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Original Article

Knowledge, attitudes, and practices of caretakers towards Individuals with epilepsy in Punuatar Oyam district. A cross-sectional study.

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Abstract

Background:

In many African settings, including rural Uganda, epilepsy is often misunderstood and associated with myths such as witchcraft and contagion. These misconceptions contribute to stigma, negative attitudes, and poor practices toward individuals with epilepsy. This study assessed the knowledge, attitudes, and practices of caretakers towards individuals with epilepsy in Punuatar, Oyam District.

Methodology:

A cross-sectional quantitative study was conducted among 80 adult residents of Punuatar selected using systematic random sampling. Data were collected using structured questionnaires through face-to-face interviews and analyzed using SPSS. Descriptive statistics such as frequencies and percentages were used to summarize findings.

Results:

The majority of respondents were aged 35–44 years (50%), female (68.8%), had primary education (40%), and were predominantly farmers (57.5%). Most respondents (75%) had heard about epilepsy, and 70% believed it could be treated with medication. However, 53.7% attributed epilepsy to witchcraft or evil spirits, and 75% believed it was contagious. Attitudes were moderately positive, with 57.5% comfortable living with individuals with epilepsy and 50% comfortable working with them. Despite this, 60% did not allow their children to interact with affected individuals, and 67.5% perceived them as dangerous. In practice, 40% preferred taking individuals experiencing seizures to traditional healers, and 68.8% had advised others to seek spiritual or traditional treatment. Additionally, 50% reported that medical treatment for epilepsy was rarely accessed in the community.

Conclusion:

Although awareness of epilepsy exists, significant misconceptions, negative attitudes, and inappropriate practices persist, contributing to stigma and delayed medical care.

Recommendations:

The Ministry of Health should strengthen community sensitization programs to address misconceptions. The District Health Office should improve access to epilepsy treatment and train health workers, while communities should promote inclusion and reduce stigma.

Keywords: *Epilepsy, Caretakers, Stigma, Traditional beliefs, Health-seeking behavior, Punuatar Oyam district.*
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Background.

Epilepsy is a chronic neurological condition that affects approximately 50 million people worldwide, making it one of the most common neurological diseases globally (World Health Organization [WHO], 2023). It is estimated that about 80% of people with epilepsy reside in low- and middle-income countries, where access to diagnostic and treatment services is often limited (Newton & Garcia, 2021). Despite the availability of effective treatment that can control seizures in up to 70% of cases, the majority of affected individuals in low-resource settings do not receive appropriate care (WHO, 2023).

In many African settings, epilepsy remains heavily stigmatized due to cultural beliefs and myths that associate it with witchcraft, contagion, or possession by evil spirits (Atim, Orach, & Opar, 2022). These misconceptions result in negative community attitudes, discrimination, and social exclusion of individuals living with epilepsy (Kaggwa, Kajjimu, Najjuka, & Nduwimana, 2023).

In sub-Saharan Africa, epilepsy is not only underdiagnosed and undertreated but also surrounded by harmful practices, such as tying up patients during seizures or seeking help from traditional healers rather than medical professionals (Abbo, Maling, & Kinyanda, 2020). These practices are often driven by a lack of knowledge about the nature and management of the condition, which further reinforces stigma and delays proper treatment (Kaggwa et al., 2023). As a result, epilepsy in this region continues to be a major public health challenge with significant social and economic implications (Newton & Garcia, 2021).

Uganda, like many low-income countries, has a significant epilepsy burden, with prevalence estimates ranging between 10 and 15 per 1,000 individuals (Ministry of Health Uganda, 2020). Although the government has made efforts to integrate epilepsy services into the primary healthcare system, limited awareness and deeply rooted cultural beliefs remain barriers to effective care (Atim et al., 2022). Studies in rural Uganda show that many community members still believe epilepsy is contagious or caused by curses, leading to fear-based reactions and limited support for affected individuals (Nakigudde et al., 2021).

