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ORIGINAL ARTICLE

Disparities in Epilepsy Knowledge, Beliefs and Cost-Effectiveness: A Comparative Analysis of Rural Healthcare Facilities in Bhakkar Hard- to-Reach District in South Punjab-Pakistan

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Abstract

Background: Although 80% of the 50million people with epilepsy reside in resource poor, developing countries. Epilepsy care in these regions remains limited and the majority of epilepsy patients go untreated due to various modifiable and non-modifiable factors.

Objective: Comparing the effectiveness of volunteer specialist intervention versus autonomous epilepsy treatment to optimize care strategies and improve patient well-being in rural areas of Bhakkar, Punjab, Pakistan.

Material and Methods: An observational study comparing treatment gap and expenses between two cohorts: one being supported and treated at Rukhsana Shafqat Medical Centre, and their counterpart's getting treatment from other facilities with spending out of their pocket was carried out June 01, 2023 to January 01, 2024 at RSMC Bhakkar, Punjab.

Results: A comparison of 100 epilepsy cases each from a major medical center (RSMC) and rural healthcare facilities shows demographic and clinical differences. RSMC patients are younger, with different gender ratios and education levels. RSMC reports 31% idiopathic epilepsy, 61% symptomatic, and 8% cryptogenic, contrasting rural centers' 14%, 78%, and 8%. Co morbidities vary, with 49 individuals having none in RSMC and 60 in rural centers. Treatment duration and disease knowledge also differ, with RSMC demonstrating better knowledge (64.57% good knowledge) compared to rural centers (52.63%). Misconceptions are higher in rural areas (50.4%) than at RSMC (36%). Monthly costs are predominantly below 5000 PKR at RSMC (87%) and in 72% of cases in rural centers, with 28% spending more than 5000 PKR.

Conclusion: The community-based rehabilitation model of care can offer an alternative approach to epilepsy care and address the reality of most people with epilepsy living in such areas of poor developing countries.

Keywords: Epilepsy, Knowledge, belief, cost effectiveness.

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Introduction

Epilepsy, a neurological disorder characterized by recurrent seizures, affects millions of individuals worldwide. According to WHO's report, epilepsy affects almost over 50 million people worldwide, making it one of the most common neurological disorders. In Pakistan, epilepsy remains a significant public health concern, with an estimation that the prevalence of epilepsy is 9.99/1000 suffering with this condition. While epilepsy is a medical condition rooted in neurological abnormalities, it is also deeply intertwined with cultural beliefs, social stigma, and limited access to healthcare, particularly in rural areas, that also in a developing country like Pakistan[5].

The purpose of this research article is to shed light on the versatile terrain of knowledge, belief and cost-effectiveness of epilepsy in the city Bhakkar, a rural area of Punjab, Pakistan. Our investigation is driven by the understanding that epilepsy, often misunderstood and masked in misconceptions, can lead to expense load, delayed treatment, and diminished quality of life for

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those affected. Previous studies done in different settings showed that misperceptions about epilepsy were present in 3% of rural areas residing 80 kilometers from Karachi, 60% among patients residing in Karachi. In Bhakkar, a rural area of Punjab, where healthcare resources are often inadequate and traditional belief systems hold strong impact,

Addressing the epilepsy-related knowledge and belief misconceptions and cost burden is pivotal to improving the lives of individuals living with this condition.

We conducted a comprehensive study to compare two healthcare facilities in rural areas. The first facility integrated specialist doctors, including psychiatrists, neurologists, and psychologists, who collaborated closely to deliver healthcare services. The second setting comprised basic rural health facilities and private clinics situated in remote rural regions. Our research aimed to assess the nature of treatments provided, their cost-effectiveness, treatment outcomes, and the prevalent misconceptions surrounding epilepsy. To achieve these objectives, we designed a study to investigate the knowledge, beliefs, and practices concerning epilepsy among parents of an epileptic child in Bhakkar, Punjab. As parents role in the treatment of this disease is crucial3. This study sought to provide valuable insights into the effectiveness of different healthcare models in rural areas and shed light on the perceptions and challenges related to epilepsy in these communities, ultimately contributing to the enhancement of healthcare services in underserved regions.

Materials and Methods

An observational study was conducted at the Rukhsana Shafqat Medical center, Bhakkar and other rural health facilities and private clinics of rural areas of Bhakkar, Punjab, Pakistan during the period 01-04-2023 to 30-09-2023. We designed a pro forma to inquire questions relating to knowledge, beliefs and cost burden of epilepsy in both settings. After taking verbal consent, the questions were asked in their native language (Saraiki) from the parents. The answers were documented in the pro forma for each patient separately. Demographic and diagnostic details like age and gender, diagnosis, comorbidities, drugs used duration and response of treatment of the patients and also level of education and marital status with regard to consanguinity of the parents were recorded. Questions were asked from the parents about epilepsy. Questions included were about the disease, its symptoms, investigations and treatment of epilepsy. The Pro-forma included questions about parent's level of knowledge and belief toward epilepsy, assessing whether they had a strong understanding or held misconceptions. Apart from this, monthly expenditure for treatment of epilepsy was inquired. The results were tabulated to summarize demographic characteristics and baseline knowledge, beliefs and cost-effectiveness in both the facilities. Data was compiled using statistical software (e.g., SPSS).

