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Community Perception and Support of Epileptic Patients in Rural Areas of Rusizi District

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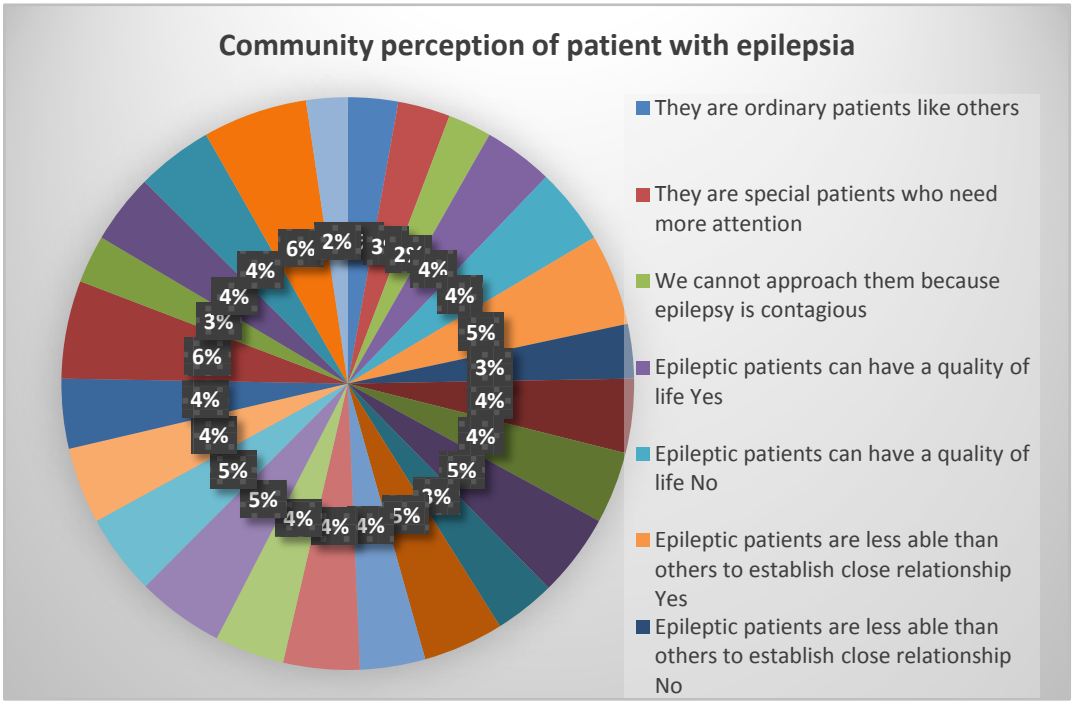
Abstract Background**:** Epilepsy is a prevalent non communicable neurological disorder of the brain, affecting approximately 50 million individuals globally. Around of 80% people living with epilepsy are in low- and middle-income countries. Beyond the medical aspects, epilepsy poses significant social burdens, including stigma and discrimination, which impact patients' quality of life. **Problem Statement:** In low-income countries, where the majority of epileptic patients reside, support systems are often inadequate, and stigma towards epilepsy remains pervasive. Community perceptions often view epileptic patients as dangerous or possessed by demons, leading to social isolation and discrimination. **Methodology:** This study aims to assess the community perception and support towards epileptic patients in the local area of Rusizi District. A quantitative research approach was adopted, utilizing a descriptive design. Data collection involved the administration of a questionnaire to individuals attending outpatient departments over three consecutive days. Ethical approval was obtained from the Kibogora Polytechnic Ethical Committee. **Conclusion:** The findings of this study provide valuable insights into the prevailing attitudes and support systems towards epileptic patients in the local community. Addressing misconceptions and stigma surrounding epilepsy for improving the quality of life and social integration of affected individuals.



