

KNOWLEDGE, ATTITUDE, AND PRACTICES TOWARDS THE CARE OF EPILEPTIC PATIENTS BY THEIR CARETAKERS ATTENDING THE OUTPATIENT DEPARTMENT IN KAPCHORWA HOSPITAL, KAPCHORWA DISTRICT. A CROSS-SECTIONAL STUDY.

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ABSTRACT.

Background:

The specific objectives were to determine the knowledge, and assess attitudes towards the care of epileptic patients among their caretakers, and to explore the common treatment practices done by the caretakers of epileptic patients attending outpatient departments in Kapchorwa Hospital, Kapchorwa District.

Methodology:

A facility-based cross-sectional study that involved both quantitative and qualitative methods was used. 50 respondents were selected using simple random sampling and interviewed using a questionnaire with closed-ended questions.

Results:

The majority (56%) of the respondents were aged >35, female (64%), Sabiny (84%), Majority (84%) of the participants had heard about epilepsy and more than half (58%) didn't know about the cause of epilepsy. The majority (96%) of them could recognize when their patients got an attack, less than half (46%) reported that loss of consciousness helped them notice an attack among their patients and less than half (40%) reported that emotional distance made their patients get an attack. The majority (64%) of the participants reported that epileptic patients are normal people, the majority (60%) reported their patients should not be employed, less than half (48%) rushed their patients to the hospital and most (36%) reported lying their patient down as the first aid they gave.

Conclusion:

Knowledge of the care of epileptic patients by their caretakers was fairly satisfactory their attitude and practices towards the care of epileptic patients were most likely to expose their patients to some degree of stigma and low self-esteem due to their belief that they are mad people, should not be employed nor get married.

Recommendations:

Health workers attending to epileptic patients and their caretakers at the outpatient department of Kapchorwa Hospital should continue to health educate caretakers to increase awareness about the cause, symptoms, and treatment options for epileptic patients and to decrease the negative attitude of the community.

Keywords: Knowledge, Attitude, Practices, Epileptic patients, Kapchorwa hospital

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BACKGROUND TO THE STUDY.

Epilepsy is a chronic non-communicable disease of the brain that affects around 50 million people worldwide (Keisha Hill, 2020). According to the World Health Organization, epilepsy is characterized by recurrent seizures, which are brief episodes of involuntary movements that may involve a part of the body (partial seizures) or the entire body (generalized seizures) and are sometimes accompanied by loss of consciousness and control of bowel or bladder

function (WHO, 2023). Seizure episodes are a result of excessive electrical discharges in a group of brain cells. It affects people of all ages though commonest in the young and elderly. According to the World Health Organization (2023), different parts of the brain can be the site of such discharges and seizures can vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions (WHO, 2023). Seizures can also vary in frequency from less than one per year to several per day (WHO, 2023). One seizure does not signify epilepsy (up to

10% of people worldwide have seizures during their lifetime) Epilepsy is defined as having 2 or more unprovoked seizures. (WHO, 2023).

The true origin of epilepsy had puzzled scientists until Wilder Penfield in 1956 established the concept of the epileptogenic anatomic lesion and the epileptogenic physiologic lesion.

Historically, epilepsy was believed to be a sacred disease that is the result of the invasion of the body by a god (Bertha C. Ekeh,2015). According to (Bertha C. Ekeh,2015), it was thought that only a god could deprive a healthy man of his senses, throw him to the ground, convulse him, and then rapidly restore him to his former self again (Bertha C. Ekeh,2015). In addition to that, this historical legacy has continued to influence public attitude to epilepsy making it a dreaded disease (Bertha C. Ekeh,2015). These beliefs have resulted in patients with epilepsy (PWE) being ostracized, stigmatized, and misunderstood, and the social implications of all these are serious.

The Global Burden of Epilepsy Report estimates that there are 13 million disability-adjusted life years due to epilepsy each year (Singh G,2020). Estimates of years lived with disability attributed to uncontrolled and untreated epilepsies and particularly raised in comparison to controlled epilepsies in countries with low socio-demographic indices (Singh G,2020). There are 50 million people with epilepsy in the world and of these, 125000 die each year and over 80% of these deaths occur in low- and middle-income countries (Singh G,2020). Overall, a global decline in the number of epilepsy-related deaths has been seen between 1990 and 2016 (Singh G,2020). The least improvement has however recorded an increase in countries with low socio-demographic indices. The 13 African countries have recorded an increase in the number of epilepsy deaths over 26 years. The huge burden of untreated and uncontrolled epilepsy and epilepsy-related deaths in low- and middle-income countries calls for urgent efforts to improve access to epilepsy management (Singh, G.2020).

The World Health Organization (WHO) has recognized epilepsy as a public health imperative due to its occurrence at all ages in all regions of the world, its high impact ([Alla Guekht,2021](#)) on disability-adjusted life years and psychosocial aspects, and the accompanying stigma (Guekht, A.B, 2021).

Fear, misunderstanding, discrimination, and social stigma have surrounded epilepsy for centuries. The stigma continues in many countries today and can impact the quality of life for people with the disorder and their families (WHO, 2016).

