunction, reduced social and leisure opportunities, and increased levels of anxiety and depression and poor self-esteem compared with people without the condition.²⁰

A central feature of the condition is its stigmatising nature.²¹ To date, however, there is scarcity of published Pakistani data assessing the social stigma and discrimination attached to epilepsy at a community level.

It is difficult to define the psychological and social problems faced by persons with epilepsy and difficult to measure the stigma they perceive but the present study is an attempt to assess the perceived social discrimination towards epileptics of Karachi, the metropolitan city of Pakistan. Assessment of the psychological burden would help identify the foci for increasing awareness and removing misinformation about epilepsy in a more targeted and effective manner.

METHODS

This quantitative cross-sectional study was carried out on the 120 diagnosed epilepsy patients at Department of Neurology, Jinnah Postgraduate Medical Centre, Karachi.

A semi-structured questionnaire was developed following an extensive literature review on the topic which ensured validity and reliability of the questionnaire. The participants were recruited using a purposive sampling technique. All male and female patients aged 18 years to 50 years, who visited Department of Neurology, Jinnah Postgraduate Medical Centre during six months from August 2015 to Feb 2016, and who resided in Karachi, Pakistan were included in the study. Those patients who were disabled or unwilling to participate were excluded from the study.

A pretest of the questionnaire was conducted with ten patients who met the inclusion criteria. The purpose of the pilot was to test the clarity and relevance of the questionnaire and to familiarize the data collectors with the instrument. The findings from the pilot study did not show potential problems.

Ethical considerations

Informed verbal consent was obtained prior to the interview. Participation was voluntary and no coercion was used in the data collection process. They were free to withdraw from the interview at any time or refuse to answer any particular question. Participants were also ensured of confidentiality. No personal identifying information was obtained for any part of the investigation.

Data analysis

After completion of data collection, each questionnaire was checked for completeness and consistency by the principal investigator before entering the data. The data were entered and analysed using Microsoft Excel and IBM SPSS VERSION for Windows 22.0 software.

RESULTS

Response rate

The sample comprises of 120 diagnosed epilepsy patients. After reassurance (due to sensitivity of the selected topic) the response rate was 100%. Questionnaires were completed by all 120 epilepsy patients.

General characteristics

The average age of the participants in the sample was 18-50 years (Table 1). Most of the respondents (68%) were male. All participants were Muslims by religion. Majority of the participant had education up to matriculation

(55%). Sixty-nine percent were single, 28.5% were married while 2.4% were divorced. Sixty percent of participants were unemployed and 40% were employed. The average monthly income of the sample

was Rs 5500. Duration of their condition varied among then, like 67% had 5 to 10 years, 23% had 11 to 20 years while 10% had more than 20 years duration of suffering. (Table 2).

Table 1: Demographic characteristics of the participants (n=120).

Variable	Category	Percentage
Gender	Male	68
	Female	32
Age (years)	18-23	20.3
	24-29	24
	30-35	31.2
	36-41	15.2
	41 and above	9.5
Education level	Uneducated	14.5
	Up to Secondary	55
	Intermediate	16.2
	Graduation	14.1
Marital Status	Married	28.5
	Unmarried	69.1
	Divorced	2.4
Employment Status	Employed	60
	Unemployed	40
Religion	Muslim	100
	Non-muslim	00

Table 2: Duration of condition (n=120).

Duration in Years	Frequency	Percentage
5-10	80	66.7
11-20	27	22.5
More than 20	13	10.8

Table 3: Types of discrimination faced by epileptics (n=120).