Keywords: *Community, Perception, Support, Epileptic, Patients, Rural*

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1. Introduction

Epilepsy is a common and chronical serious neurological condition with an estimated 50 million people affected worldwide [1]

Although it is common, epilepsy is not evenly distributed. Approximately 80% of people impacted reside in nations with low and moderate incomes. Certain risk factors may be connected to the greater prevalence of epilepsy in certain areas. Preventive measures that address head trauma, CNS infections, neonatal traumas, and pregnancy difficulties must thus be put into place. Despite the excellent success rates of epilepsy treatment, more than 75% of patients in underprivileged regions do not obtain therapy. Cultural views, differences in public health services, inadequate healthcare infrastructure, and a lack of antiepileptic drugs are all contributing factors to this treatment disparity in low- and middle-income nations. As a result, people face medical and mental obstacles that restrict their access to school and work prospects and prevent them from leading fulfilling social lives. [2,3] Social burdens that arise not only from the condition itself but also its social meanings and actual or feared discrimination. This situation is often conceptualized in terms of stigma. The notion of stigma was developed by Goffman in interactionist terms, defining it as the process by which the reaction of others spoils normal identity. Some of epileptic patients and general people conclude that epilepsy is a result of possession by an evil spirit or the wrongdoings of ancestors. [4] The most frequently reported causes of epilepsy were stress (91%), substance use (61.8%), and bad spirits (49.8%), according to a study that sought to evaluate the stigma associated with epilepsy from the viewpoints of both people with epilepsy and the general public, as well as to investigate the effects of perceived stigma, mood, and quality of life. Epilepsy symptoms included collapsing (80.7%), losing consciousness, and having trouble sleeping (78%). Just 13.1% of participants thought they could have an increased risk of epilepsy. Furthermore, just 6.7% of participants said they would be okay with a family member marrying someone who has epilepsy, and 94.2% of people said they would not hire someone who had the illness. [5,6] Common misunderstandings regarding epilepsy continue to have a detrimental impact on the condition's care in many African nations. Anxiety and hesitancy when it comes to dealing with or confronting an epileptic seizure are mostly caused by public fear and ignorance. [7] Among the many myths about epilepsy that were found were the notions that it is a contagious disease, a genetic disorder, or that it is spread by insects, saliva, or contact with a person of the same sex during seizures. The majority of persons with epilepsy, it was also thought, had either stopped taking anti-epileptic medicine or had not received it. [8,9]

2. Problem Statement

The majority of worldwide epileptic patients is found in low-income countries where the Support still being poor and the prevalence is higher than in developed countries. [1,10] Prevalence survey in different parts of Africa produce widely differing estimates ranging from 0.2%-5.8% in one review [11] According to a different analysis of door-to-door surveys, between 0.5% and 7.4% of people with epilepsy reported feeling supported. [7] In sub-Saharan Africa, the brain and central nervous system, infections including cysticercosis, and genetic factors were identified as potential causes of epilepsy. [12] Malnutrition has also been highlighted as a potential cause, along with brain tumors, vascular disorders, head injuries, and meningitis and malaria in both children and adults. [13,14,15] The public frequently perceives people with epilepsy as dangerous and avoids or runs away from them because of false beliefs, such as the idea that demonic possession is the source of their seizures. The stigma is further increased by the false notion that seizures and flatulence associated with epilepsy are communicable. As a result, people with epilepsy encounter difficulties in their personal relationships, careers, marriage, and education. It is critical to recognize that the effects of epilepsy go beyond its medical components, given the substantial psychological and social challenges people face. Sadly, present attempts to lessen stigma are insufficient, underscoring the pressing need for more thorough and efficient approaches to the problem. [16,17] Assessing the level of community support for people with epilepsy in the Gihundwe sector was the aim of this study. In the Rusizi District, specifically in the Gihundwe Sector, the study sought to examine the community's attitudes, beliefs, and methods of supporting people with epilepsy.

3. Research Methodology

In order to evaluate how the community views and supports people with epilepsy, the study "Community Perception and Support of Epileptic Patients in the Local Area of Rusizi District" used a quantitative research approach and a descriptive cross-sectional design. Using the Taro Yamane formula, the sample size was determined, and 67 people were chosen from the Gihundwe population using non-probability purposive sampling. A questionnaire was used to obtain the data.To guarantee adherence to ethical standards during the whole research procedure, ethical permission was acquired from the Kibogora Polytechnic Ethical Committee before the study started.

4. Results

The first section deals with the presentation of demographic data of the sample of the participants, the second section is the description of findings about community perception and support of epileptic patients in local area of Rusizi district. This study was done in Gihundwe District Hospital.