The study conducted to describe the current demographics of people with epilepsy (PWE) attending hospital-based care in Uganda and the epilepsy treatment practices within three of the largest Ugandan public referral hospitals found that people with epilepsy attending hospital-based care in Uganda tend to have severe forms of epilepsy requiring management with AEDs. Current hospital-based practices show a positive trend for seizure burden and quality of life

of PWE in Uganda Fuller, (A. T.M 2021).

General Objective.

This study aims to determine the Knowledge, Attitude, and practices towards the care of epileptic patients by their caretakers attending outpatient departments in Kapchorwa Hospital, Kapchorwa district.

Specific objectives.

- To determine the level of knowledge towards the care of epileptic patients among their caretakers attending the outpatient department in Kapchorwa Hospital, Kapchorwa district.
- To assess the attitude towards the care of epileptic patients among their caretakers attending outpatient departments in Kapchorwa Hospital, Kapchorwa district.
- To explore the common treatment practices carried out by the caretakers of epileptic patients attending the outpatient department in Kapchorwa Hospital, Kapchorwa district.

METHODOLOGY.

Study Design.

This was a cross-sectional study. This was because the study does not require follow-up of clients over a while. The information required was collected from the study participants.

Study Setting.

The study was conducted at Kapchorwa Hospital located in Kapchorwa district, Eastern region of Uganda; therefore, it is a facility-based study. The district is bordered by the Kween district to the North East and east, the Sironko district to the south, and Bulambuli district to the west.

Study Population.

The study population included the caretakers of epileptic patients only above 15 years of age.

Sample Size Determination.

The sample was determined using the Burtons formula 1965 as seen below; Sample size $[n] = [QR] O$

Where Q is the total number of days taken for data collection
R is the maximum number of respondents who were interviewed per day
O is the maximum time that was spent on each respondent per day

Values are Q=10 days

R=05 respondents O=1hour

Therefore $n = [QR] O$
 $n = [10 \times 5] 1 = 50$ respondents
Therefore 50 respondents were used in the study.

Sampling Techniques.

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The study employed a simple random procedure to select the sample. A simple random procedure refers to selecting a sample without biases from the target population. It's preferred to other techniques because it ensures that each member of the target population has an equal and independent chance of being included.

Sampling procedure.

Each member of the population was assigned unique numbers which were written on small pieces of paper, folded and placed in a bowl, and thoroughly mixed and one of the research assistants selected one at a time without replacement until 50 respondents were got.

Data Collection Method.

Data were collected by survey method using physically structured questionnaires that were served to each respondent.

Data Collection Tools.

Structured self-made questionnaires with closed-ended questions were employed.

Data Collection Procedure.

A letter meant to introduce the researcher to Kapchorwa Hospital was received from the Kampala School of Health Sciences and taken to the hospital. The researcher then asked for permission to conduct the study and was granted permission she was assisted by trained research assistants who were two student psychiatric clinical officers and collected the data using a questionnaire. All those who fulfilled the inclusion criteria were interviewed from a quiet and private room that was identified from the hospital. The interviewers were knowledgeable in the local language translated the information and filled the data directly in English. The researcher then checked the data filled in before the respondents and thanked each respondent for participating in the study before leaving the study site.

Dependent variable.

The care of epileptic patients by the caretakers.

Independent variables.

Were knowledge, attitude, and practices towards the care of epileptic patients by their caretakers.

Quality Control.

Pretesting of the research tool was carried out at Kakwomuria Health Center II Inclusion criteria had those confirmed to be caretakers of epileptic patients consented and aged 15 years and above.

After collecting data, it was checked thoroughly for completeness and accuracy

Those that were inaccurately or incompletely filled were removed and disposed of. Accurate and filled ones were locked in a cupboard to provide no access to other people. This maximized confidentiality. The collected questionnaires were allocated numbers, cross-checked, and properly stored to avoid errors in data processing. When the assignment was completed, the files were organized and kept neat in a cupboard until they were picked up for analysis.

Data Analysis and Presentation.

Data was counted by tallying using a pen and A4 sheets of paper. The results were entered into a computer and analyzed using Microsoft Excel programming to generate tables and figures

Ethical Considerations.

A letter meant to introduce the researcher to Kapchorwa Hospital was from the Academic Registrar of Kampala School of Health Sciences and taken to Kapchorwa Hospital. The researcher then asked for permission to conduct the study and when granted permission, she made sure respondents consent first using a sign or thumbprint. The identities of the respondents were salient features in the study. Each individual was interviewed alone and the information got was not disclosed to the colleagues.

RESULTS.

Demographic characteristics of the respondents.

A total of 50 respondents were interviewed using questionnaires and their characteristics were listed in table 1.