Inclusion Criteria

- All pediatric patients (birth to 14 years) who presented with signs and symptoms of epilepsy.

Patients presented with abnormal EEG with history of fits.

Exclusion Criteria

Patient aged 15 years and older.

Data Analysis

The parents completed the Performa as instructed. The results are tabulated to summarize demographic characteristics and baseline knowledge, beliefs and cost-effectiveness in both the facilities. Data was compiled using statistical software (e.g., SPSS) and checked for its completeness and correctness, and it was analyzed. In all statistical analysis p-value <0.05 was considered significant.

Table I: Chi-square test applied on thyroid disorders and BMI

Data Management

All data collected will be securely stored and protected to ensure privacy and confidentiality.Table 1: Socio-Demographic and diagnostic parameters of the study =participants.(n=100)

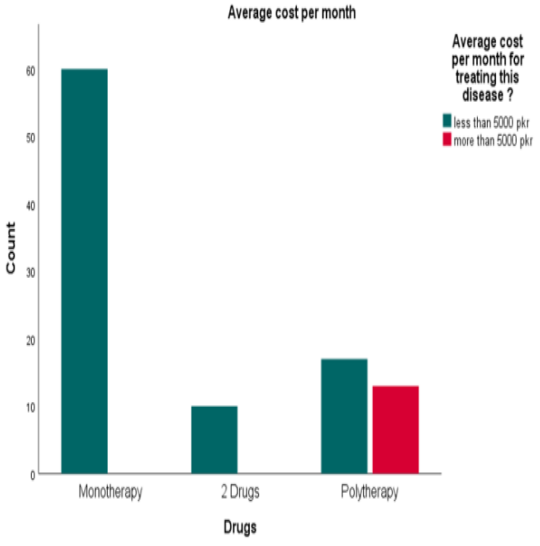
Sr.no	VARIABLES	Attributes		Frequency(%) RSMC	Frequency(%) Rural Healthcare
1.	Age	Less than 2 years		21	20
		Less than 5 years		40	60
		Less than 14 years		39	20
2.	Gender	Male		60	62
		Female		40	38
3.	Educational Qualification of parents	Father	Uneducated	56	37
			Primary Education	36	56
			Tertiary Education	8	7
		Mother	Uneducated	70	65
			Primary Education	30	29
			Tertiary Education	0	6
4.	Consanguineous marriages	Yes		79	92
		No		21	8
5.	Diagnosis	Idiopathic Epilepsy		31	14
		Symptomatic Epilepsy		61	78
		Cryptogenic Epilepsy		8	8
6.	Comorbidities	CP		21	22
		Learning disorder		4	8
		MR		14	0
		ASD		1	0
		Regression		1	4
		GDD		10	6
		None		49	60
7.	Duration of treatment	<6 months		20	16
		6 months		20	38
		12 months		20	22
		13-24 months		16	12
		>2 Years		24	12
8.	Response of treatment	Seizures Controlled		44	42
		Partially Controlled		38	32

Results

A total of 200 cases were included in this study. 100 cases were included from RSMC and 100 cases from other rural healthcare facilities. A comparative analysis of epilepsy cases between RSMC and rural healthcare centers reveals significant demographic and clinical disparities. At RSMC, the age distribution exhibited 21% of patients being less than 2 years old, 40% less than 5 years old, and 39% less than 14 years old. In contrast, rural healthcare centers reported slightly different proportions, with 20%, 60% and 20% respectively.

Gender distribution at RSMC showed a male-to-female ratio of 60% to 40%, while rural healthcare centers had a ratio of 62% males to 38% females. Parental education levels showed that the majority of fathers had primary education (56%), while most mothers had no formal education (65%). Few had tertiary education, but mostly parents were uneducated who belonged to remote rural areas. Consanguineous marriages were notably prevalent in remote rural areas at 92%, compared to 79% in parents at RSMC. In terms of epilepsy diagnoses, RSMC reported 31% idiopathic epilepsy, 61% symptomatic epilepsy, and 8% cryptogenic epilepsy, whereas rural healthcare centers had a different distribution of 14%, 78%, and 8%, respectively. Comorbidities were present, with various conditions affecting a subset of cases, while 49 individuals had no comorbidities in RSMC and 60 in rural healthcare centers. The duration of treatment ranged from less than 6 months to over 2 years, with varying response levels. Among the participants presented in RSMC, 64.57% demonstrated a good level of knowledge about disease, while 35.41% had limited or poor knowledge regarding the condition. However, this drops to 52.63% and 47.36 respectively in rural healthcare centers. Moreover, participants in rural areas had more misconceptions (50.4%) about the disease than in participants presented to RSMC (36%). At the medical center, 87% had monthly costs below 5000 PKR, with 13% exceeding 5000 PKR. In rural centers, 72% had lower expenses, while 28% were spending more than 5000 PKR for the treatment of epilepsy.