Variable	Category	Frequency	Percentage
Discrimination in educational Opportunities	Yes	72	60
	No	48	40
Social problems	Faced Social Problems	90	75
	Avoided to get married	53	58.8
	Discriminated	27	30
	Segregated	10	11
Discrimination in job opportunities	Yes	91	75.8
	No	29	24.2

Social stigma

The study findings were focused on the problem of stigmatization, which were also showed in a number of studies. Reported by 72 (60%) respondents that they faced discrimination in educational opportunities, and 91 (78.5%) faced discrimination in job opportunities (Table 3). Results indicated that 90 (75%) participants

encountered social problem like being discriminated (30%) and segregated (11%) in performance of daily tasks. More than half (58.8%) respondents were avoided more often with the belief that people with epilepsy should not marry as their epilepsy is an infectious disease. Thus their chance of marriage and of having children was prejudiced due to this misconception (Table 3).

DISCUSSION

Epilepsy is a disorder associated with significant psychological and social consequences for everyday living.²² For many people with the condition, seizures may occur at any time with little or no warning. The constant threat of a sudden unpredictable loss of control has been thought to compromise a fundamental facet of the condition. Beliefs about the unpredictability of the condition appear to render individuals susceptible to social inequity and psychopathology.²³

Psychosocial variables of epilepsy include fear of seizures, perceived stigma, and discrimination; degree of adjustment to the diagnosis; other life events and level of social support. A number of studies have reported that the quality of life of people with epilepsy can be severely compromised because epileptics are more likely to be un- or underemployed, resulting in problems for their well-being and independent living.²⁴

It is also affirmed by the findings of current study that 40% of the sample was unemployed and the average monthly income of them was Rs 5500. It is quite evident from our findings that people with epilepsy have lower rates of marriage and greater social inequity (75%) has been noted by our participants. The study by Hasan Aziz et al, reported 20.3% of subjects as married which is almost similar to our study results where 28.5% were married. The concept of not marrying an epileptic person was also affirmed by the M. Shafiq and his colleagues in their study in Karachi.^{18,25}

A review of the literature from developing countries also has suggested that people with epilepsy experience problems with education, marriage, social isolation, and employment. The evidence to date is that in both the developed and developing countries, epilepsy is perceived as stigmatising. What might be different is the level of enacted stigma.²⁶⁻³⁰ Present study revealed the extent of perceived stigma among participants by their experience of being ignored, discriminated and segregated by the society with myth of infectious nature of the condition.

This finding is in consensus with a study conducted by Shafiq M, et al in Karachi, Pakistan, which identified this common misconception that epilepsy is infectious as it has such a tremendous bearing on people's attitudes.²⁵ Reports from studies conducted in Nigeria, Africa, and Kenya also show that people with epilepsy are discriminated against on the grounds that epilepsy is considered to be infectious.¹⁸

According to our study majority (55%) of respondents were educated up to matriculation while 14% were graduated. This signifies a positive trend in this regard. Even though the education level is not sufficient but it has improved significantly in two decades as reported by Hasan Aziz and his colleagues in 1997 that only 27.5% of

persons with epilepsy were educated and they have got primary education.¹⁸

A very interesting observation is, comparison of the findings of our study with a study conducted in Pakistan in Department of Neurology, Jinnah Postgraduate Medical Centre, Karachi, Pakistan in 1997.¹⁸ Contrary to the observations of our study regarding stigmatization, results of that survey did not indicate a very strong stigmatization in Pakistan. However, they reported a marginal association between epilepsy and educational possibilities, performance of daily duties, and the possibility of marriage and having children.¹⁸

CONCLUSION

The study concludes that there is significant (75%) perceived stigma among epileptics living in a big metropolitan city of a developing country. The nature of stigma includes discrimination in education, marriage and job opportunities. There is a need for public awareness programmes to address this ignored facet of epilepsy, since it has both medical as well as social implications.

Limitations of study

- The current study included only those patients coming to hospitals not the traditional healers.
- Only epileptics who were willing to fill the questionnaire were included which may result in voluntary bias.
- The study results are based on self-reported responses of the sample.
- A large scale in-depth analysis is needed to generalise the findings. This study results may not be generalized but help in understanding of problem and planning of a large scale study.

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