Table 1: Shows respondent's socio-demographic data. (N=50)

Items	Frequency (n)	Percentage (%)
Age in years		
15-19	10	20
20-35	12	24
≥35	28	56
Total	50	100
Sex		
Males	18	36
Females	32	64
Total	50	100
Tribes of the respondents		
Sabiny	42	84
Mugisu	06	12
Kikuyu	02	04
Total	50	100
Religion of the respondents		
Catholic	12	24
Moslem	10	20
Protestant	15	30
Born again	13	26
Total	50	100
Level of education		
Primary	15	30
Secondary	18	36
Tertiary	12	24
Never went to school	05	10
Total	50	100
Respondent's occupation		
Peasant	20	40
Civil servant	08	16
Health worker	03	06
Unemployed	19	38
Total	50	100

According to table 1; it's evident that more than half (56%), of the respondents were aged >35 years where as the least (20%) were aged between 15-19 years. The majority (64%), of the respondents were females while the least (36%) of the respondents were males. The majority (84%), of the respondents, was of the tribe of Sabiny where the least (04%) of the respondents were Kikuyu. Most (30%) of the respondents interviewed were protestants whereas the least (20%) were Muslims. Most (34%) of the respondents

studied up to the secondary level while the least (10%) of the respondents never went to school. most (40%) of the respondents were peasants, while the minority (06%) of the respondents were health workers.

Knowledge towards the care of epileptic patients among their caretakers attending outpatient department.

Figure 1: Shows the knowledge of the respondents about the term epilepsy.(N=50)

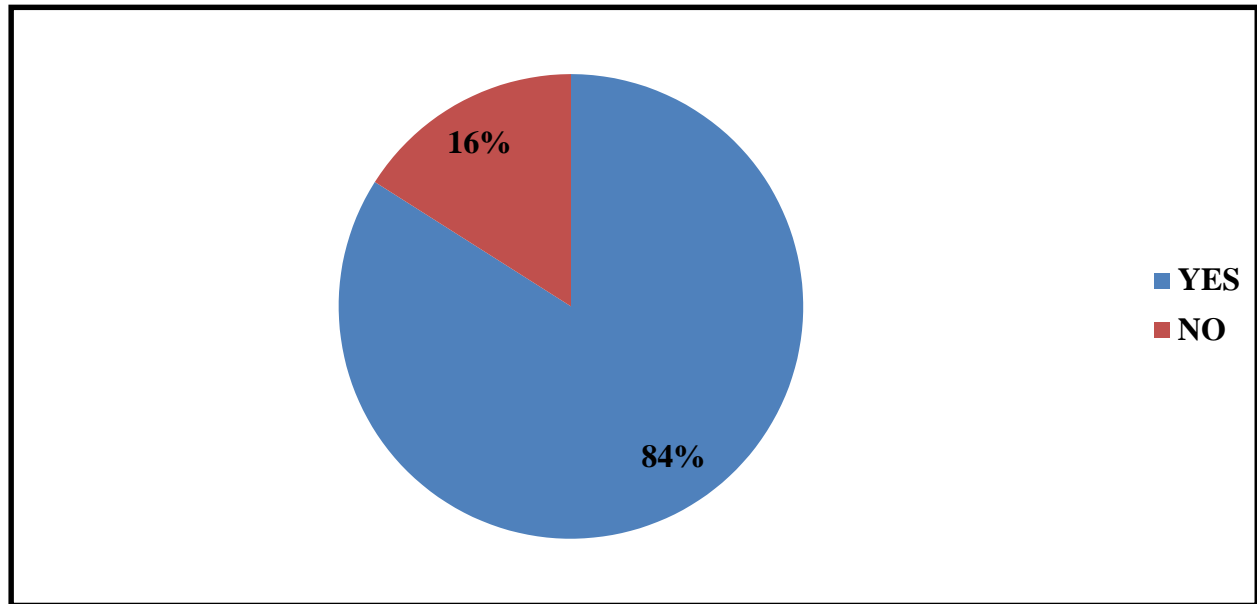


Figure 1 shows that the majority (84%) of the respondents reported that they know about epilepsy whereas the least (16%) of the respondents didn't know about epilepsy.

Table 2: Showing the respondents' thinking about the term epilepsy. (N=50)

Item	Frequency (n)	Percentage (%)
Disease of the brain	25	50
Disease of specific families	09	18
I don't know	16	32
Total	50	100

It is observed from Table 2 that half (50%) of the respondents reported that epilepsy is a disease of the brain and the least (18%) of the respondents reported that it was a disease of specific families.

Figure 2: Shows the distribution of respondents according to their knowledge about the causes of epilepsy.(N=50)