In northern Uganda, particularly in districts such as Oyam, there is limited access to specialized epilepsy care and community-based health education programs (Abbo et al., 2020). Local populations often rely on traditional explanations and remedies, which hampers timely medical intervention and perpetuates stigma (Atim et al., 2022). In areas like Punuatar, a rural sub-county in Oyam District, these challenges are likely exacerbated by poverty, low literacy levels, and minimal health infrastructure (Ministry of Health Uganda, 2020).

There is a scarcity of localized data on the knowledge, attitudes, and practices of rural Ugandan communities toward epilepsy, despite increasing evidence of how community perceptions impact care and quality of life for patients (Kaggwa et al., 2023). Conducting a study to explore the knowledge, attitudes, and practices of residents in Punuatar will help bridge the gap between national health policies and actual community realities. This study assessed the knowledge, attitudes, and practices of caretakers towards individuals with epilepsy in Punuatar, Oyam District.

Methodology.

Study Design

This study utilized a cross-sectional quantitative research design to assess the knowledge, attitudes, and practices (KAP) of residents of Punuatar towards individuals with epilepsy in Oyam District.

Study setting.

The study was conducted in Punuatar, a rural sub-county located in Oyam District, Northern Uganda.

Study Population.

The target population included adult residents aged 18 years and above who have resided in Punuatar for a minimum of six months. Adults were selected as they are more likely to possess knowledge and hold attitudes and practices relevant to epilepsy within their community.

Sample Size Determination.

The sample size was determined using **Yamane's (1967) formula** for a known population:

$$n=\frac{N}{1+N(e)^2}$$

Where:

- n = sample size
- N = estimated population of individuals with epilepsy (**100**)
- e = margin of error (**0.05**)

$$n=\frac{100}{1+100(0.05)^2}$$

n=80

Thus, the calculated sample size was **80 respondents.**

Sampling method and procedure

This study employed a systematic random sampling technique to select individuals in the Punoatar community. The first participant was selected randomly from the first k individuals using simple random sampling (for example, by drawing lots). Subsequently, every kth community caretaker who met the inclusion criteria was selected until the desired sample size was attained. This sampling method ensured that each individual member of Punoatar had an equal and known chance of selection, thereby reducing selection bias and enhancing the representativeness of the sample.

Inclusion and exclusion criteria

Inclusion Criteria:

- Adults aged 18 years and above.
- Residents of Punuatar for at least six months.
- Willing and provided informed consent.

Exclusion Criteria:

- Visitors or non-residents.
- Individuals with cognitive impairments or serious illnesses that impede participation

Study Variables

Independent variables

included knowledge, attitude, and practices

Dependent variables

included individuals with epilepsy.

Research Instruments

Data was collected using a structured questionnaire developed based on previously validated KAP tools relevant to epilepsy. The questionnaire had four sections:

sociodemographic information, knowledge, attitudes, and practices towards epilepsy. Questions were closed-ended to facilitate quantitative analysis.

The questionnaire was translated into the local language (Lango) for individuals who had difficulty understanding English and was back-translated to maintain consistency. It was pretested on 5% of the sample (3 individuals) in a neighboring sub-county to ensure clarity and reliability. Adjustments were made based on pilot feedback.

Data Collection Procedure

Data was collected through face-to-face interviews conducted by trained research assistants fluent in English and Lango. Upon obtaining informed consent, the assistants administered the questionnaire in a private setting, usually at respondents' homes, to ensure privacy and reduce response bias. Each interview was estimated to take approximately 25–30 minutes.

Data Management and Analysis

Completed questionnaires were checked daily for completeness and consistency. Data was coded and entered into a password-protected database. Backup copies were maintained to prevent data loss. Data was analyzed using SPSS. Descriptive statistics (frequencies, percentages, and means) summarized socio-demographic characteristics and other factors. Results were presented in tables, charts, and narrative summaries.

Quality Assurance: Validity and Reliability

Validity was ensured by submitting the questionnaire to the research supervisor for evaluation of item relevance in relation to the study objectives. Any inappropriate or irrelevant items were replaced with suitable ones.