Figure 1: Average Cost per month on treatment of patient presenting in RSMC. (n=100)



* This indicates that 87% of participants incur less than 5000 PKR per month, while 13% spend more than 5000 PKR, with monotherapy being the predominant, highlighting varying healthcare expenditure patterns within the surveyed group.

Table 2: Knowledge of study participants about treatment of Epilepsy.

Table 2 contains responses from study participants regarding their knowledge of treatment of disease.

Sr.no	VARIABLES	Good Knowledge	Poor Knowledge
		Frequency(%)	Frequency(%)
1.	Do you know epilepsy treatment is possible only with drugs?	51	49
2.	Do you know that specific dietary therapy has a key role in controlling seizure attacks?	68	32
3.	Do you know that about 75 to 80% of people with epilepsy can be managed easily with one drug?	66	34
4.	Do you believe that it is necessary to take medicines as advised by your doctor?	99	1
5.	Do you believe that the time at which the medication taken will influence its effectiveness?	77	23
6.	Do you know that the antiepileptic drug therapy may not have an immediate effect?	67	33
7.	Do you know that the dose of medication is determined by your child's body weight?	94	6
8.	Do you think that missing doses and/or taking them late or incorrectly will affect the treatment response?	90	10
9.	Do you think it is wise to use any other alternative systems of medicine while on antiepileptic drugs?	37	63
10.	Do you believe that it is not advisable to change frequently the brands of the drug?	79	21
11.	Do you think that antiepileptic drug therapy will have side effects?	84	16
12.	Do you think that complete seizure freedom for a period is absolutely essential for stopping antiepileptic drugs?	63	37

* Among the participants, 72.91% demonstrated a good level of knowledge regarding treatment, while 27.08% had limited or poor knowledge regarding the condition.

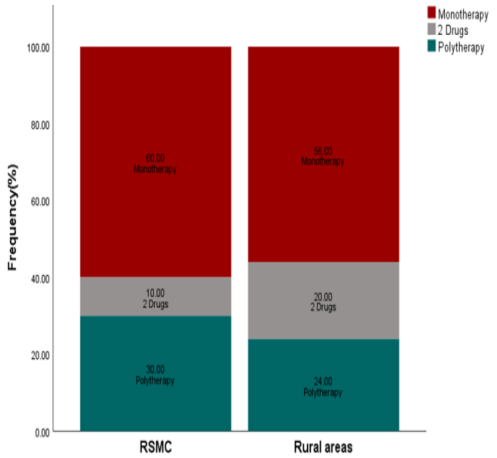
Table 3: Belief of study participants about Epilepsy and its treatment.

Table 7 contains responses from study participants regarding their belief about the disease.

Sr.no	VARIABLES	True Belief	False Belief
		Frequency(%)	Frequency(%)
1.	Do you think epilepsy is always incurable?	97	3
2.	Is epilepsy due to supernatural powers?	65	35
3.	Do you think it is not necessary to disclose your child's epileptic condition while consulting a General Physician?	97	3
4.	Do you believe that by taking antiepileptic medication the user will become addicted and therefore be unable to stop taking it?	39	61
5.	Do you think that the some antiepileptic drugs can affect memory and concentration of your child?	22	78

*Among the participants, 64% demonstrated strong understanding about the disease, while 36% had misconceptions regarding the condition.

FIGURE 2: DRUGS USED REGARDING TREATMENT OF EPILEPSY.



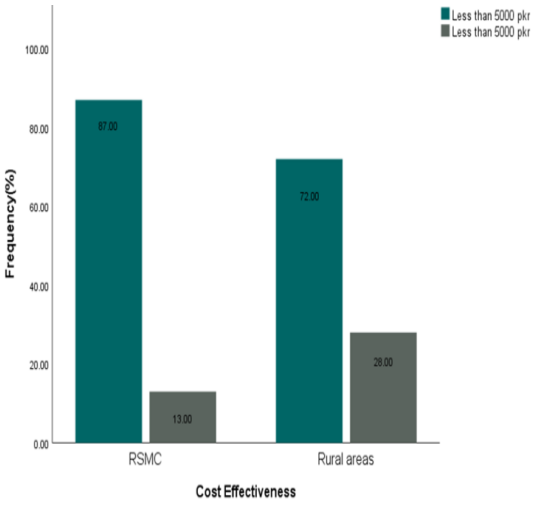
*Regarding treatment approaches, at RSMC, 60% of patients received monotherapy, 10% were prescribed two drugs, and 30% underwent polytherapy. In rural healthcare centers, the treatment distribution was 56%, 20% and 24% respectively.