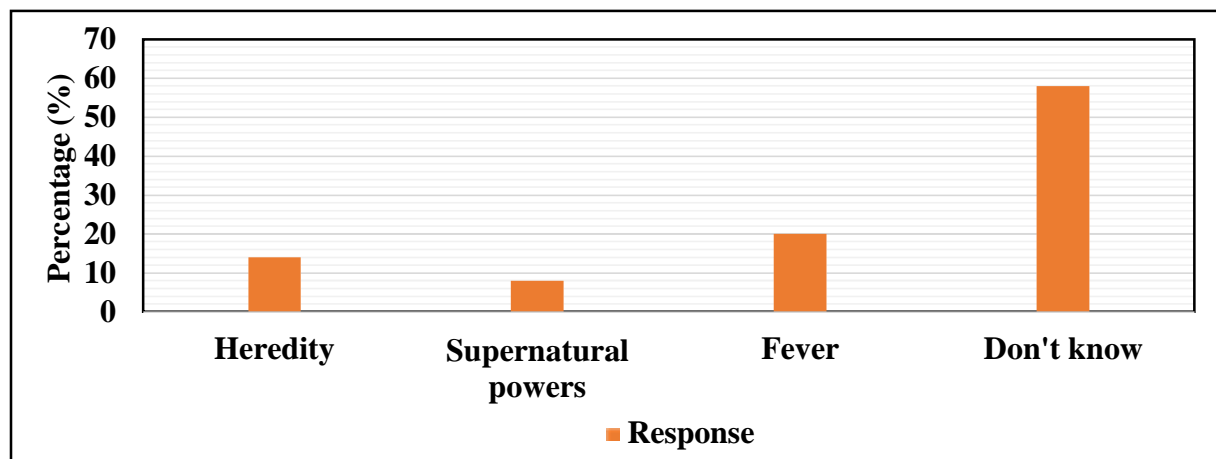


Figure 2 indicates that (58%) of the respondents interviewed reported that they did not know about the cause of epilepsy while least (8%) said supernatural powers.

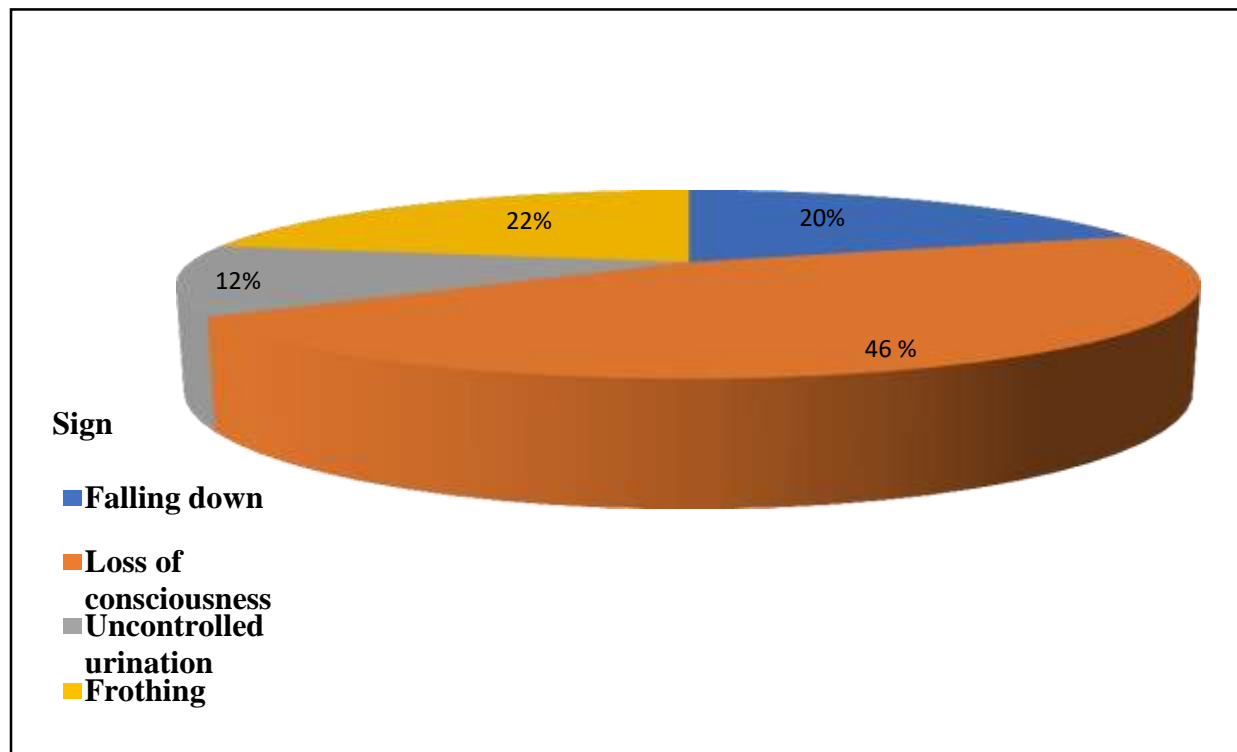


Figure 3: Shows respondents' responses according to which signs helped the caretakers to recognize an epileptic attack. (N=50)

Figure 3 shows that less than half (46%) of the respondents reported that loss of consciousness was the sign that could help caretakers recognize and attack while a minority (12%) reported uncontrolled urination.

Table 3: Showing situations that made epileptic patients experience an attack. (N=50)

Situation	Frequency (n)	Percentage (%)
Fever illness	13	26
Noise	08	16
Flickering lights	09	18
Emotional disturbance	20	40
Total	50	100

Table 3 shows that most (40%) of the respondents reported emotional disturbance while the least (16%) of the respondents mentioned noise as things or situations that made their epileptic patients experience an attack.

Attitude towards the care of epileptic patients among their caretakers.