Reliability was addressed through the use of a standardized questionnaire. A pilot study involving five community members was conducted to assess comprehension and interpretation of the questions. Based on the findings, necessary adjustments were made in consultation with the supervisor. To further enhance reliability, the researcher personally administered all questionnaires to minimize data collection bias.

Ethical Considerations

A letter of introduction was obtained from the Principal of Florence Nightingale School of Nursing and Midwifery, introducing the researcher and seeking permission to carry out the study from the administration of the Punoatar community. After permission was granted, the researcher was introduced to the chairman, LC1 of Punuatar, who introduced the researcher to the respondents. Participants were assured of maximum confidentiality, and numbers instead of names were used to identify respondents. The study only commenced after the objectives of the study had been well explained to participants, and they had understood and consented to participate in the study.

RESULTS.

Socio-demographic characteristics of the respondents

The majority of respondents were aged 35–44 years, 40(50%), while the least were aged 18–24 and 45 and above, 10(12.5%) each. Most respondents were female, 55(68.8%), compared to the fewest who were male, 25(31.2%). The majority had attained primary education, 32(40%), whereas the least had no formal education, 10(12.5%). Most respondents were farmers, 46(57.5%), while the least were in other occupations, 8(10%). The majority had stayed in Punuatar for 6–10 years 45(56.3%), whereas the least had stayed less than 1 year 5(6.2%).

Table 1: showing socio-demographic characteristics of the respondents (n=80)

Variable	Category	Frequency (f)	Percentage (%)
Age	18-24	10	12.5
	25-34	20	25
	35-44	40	50
	45 and above	10	12.5
Gender	Male	25	31.2
	Female	55	68.8
Highest Level of Education	No formal education	10	12.5
	Primary	32	40
	Secondary	24	30
	Tertiary	14	17.5
Occupation	Farmer	46	57.5
	Trader	15	18.8
	Employed	11	13.7
	Other (specify)	8	10

Duration of Stay in Punuatar	Less than 1 year	5	6.2
	1–5 years	10	12.5
	6–10 years	45	56.3
	More than 10 years	20	25

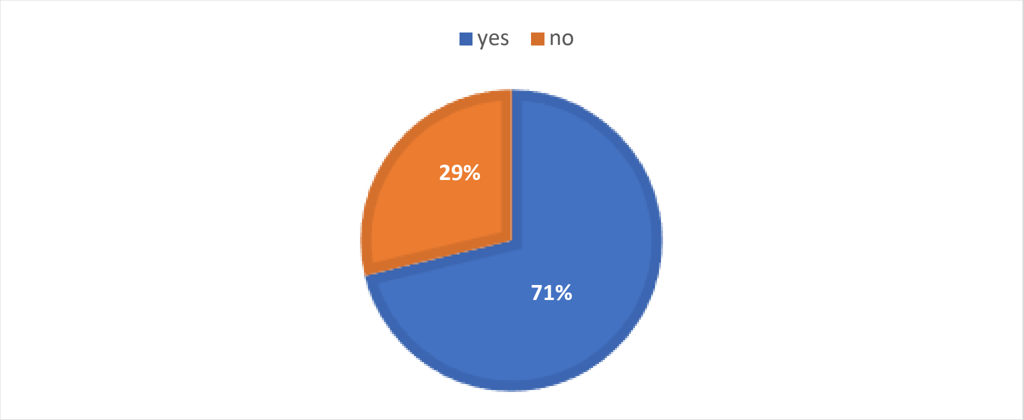
Knowledge of caretakers Towards Individuals with Epilepsy.

The majority of respondents had heard about epilepsy, 60(75%), while the least had not, 20(25%). Most respondents perceived epilepsy to be caused by witchcraft or evil spirits, 43(53.7%), compared to the least who did not know its cause, 5(6.3%). The majority believed epilepsy can be treated with medication, 56(70%), whereas the least did not know, 4(5%). Most respondents believed that epilepsy is contagious, 60(75%), while the least did not know, 5(6.2%).