Table 1. The below table shows socio-demographic characteristics of the participants. The majority of participants were females on 50.74% while males were 49.25% and majority of the participants were aged between 22 and 35 years representing 53.73%. About marital status, the majority were married on representation

of 47.76%.the majority of participants had a primary level of education

Table 2. Assessment of community knowledge about epilepsy

As shown in the table above, the majority of respondents think the causes of epilepsy may be evil spirits and/or genetic factors(32.83% for each).89.55% of respondents had seen at least 1 epileptic patient; seizures are the most known symptoms of epilepsy(44.77%).About risk factors, the majority considered family history of having epilepsy and head injury(26.86% for each).About treatment, the majority knew epilepsy as a chronic disease which never heals(40.29%),other think it is treated traditionally(35.82%)and 23.88% of them were thinking it is treatable at hospital.

Table 1. Identification of socio-demographic characteristics of the participants

Variable	Frequency	Percentage
Gender		
Male	33	49.25%
Female	34	50.74%
Total	67	100%
Age		
18-21	13	19.40%
22-35	36	53.73%
>36	18	26.86%
Total	67	100%
Marital status		
Single	12	17.91%
Married	32	47.76%
Window	8	11.94%
Separated	5	7.46%
Total	67	100%
Level of education		
A0	1	1.49%
A1	8	11.94%
A2	22	32.83%%
Primary	23	34.32%
Illiterate	13	19.40%
Total	67	100%

Table 2. Assessment of community knowledge about epilepsy

Causes of epilepsy	Number of respondents	Percentage
Malnutrition	3	4.47%
Brain injury	17	25.37%
Poverty	3	4.47%
Evil spirits	22	32.83%%
Genetic factors	22	32.83%
Do you know epilepsy (Have you seen epileptic)		
Yes	60	89.55%
No	7	10.44%
Signs and symptoms of epilepsy		
Seizures	30	44.77%
Loss of consciousness	12	17.91%
Memory lapses	15	22.38%
Staring spell	10	14.92%
Risk factors of epilepsy		
Family history	18	26.86%
Head injury	18	26.86%
Brain infection	16	23.88%
Seizures in childhood	15	22.38%
Knowledge about treatment of epilepsy		
It is a curable disease treated at hospital	16	23.88%
It is a traditional disease not cured at health facilities	24	35.82%
It is a chronic disease which never heals	27	40.29%

Table 3. Community perception of epileptic patients

Epileptic patients' perception		Number of respondents	Percentage
They are ordinary patients like others		23	34.32%
They are special patients who need more attention		24	35.82%
We cannot approach them because epilepsy is contagious		20	29.85%
Epileptic patients can have a quality of life	Yes	32	47.76
	No	35	52.23
Epileptic patients are less able than others to establish close relationship	Yes	42	62.68
	No	25	37.31%
Patients with epilepsy are considered as handicap people	Yes	34	50.74%
	No	33	49.25%
A lot of people are afraid of patients with epilepsy	Yes	38	56.71%
	No	28	41.79%
Epilepsy is a mental disease	Yes	37	55.22%
	No	30	44.77%
People with epilepsy are difficult to be managed in community	Yes	35	52.23%
	No	32	47.76%
A patient with epilepsy is not flexible with others	Yes	40	59.70%
	No	37	55.22%
People with epilepsy are less productive at work than others	Yes	35	52.23%
	No	32	47.76%
People with epilepsy are more aggressive than others	Yes	45	67.16%
	No	22	32.83%
People with epilepsy are less active than others	Yes	32	47.76%
	No	35	52.23%
People with epilepsy have more learning difficulties than others	Yes	48	71.64%
	No	19	28.35%

Table 3. Community perception of epileptic patients

About community perception of epileptic patients in general, 24 respondents among 67(35.82%) said patients with epilepsy are special patients who need more attention, other 23(34.32%) said they are ordinary patients like others, and 20 others (29.85%) cannot approach them because they think epilepsy is contagious. The table shown also that the think that a lot of people are afraid of epileptic patients(56.71%), epileptic patients are not flexible(59.70%),they are thought to be more aggressive(67.16% of respondents),considered as less productive at work by 52.23% of respondents and to have more learning difficulties than others(71.64%).