Table 4: Responses of treatment in study participants.

Table 8 contains responses from study participants regarding Response of treatment in both settings.

	Seizure Controlled	Partially Uncontrolled	Uncontrolled	Worsen
	Frequency (%)	Frequency (%)	Frequency (%)	Frequency (%)
RSMC	44	38	17	1
Rural areas	42	32	10	16

Figure 3: Cost burden among participants



* At the medical center, 87% had monthly costs below 5000 PKR, with 13% exceeding 5000 PKR. In rural centers, 72% had lower expenses, while 28% faced higher healthcare costs, highlighting significant economic disparities in accessing treatment between the two settings.

Discussion

The comparative analysis conducted between Rukhsana Shafqat Medical Center (RSMC) and rural healthcare centers has provided valuable insights into the complex landscape of epilepsy management.This study's demographic findings reveal significant disparities between the two settings, particularly in terms of age distribution. The concentration of younger epilepsy patients in rural areas may be indicative of limited healthcare access and potentially distinct epidemiological factors affecting this demographic. Additionally, variations in gender distribution highlight potential differences in healthcare-seeking behaviors or the prevalence of epilepsy among genders in these settings. Socioeconomic factors emerge as a critical determinant of epilepsy management challenges. The low levels of parental education in rural areas underscore the educational hurdles faced by individuals in remote settings. A study conducted in rural areas of Sindh showed that (70.0%) Educated families considering epilepsy a disease still visit shrines but this was significantly low compared to uneducated families (65.0%)2. The prevalence of consanguineous marriages in rural regions raises genetic implications and underscores the importance of genetic counseling and awareness programs in areas with a high prevalence of this cultural practice. The clinical profile of epilepsy cases also exhibits disparities between RSMC and rural healthcare centers. The distribution of epilepsy diagnoses revealed disparities as well. RSMC reported 31% idiopathic epilepsy, 61% symptomatic epilepsy, and 8% cryptogenic epilepsy. In contrast, rural healthcare centers had a different distribution with 14%, 78%, and 8%, respectively. Differences in epilepsy diagnoses may be attributed to variations in healthcare infrastructure and diagnostic capabilities, such as EEG, emphasizing the need for improved access to advanced diagnostic tools in rural areas. A significant people believe that epilepsy can be treated by the doctors4. Misconceptions were more prevalent among participants in rural areas (50.4%) compared to those presented at RSMC (36%). The presence of comorbidities, albeit with different profiles, further underscores the complexity of epilepsy cases in both settings. Knowledge levels among participants and the prevalence of misconceptions present crucial areas for intervention. Lower knowledge levels and a higher prevalence of misconceptions in rural areas emphasize the need for targeted educational initiatives and awareness programs to improve understanding and reduce stigma surrounding epilepsy. Overall, research on general population attitudes towards intellectual disability is

lacking, with a particular gap in understanding public knowledge and causal beliefs in this context6. The comparison between Rukhsana Shafqat Medical Center and rural healthcare centers reveals distinct financial patterns. The majority of participants at RSMC had monthly epilepsy treatment expenses below 5000 PKR (87%), whereas in rural healthcare centers, a higher proportion (28%) exceeded this cost threshold. This highlights the need for financial support mechanisms and healthcare reforms to ensure equitable access to epilepsy care. In conclusion, this research underscores the multifaceted challenges faced by individuals with epilepsy in diverse healthcare settings, particularly in rural areas of Pakistan. These findings describe dire need of healthcare interventions, awareness programs, and improved access to epilepsy care. They also lay the groundwork for future studies and targeted interventions aimed at achieving equitable and effective epilepsy management strategies.

Conclusion

In conclusion, participants who visited RSMC had better knowledge and understanding about the disease due to integrated system and had low burden of treatment than who visited other rural healthcare centers but still there is lower knowledge levels and a higher prevalence of misconceptions in rural areas shows that still there is pressing need to bridge the gap between epilepsy knowledge and belief in rural areas of Pakistan. By doing so, we aspire to contribute to the development of means that promote better understanding, reduce stigma, and improve the quality of life for individuals living with epilepsy in these underserved communities.

Recommendation

A mass awareness campaign is needed for awareness of public knowledge about various neurological diseases including epilepsy across the country. This could be done with the help of mobile phone operators through short message services (SMS) or a social media platform to ensure proper guidance.

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Ethical approval: The study was approved by the Institutional Ethics Committee

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