Figure 4: Shows the distribution of respondents according to how other people think about people with epilepsy. (N=50)

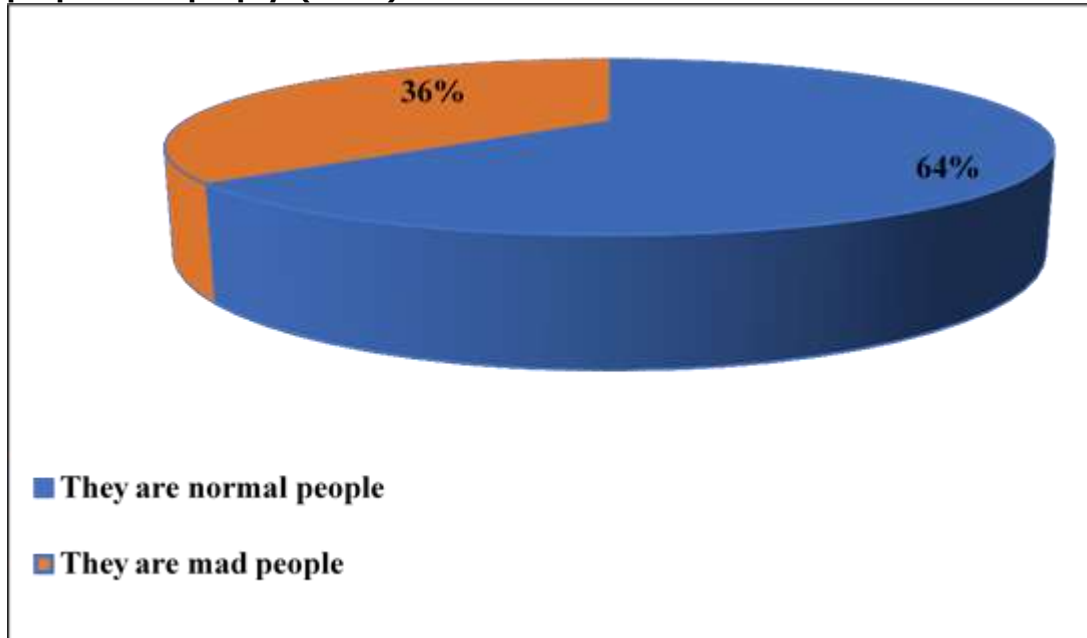


Figure 4 indicates that the majority (64%) of respondents reported that other people thought epileptic patients were normal people whereas most (36%) of the respondents reported that other people thought that epileptic patients were mad people.

Figure 5: Shows the distribution of responses according to whether epileptic patients should be employed or not.

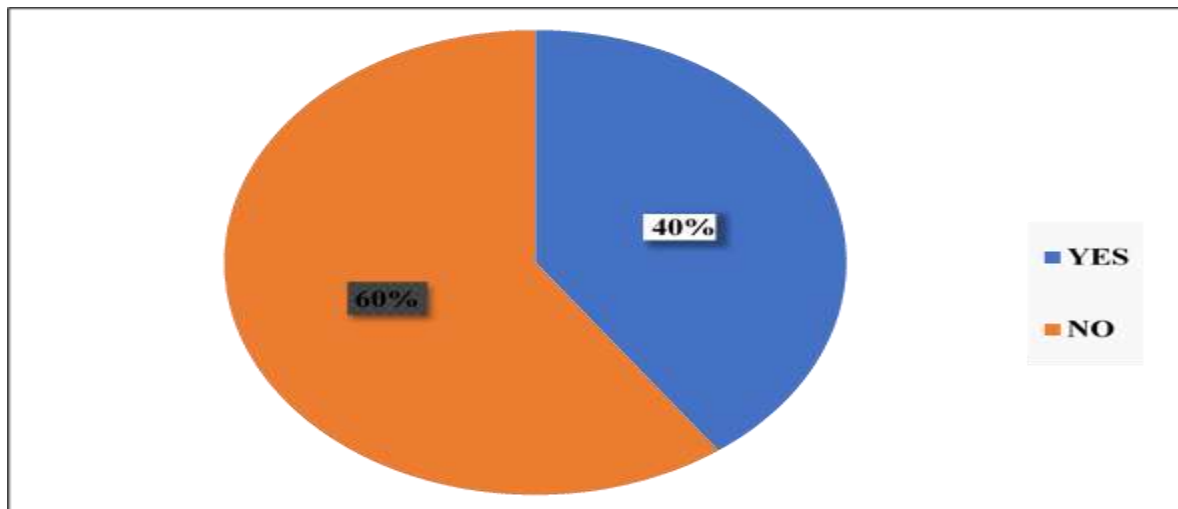


Figure 5 shows that the majority (60%) of respondents said epileptic patients should not be employed while less than half (40%) of the respondents reported that they should be employed and among those who reported that epileptic

patients should not be employed gave reasons to support their answers as; they may get attacks to work, their mental capacity is reduced, etc.