Table 4. Community support of epileptic patients with crisis

According that table, the majority of respondents (58.20%) said that in case of epileptic crisis they make first aids interventions by putting something in the victim's mouth (52. 23%). About proposed improvement, the majority (29.85%) were thinking on training of people and family members about first aids and increase community knowledge about the support of epileptic patients through health education. About marriage with epileptic patients, the majority (28.35%) said they would keep normal marriage if their spouse became epileptic, other 28.35% said they would continue to live together but without sexual intercourse or using condoms in order to prevent conception while 16.41% would propose divorce.

The Relationship Between Community Perceptions and Support Provided to Individuals with Epilepsy

The study examined the relationship between community perceptions of epilepsy and the support provided to patients, revealing notable correlations with demographic factors. For instance, those who view epilepsy as a mental illness (55.22%) often provide inadequate support, such as neglecting first aid, with this perception being more prevalent among individuals with lower education levels (e.g., A0, A1), shown by a p-value of 0.05. Conversely, the belief that epilepsy is a chronic condition (40.29%) correlates with effective first aid practices, like placing the patient on their side, and is more common among those with higher education levels (e.g., Primary, A2), with a statistically significant p-value of 0.01*. The notion that epilepsy is treatable at hospitals (23.88%) is linked to appropriate medical interventions and is prevalent among younger age groups (18-21, 22-35), though this correlation is less significant (p-value of 0.08). A belief that epilepsy is caused by evil spirits (32.83%) leads to less effective support and is more common among older individuals (>36), with a highly significant p-value of 0.002*. In contrast, those who perceive epilepsy as caused by genetic factors (32.83%) are more likely to provide proactive crisis management, and this belief is more common among married individuals (p-value of 0.01*). The idea that epilepsy is contagious (29.85%) results in avoidance behavior and less interaction with patients, particularly among single and widowed individuals (p-value of 0.08). Perceptions that epileptic patients are aggressive (67.16%) or have learning difficulties (71.64%) are associated with increased fear and a perceived need for special support, with the former being more prevalent among those with lower education levels and the latter among younger age groups, though neither shows significant correlations (p-values of 0.781 and 0.76, respectively). The belief that epileptic patients are less productive at work (52.23%) correlates with a perception of needing less responsibility, common among lower education groups (p-value of 0.051), while those

who think epileptic patients need more attention (35.82%) are more likely to provide individualized support, particularly among married individuals (p-value of 0.0534). Finally, the belief that epilepsy is a traditional disease (35.82%) leads to reliance on traditional support methods and is more prevalent in older age groups (p-value of 0.052). This analysis underscores the impact of community beliefs on the type and effectiveness of support provided to epileptic patients and highlights the need for addressing misconceptions through targeted education and intervention.

Table 4. Community support of epileptic patients with crisis

Support of a patient with epileptic crisis	Number of respondents	Percentage
Nothing is done	5	7.46%
Calling the family	18	26.86%
Make first aids	39	58.20%
Crisis does not need any attention	5	7.46%
First aids interventions done in epileptic crisis		
Keep other people out of the way	9	13.43%
Put something in the mouth	35	52.23%
Place them on their side to help keep their airways clear	10	14.92%
Don't try to hold them down or stop the movements	13	19.40%
What can be improved in community to support epileptic patients		
Increase community knowledge about the support of epileptic patients through health education	20	29.85%
Train the people and family members about first aids	20	29.85%
Train community health workers about first aids	32	47.76%
Reassure the community that epilepsy is not a contagious disease	5	7.46%
Advice to a partner of a new epileptic case		
Body separation (stop sexual intercourse)	19	28.35%
Divorce	11	16.41%
Keep their normal marriage	25	37.31%

Table 5.