Table 2: showing knowledge of caretakers Towards Individuals with Epilepsy (n=80)

Variable	Category	Frequency (f)	Percentage (%)
Heard about epilepsy	Yes	60	75
	No	20	25
Perceived causes of epilepsy	Brain disease or injury	10	12.5
	Witchcraft or evil spirits	43	53.7
	Hereditary/family condition	22	27.5
	Don’t know	5	6.3
Can epilepsy be treated with medication?	Yes	56	70
	No	20	25
	Don’t know	4	5
Belief that epilepsy is contagious	Yes	60	75
	No	15	18.8
	Don’t know	5	6.2

Figure 1; showing whether respondents believe people with epilepsy can live a normal life (n=80)



The majority of respondents believed that people with epilepsy can live a normal life, 57(71%), while the least did not, 23(29%).

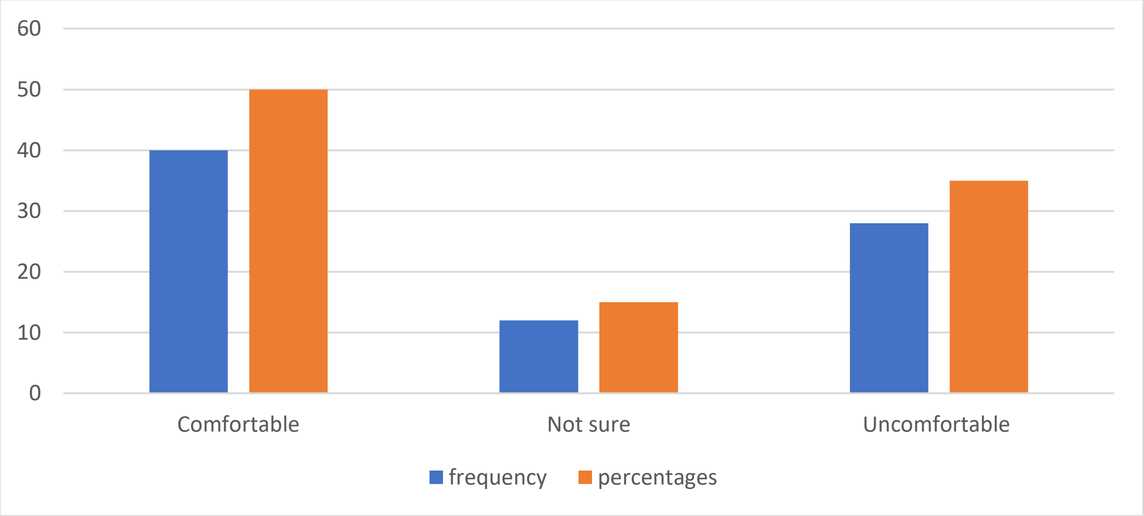
Attitudes of caretakers Towards Individuals with Epilepsy

The majority of respondents were comfortable having a person with epilepsy as a neighbor, 46(57.5%), while the least were not, 34(42.5%). Most respondents believed that people with epilepsy should marry and have children, 42(52.5%), compared to the fewest who did not, 38(47.5%). The majority did not allow their child to play or attend school with a child with epilepsy, 48(60%), whereas the least allowed it, 32(40%). Most respondents believed that people with epilepsy are dangerous or should be feared, 54(67.5%), while the least did not, 26(32.5%).

Table 3: showing attitudes of caretakers Towards Individuals with Epilepsy (n=80)

Variable	**Category**	**Frequency (f)**	**Percentage (%)**
Comfort with a person with epilepsy as a neighbor	Yes	46	57.5
	No	34	42.5
The belief that people with epilepsy should marry and have children	Yes	42	52.5
	No	38	47.5
Allow a child to play/attend school with a child with epilepsy	Yes	32	40
	No	48	60
Belief that people with epilepsy are dangerous/should be feared	Yes	54	67.5
	No	26	32.5

Figure 2: showing comfort working with someone with epilepsy (n=80)



The majority of respondents were comfortable working with someone with epilepsy, 40 (50%), while the minority were not sure, 12 (15%).