Figure 6: Showing responses about whether epileptic patients should marry or get married. (N=50)

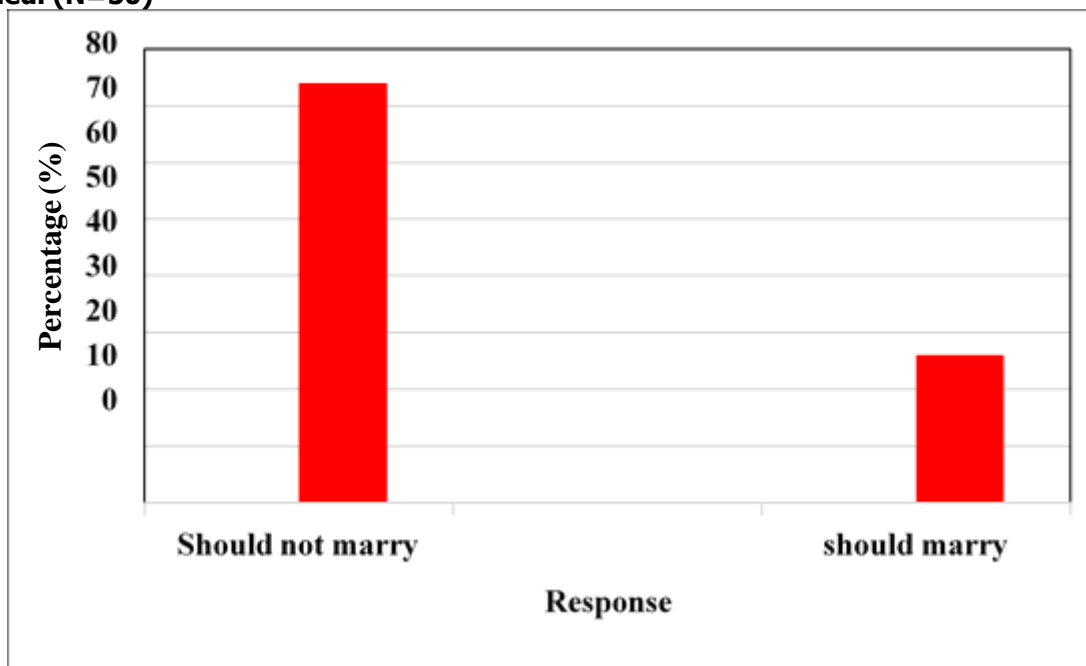


Figure 6 shows that the respondents were asked whether epileptic patients should marry or get married and a majority (74%) reported that they should not marry or get married whereas the least (26%) reported that they should marry and

among those who reported that they should not marry or get married supported their answers with reasons like, people with epilepsy are abnormal people, they will pass the disease to their children, etc.

Table 4: Shows distribution according to respondents' thinking on whether an epileptic patient should associate with others or not(N=50)

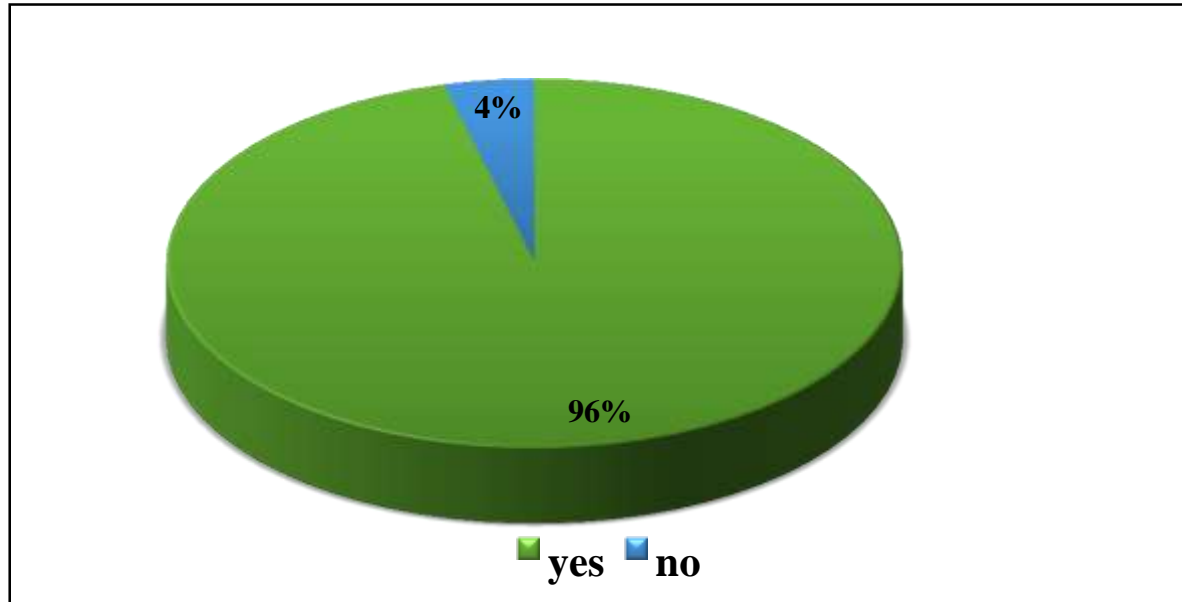
Response	Frequency (n)	Percentage (%)
Yes	42	84
No	08	16
Total	50	100

Table 4 shows that the respondents were asked whether epileptic patients should associate with others, majority (84%) of the respondents reported that epileptic patients should associate with others while the minority (16%) of the respondents reported that they should not associate with others and give reasons to support their answers as; they

can transmit the disease to other people, they may transfer the sickness/ madness to other people, etc.

The common treatment practices done by caretakers of epileptic patients.