Support Provided	Number of Respondents	Percentage	p-Value	Demographic Data
Inadequate support, e.g., no first aid	37	55.22%	0.05	Higher in lower education groups (e.g., A0, A1)
Effective first aid, e.g., placing on side	27	40.29%	0.01*	More common among those with higher education (e.g., Primary, A2)
Appropriate medical intervention, e.g., calling family or professional help	16	23.88%	0.08	More frequent among younger age groups (18-21, 22-35)
Less effective support, e.g., incorrect first aid practices	22	32.83%	0.002*	More prevalent in older age groups (>36)
More proactive crisis management, e.g., making first aid	22	32.83%	0.01*	More common among married individuals
Avoidance behavior, e.g., less interaction and support	20	29.85%	0.08	Higher among single and widowed individuals
Increased fear and avoidance, less support	45	67.16%	0.781	Higher in lower education groups (e.g., A0, A1)
Perceived need for special educational support	48	71.64%	0.76	Higher in younger age groups (18-21)
Perceived as needing less responsibility	35	52.23%	0.051	More common among lower education groups
More individualized support, e.g., specific first aid actions	24	35.82%	0.0534	More prevalent among married individuals
Reliance on traditional support methods, less medical intervention	24	35.82%	0.052	More common in older age groups (>36)

5. Discussion

The information demonstrates the community's sociodemographic makeup, attitudes, and level of epilepsy knowledge. The majority of participants (53.73%) are between the ages of 22 and 35, suggesting that a youthful generation is influencing community sentiments. The gender distribution is about equal (50.74% females and 49.25% males). The fact that most only have an elementary education point to a knowledge gap in comprehending intricate medical topics. This highlights the necessity of focused educational initiatives that accommodate varying reading levels in order to raise awareness and lessen the stigma associated with epilepsy [18,19] The community's conflicting views on the origins of epilepsy 32.83% believe it is caused by both hereditary elements and bad spirits reflect a combination of traditional and medical perspectives, underscoring the necessity for culturally relevant teaching initiatives. [20] Despite 89.55% of participants having encountered at least one person with epilepsy, there is a significant lack of understanding about its symptoms and treatment. A common misconception is that epilepsy is a chronic, incurable disease, with 40.29% of participants holding this view, while 35.82% prefer traditional remedies. This underscores the urgent need for clear, evidence-based education on epilepsy management. The community also holds strong stigmas: 35.82% believe individuals with epilepsy require special attention, 29.85% avoid them out

of fear of contagion, and harmful stereotypes persist, such as the belief that people with epilepsy are more aggressive (67.16%), less productive (52.23%), and have greater learning difficulties (71.64%). These misconceptions perpetuate social stigma and discrimination. [9,21] With 58.20% of respondents mistakenly thinking that putting an object in a seizure victim's mouth is permissible, misconceptions regarding first aid during seizures are also common. This harmful misunderstanding emphasizes how urgently targeted community training initiatives are needed. To address these difficulties, resources should be dedicated to design and implement extensive community education programs that refute stereotypes about epilepsy, concentrating on its origins, symptoms, and contemporary treatment options. To guarantee a wide comprehension, these programs ought to accommodate varying reading levels. It is essential to conduct first aid training courses, with a focus on the risks associated with putting things in the mouth during seizures. Accurate training will be ensured by cooperation with regional healthcare providers. Creating support groups will offer emotional assistance to families and individuals with epilepsy. [22,23] Encouraging community leaders to advocate for inclusion and acceptance of individuals with epilepsy, utilizing media to challenge negative stereotypes, and improving access to medical facilities will enhance community support. Additionally, providing resources for traditional healers to understand medical treatments will foster a more integrated approach to care. [23,24] These initiatives seek to enhance the quality of life for individuals with epilepsy by reducing stigma and fostering greater community support. By addressing misconceptions and promoting understanding, they aim to create a more inclusive environment where individuals with epilepsy are accepted, supported, and empowered to lead fulfilling lives. [25]

6. Conclusion

The report emphasizes how urgently needs of a comprehensive strategy to provide assistance for people with epilepsy. Positive change is possible because of the population's youth and influence. Misconceptions regarding the causes, symptoms, and management of epilepsy, however, lead to serious information gaps that support prejudice and stigma. In order to increase comprehension and deliver accurate, evidence-based information, targeted educational interventions are essential. Correcting detrimental assumptions and promoting appropriate seizure treatment can be achieved by customizing programs to various reading levels and providing specialized first aid training. The transparency of the community indicates that these programs may successfully lessen stigma and improve assistance for people with epilepsy.

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