Practices of caretakers Towards Individuals with Epilepsy (n=80)

The majority of respondents would take a person having a seizure to a traditional healer, 32(40%), while the least would remove dangerous objects from around the person, 12(15%). Most respondents had advised someone to seek traditional or spiritual healing instead of medical treatment, 55(68.8%), compared to the least who had not, 25(31.2%). The majority considered it inappropriate to isolate or avoid people with epilepsy during community activities, 47(58.9%), whereas the least considered it appropriate, 33(41.2%). Most respondents indicated that it is rare for people with epilepsy to receive medical treatment in the community, 40(50%), while the least indicated it never happens, 5(6.2%).

Table 4: showing practices of caretakers Towards Individuals with Epilepsy (n=80)

Variable	**Category**	**Frequency (f)**	**Percentage (%)**
Action if witnessing a seizure	Call a health professional immediately	25	31.2
	Remove dangerous objects from around the person	12	15
	Take the person to a traditional healer	32	40
	Other (please specify)	11	13.8
Advised someone to seek traditional medical treatment	Yes	55	68.8
	No	25	31.2

Appropriateness of isolating people with epilepsy	Yes	33	41.2
	No	47	58.9
Frequency of people with epilepsy receiving medical treatment in the community	Very common	15	18.8
	Somewhat common	20	25
	Rare	40	50
	Never	5	6.2

Discussion.

Knowledge of caretakers towards Individuals with Epilepsy.

More than half of the respondents perceived epilepsy to be caused by witchcraft or evil spirits, while a few did not know its cause. This finding shows that supernatural beliefs remain dominant in shaping community understanding of epilepsy, often overshadowing biomedical explanations. Such beliefs arise from limited awareness about epilepsy as a neurological condition caused by abnormal electrical activity in the brain, leading communities to interpret seizures through cultural or spiritual lenses. Similar findings by Abbo, Maling, and Kinyanda (2020) revealed that in many communities, epilepsy is commonly attributed to witchcraft or evil spirits, which delays appropriate medical care and increases stigma. This implies that there is a critical need for intensified community health education to correct misconceptions, promote timely treatment, and reduce stigma associated with epilepsy.

The majority believed epilepsy can be treated with medication, 56(70%), while the least, 4(5%), did not know. This reflects increasing awareness that epilepsy is a neurological condition that responds well to consistent medication use, rather than a spiritual or supernatural problem. Similar studies in sub-Saharan Africa, however, show that misconceptions still remain widespread; for instance, Nakigudde et al. (2021) reported that many individuals were unaware of the medical nature of epilepsy or the availability of treatment. Likewise, Kaggwa et al. (2023) found that in rural Uganda, fewer than half of community members could correctly identify epilepsy as a brain disorder, with others believing it was contagious or hereditary. The implication is that although awareness of medication as treatment is improving, continuous community sensitization is needed to address the remaining misconceptions and enhance timely health-seeking behavior.

Attitude of caretakers towards Individuals with Epilepsy

The majority of respondents were comfortable having a person with epilepsy as a neighbor, 46(57.5%), while the least were 34(42.5%). Comfort with living near a person with epilepsy reflects improved understanding that epilepsy is a medical condition rather than a transmissible or harmful disorder. However, a substantial proportion still expressed discomfort, showing that misconceptions persist. In many African contexts, epilepsy is commonly linked to supernatural causes such as witchcraft, evil spirits, or divine punishment, which contributes to fear, discrimination, and social distancing (Abbo, Maling, & Kinyanda, 2020). The implication is that while attitudes are improving, targeted community education is needed to dispel longstanding myths, promote acceptance, and support the full integration of individuals with epilepsy into community life.