Figure 7: Showing respondents' responses if they have ever witnessed their patients experiencing an epileptic attack (N=50)



According to figure 7, it was seen the majority (96 %) of the respondents reported that they had ever witnessed when their epileptic patients experiencing an attack while (4%) reported that they had never witnessed their patients experiencing an attack.

Figure 8: Showing respondents' responses when they rushed their patients the firsttime, they experienced an epileptic attack.(N=50)

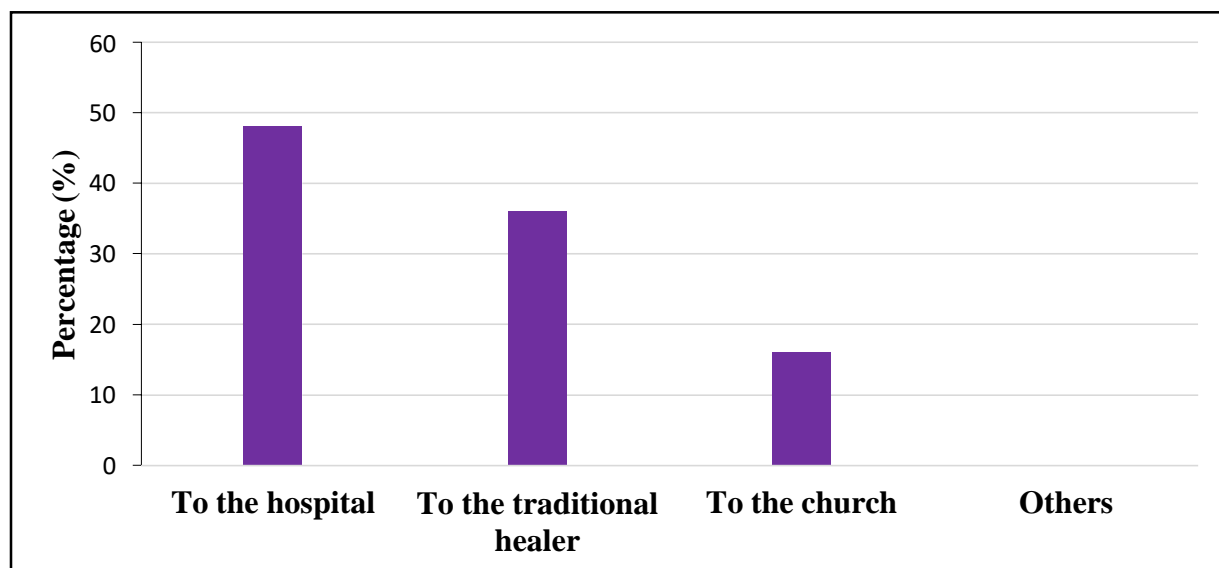


Figure 8 shows that less than half (48%) of them said they rushed their epileptic patients to the hospital the least(16%) of the respondents mentioned church.

Table 5: Showing respondents' responses about the first aid they have ever given to their patients the first time they experienced an epileptic attack. (N=50)

First aid given	Frequency (n)	Percentage (%)
Removing dangerous objects away from the patient	14	28
Protection of the patient's head	02	04
Lying the patient down	18	36
Putting an object between the teeth	10	20
Rushing the patient to the hospital.	06	12
Total	50	100

Table 5 shows that the respondents were asked to mention the first aid they have ever to their patients and most (36%) of them reported, lying down the patient and the minority (4%) of them reported protection of the head respectively.

DISCUSSIONS.

Knowledge of the care of epileptic patients among their caretakers.

The study found that the majority (84%) of the respondents knew about the term epilepsy and this was contrary to the study (Morocco Kissani, N.C, 2020). which revealed that despite having a relative with epilepsy, the participant's knowledge about epilepsy was very poor, and low levels of education and income seem to be the two major contributing factors

It also revealed that half (50%) of the respondents reported that epilepsy was a disease of the brain and this showed that there were reduced misconceptions among caretakers of epileptic patients.

Also, more than half (58%) of the respondents reported that they don't know about the causes of epilepsy however this highlights the fact that the true origin of epilepsy is unknown, unlike its associated factors.

The majority (96%) of the respondents reported that they could recognize an epileptic attack however it was more difficult to recognize a seizure in newborns and young children because seizures and convulsions are common presenting symptoms of common illnesses like severe complicated malaria among others.

It was found that less than half (46%) of the respondents could recognize an epileptic attack through observing loss of consciousness among their patients which was the most common sign of identifying an epileptic attack among people with epilepsy. Less than half (40%) reported what usually made their patients experience an attack was emotional disturbance which was true according to what

triggers an epileptic attack for example emotional disturbance like stress, sleep deprivation, anxiety, etc.

Attitude towards the care epileptic patients among their caretakers.

The research study revealed that the majority (64%) of the respondents reported that other people's thinking about epileptic patients is that they are normal people which was contrary

to the research study done in Ethiopia (Fekadu, W.M, 2019). which found out that the knowledge about the cause, possible susceptibility, better treatment options, and attitude of participants was similar to other low-income settings, the negative attitude was high and multidimensional

The study showed that the majority (60%) of the respondents reported that epileptic patients should not be employed however they supported their answers with reasons such as "they may get an attack during work".