The findings showed that the majority of respondents were comfortable working with someone with epilepsy 40 (50%), while the minority were not sure 12 (15%), and scientifically this may be because individuals with some basic awareness or prior exposure to epilepsy tend to feel more at ease, whereas those who are unsure often lack accurate information and therefore remain hesitant; this relates to broader community perceptions where uncertainty and misconceptions commonly contribute to social distance and fear, and the implication is that despite most people being accepting, the presence of hesitant individuals can still create barriers that negatively impact the psychological well-being of people living with epilepsy and limit their access to opportunities such as education, employment, and social engagement (Newton & Garcia, 2021).

Practices of caretakers towards Individuals with Epilepsy

The findings showed that most respondents had advised someone to seek traditional or spiritual healing instead of medical treatment, 55 (68.8%), compared to the fewest who had not, 25 (31.2%). This may be because many community members believe epilepsy has supernatural causes, making traditional or spiritual healers seem more appropriate than medical professionals; this relates to evidence from sub-Saharan Africa showing that traditional and faith-based healing is often preferred due to cultural norms and limited access to biomedical services (Abbo, Maling, & Kinyanda, 2020). This implies that such preferences can delay effective treatment, reinforce misconceptions about epilepsy, and negatively affect the health outcomes and quality of life of people living with the condition.

The findings showed that most respondents indicated it is rare for people with epilepsy to receive medical treatment in the community, 40 (50%), while the least indicated it never happens, 5 (6.2%). This may be because many community members rely on herbal remedies and spiritual rituals, reflecting limited awareness of epilepsy as a medical condition; this relates to evidence from rural Uganda, where traditional practices are commonly used for seizure control, often delaying the start of antiepileptic medication (Nakigudde, Mutamba, & Okello, 2021). This implies that such practices can hinder timely medical care, worsen seizure management, and perpetuate misconceptions and stigma around epilepsy.

Conclusion

The study showed that while most caretakers had heard about epilepsy and recognized that it can be treated with medication, many still attributed its cause to witchcraft or evil spirits and believed it to be contagious.

Attitudes toward people with epilepsy were somewhat positive, with many respondents comfortable living near or working with them and believing they could live normal lives. However, stigma remained evident, as some restricted children from interacting with peers with epilepsy or perceived them as dangerous.

In practice, traditional or spiritual healing was commonly preferred over medical treatment, and access to formal care was seen as limited. Such practices can delay effective treatment and worsen outcomes.

Limitation of the Study

The small sample size limited the generalizability of the findings to the wider population of Punuatar and beyond.

Additionally, self-reported data may have been affected by social desirability bias, particularly regarding attitudes and practices.

Recommendations

The Ministry of Health (MoH) should implement targeted community health education programs to increase awareness about epilepsy, emphasizing its neurological causes, treatment options, and non-contagious nature to reduce misconceptions and stigma.

The District Health Office (DHO) of Oyam should strengthen healthcare services by ensuring the availability of antiepileptic medications, training health workers on epilepsy management, and supporting community-based interventions to promote timely medical treatment.

The community should foster positive attitudes and social inclusion of people with epilepsy by accepting them in homes, schools, and workplaces, and discouraging practices that isolate or discriminate against them.

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List of abbreviations.

DHO – District Health Office
KAP – Knowledge, Attitudes, and Practices
LC1 – Local Council One
MoH – Ministry of Health
SPSS – Statistical Package for the Social Sciences
WHO – World Health Organization

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The study was not funded.

Conflict of interest.

There is no conflict of interest.

Availability of data.

Data used in this study are available upon request from the corresponding author.

The author's contribution.

JO designed the study, conducted data collection, cleaned and analyzed data, and drafted the manuscript.

RA supervised all stages of the study from conceptualization of the topic to manuscript writing and submission.

DO supervised all the research process.

TMO supervised the research process.

LO supervised the research process.

Author's biography.

Justine Owor is a student of a diploma in nursing extension at Florence Nightingale School of Nursing and Midwifery.

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