The majority (74%) reported that people with epilepsy should not marry or get married and this coincides with a research study report ((Singh, G. 2018). This revealed that people with epilepsy frequently experience problems in marriage including reduced marital prospects, poor marital outcomes, and diminished quality of married life.

A majority (84%) of respondents reported that people with epilepsy should associate with others and among those who said that they should not associate with others mention reasons like they can transmit the illness to others.

The common treatment practices are done by caretakers of epileptic patients.

The study revealed that the majority (96%) of the respondents reported that they had ever witnessed their patients experiencing an attack.

It was also found out less than half (48%) of respondents reported that they rushed their patients to the hospital the

first time they experienced an epileptic attack this coincides with the research study in eastern Uganda (Sakar, N.B.A2021) which revealed that across all interviews highlight that chosen-help-seeking itineraries were largely pluralistic, combining and alternating between traditional healing practices, and biomedical care, regardless of the specific MNS disorder, seeking pathways-e.g., where one patient received traditional help or no care at all, while the others received biomedical care-depended on caregivers' perceived contextual illness narrative for each patient, If interpreted as a form of bewitchment, traditional medicine, and healing was often the first form of care sought.

The study findings found that most (36%) of the respondents reported that lying the patient down is the first aid they have ever given their patients when they have experienced an attack. This was in agreement with a study by (Iran, et al. 2021) which investigated the opinions of the caregivers of people with epilepsy and the related healthcare professionals about first aid measures for helping a person experiencing a seizure and found out that while

some actions may help prevent or reduce the chance of harmful consequences of epileptic seizures, but many caregivers of PWE and healthcare professionals do not apply measures to help a patient experiencing a seizure.

CONCLUSIONS.

The overall results of knowledge of the care of epileptic patients by the caretakers was satisfactory since the majority (85%) of respondents knew about the term epilepsy however they did not more about it but just at least had ever heard about it. Half (50%) of the respondents knew that epilepsy was a disease of the brain by associating it with the signs they observed whenever their patients experienced an attack. The study also illustrated that more than half (58%) of respondents did not know about the causes of epilepsy. The majority (96%) of the respondents reported that they could recognize whenever their patients experienced an epileptic attack. Less than half (46%) of respondents use the loss of consciousness as a sign that can help them to recognize an epileptic attack which is indeed the most common and always the first sign of a seizure. Less than half (40%) of the respondents associated emotional disturbance as what usually made their patients experience an attack.

Generally, the attitude towards the care of epileptic patients was not pleasing since the majority (64%) of respondents reported that other peoples' thinking about PWE is that they are normal people. A majority (60%) of the respondents also reported that PWE should not be employed. The study findings revealed that a majority (74%) of the respondents reported that PWE should not marry/ get married. The majority (84%) of respondents also reported that PWE should associate with others. However, their overall attitude reveals that their patients are prone to stigma and low self-esteem.

The overall practices carried out by the caretakers of

epileptic patients are promising to some extent because most (36%) respondents laid down the patients as the first aid they had ever given to their patients whenever they experienced an attack hence protecting them from injuring themselves during a seizure which was a good practice. The study findings also revealed that less than half (48%) of the respondents interviewed rushed their patients to the hospital the first time they experienced an epileptic attack.

Therefore researcher concluded that knowledge of the care of epileptic patients by their caretakers was fairly satisfactory because most of them knew about epilepsy however, their attitude and practices towards the care of epileptic patients were most likely to expose their patients to some degree of stigma and low self-esteem due to their believes that they are mad people, should not be employed nor get married/marry. Even though most of them rushed their patients to the hospital the first time they experienced an attack the practice of consulting the traditional healers is still a problem that needs to be addressed.

RECOMMENDATIONS.

The government through the MOH should set priorities including infrastructure strengthening, multilevel educational investments, and an ambitious, extensive program of community sensitization to eradicate misconceptions and cultural beliefs about epilepsy and PWE, these proposed priorities and actions outline a way forward through formidable but surmountable challenges but require harmonized efforts by government and other relevant stakeholders, scholars, clinicians, and community leaders.

WHO in collaboration with MOH should develop standardized seizure first aid training programs for the general public and healthcare professionals alike. There is also a need for the powerful influence of patient and family education and clearly articulated the need for community sensitization and support through engaging the private sector and community health workers, conducting community outreaches with messages tailored for audiences including the young, older epileptics,

All health workers must work to increase awareness about the cause, symptoms, and treatment options for epilepsy and to decrease the negative attitude of the community. The main objective should be to develop a multi-sectoral action plan with interventions at several different levels involving different stakeholders to mitigate the stigma associated with epilepsy in matrimony.

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LIST OF ABBREVIATIONS.

AEDs	: Anti-epileptic drugs
DALYS	: Disability-adjusted life years
EEG	: Electroencephalograms
GBD	: Global burden of disease
IHBAS	: Institute of human behavior and allied sciences
KAP	: Knowledge, attitude, and practice
MNS	: Mental, neurological, and substance use
PWE	: People with epilepsy
SUDEP	: Sudden unexpected death of epileptic patient
WHO	: World Health Organization

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