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## Exploration of Knowledge, Attitudes and Practices Among Family Caregivers Towards Epileptic Patients in a Selected District in Rwanda.

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### **Abstract**

This study explored how, in low income countries, the care of persons with epilepsy often falls onto family members and friends. This study aimed at exploring the knowledge, attitudes and practices among family caregivers of epileptic patients in their community. An exploratory-descriptive design was used and data were collected using a face-to-face questionnaire to interview 60 family caregivers of epileptic patients. Data were analyzed using SPSS version 18. The Chi-Square test ( $\chi^2$ ) was used and considered  $p$ -value 0.05 as the level of significance at 95% Confidence Interval (95% CI). Findings of this study showed the majority of respondents (98.3%) have helped or seen an epileptic while convulsing. The study has shown also a strong relationship between the level of education and knowledge of the disease and attitudes and practices done to epileptic patients.

**Keywords:** Attitudes, Family Caregiver, Knowledge, Practices, Seizures, Quality of life

### **1. Introduction**

Epilepsy is a major public health concern that affects an estimated 50 million worldwide and involves an additional many people such as family member caregivers of patients [1-5].

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Family circumstances such as family caregiver characteristics, social support are among factors contributing to quality of life in epilepsy [6-10]. Low and middle income countries are not accredited to not have patients with epilepsy [5,7]. Therefore, the care of persons with epilepsy often falls onto family members and friends [10,11]. This study was conducted in chronic care clinic at Kirehe district hospital in Eastern province of the republic of Rwanda to explore knowledge, attitudes and practices among family caregivers of epileptic patients in their community.

Epilepsy is a major public health concern, directly affecting an estimated 50 million people worldwide, around 80% reside in resource-poor countries, which are ill-equipped to tackle the enormous challenges posed by epilepsy and involving an additional 500 million people as family members and caregivers of patients [1, 9-15]. Even if it was showed that most adult patients with epilepsy live alone and manage themselves, significant proportions are dependent on family members and partners for medical care [1,5,14]. The authors [1,15] have reported that in China and India epilepsy is commonly viewed as a reason for prohibiting or concealing marriages while in the United Kingdom (UK), a law forbidding people with epilepsy to marry was repealed only in 1970. They [1,15] reported also that in the United States, until the 1970s, it was legal to deny people with seizures access to restaurants, theatres, recreational centers and other public buildings. However, in Low and Middle Income Countries (LMICs), the care of persons with epilepsy often falls onto family members and friends [1,5,11,15]. These authors confirmed that one of the major conflicts in LMICs is the community's beliefs of the cause of epilepsy, in many societies, epilepsy is not thought to be caused by diseases of the brain, but is attributed to traditional beliefs such as spirits and thus its treatment. Studies [7,10,16,17] have revealed that people with epilepsy and their family members have limited knowledge of epilepsy, therefore this results in many complications and impairment of their understanding of epilepsy and the need to take antiepileptic drugs daily due to cognitive impairment and psychiatric disorders. Other studies [1,3,8,17] showed the gaps in the level of knowledge and understanding about epilepsy among relatives of epileptic patients and the needs of community educational programmes to bridge those gaps, ameliorate misconceptions and minimize the social stigma. Also, many researches [1,17] on caregiver impression of the patient's quality of life have consistently shown that family caregiver's positive appraisal of the patient has a positive impact on patient's clinical outcome. Their impression was also a significant predictor of the overall quality of life of the patient and that of the caregiver [2,4,8,18]. The majority of people with epilepsy (59.6%) had never received medical treatment for it in Rwanda [7,8,14]. Furthermore this disease was as well associated with a significantly reduced quality of life of epileptic patients and as it was identified by a case history and physical examination, an accident during a seizure caused permanent musculoskeletal impairment [19]. However, this study didn't address epilepsy management especially on knowledge, attitudes and practices among family caregivers who give the first assistance to epileptic patients in the community when the seizures surprise them.

## **2. Methods**

An exploratory-descriptive design was used in this study. Data were collected using a face-to-face questionnaire to interview 60 family caregivers who accompanied epileptic patients. Questionnaires were filled in alongside the interview by the researcher. Data were analyzed using the Statistical Package for Social Sciences, Version 18.0. The Chi-Square test ( $\chi^2$ ) was used and considered p-value 0.05 as the level of significance at 95%

Confidence Interval (95% CI).

### 3. Discussion

A total of 60 participants took part in the study. The respondents were between 15 and 66 years old. The mean age of respondents was 28.1 years old with Standard Deviation of 10.59. The skewness of the curve on the right side shows that the majority of respondents were between the age of 15 and 45 and fewer of them were between the age of 45 and 66(Figure 1).

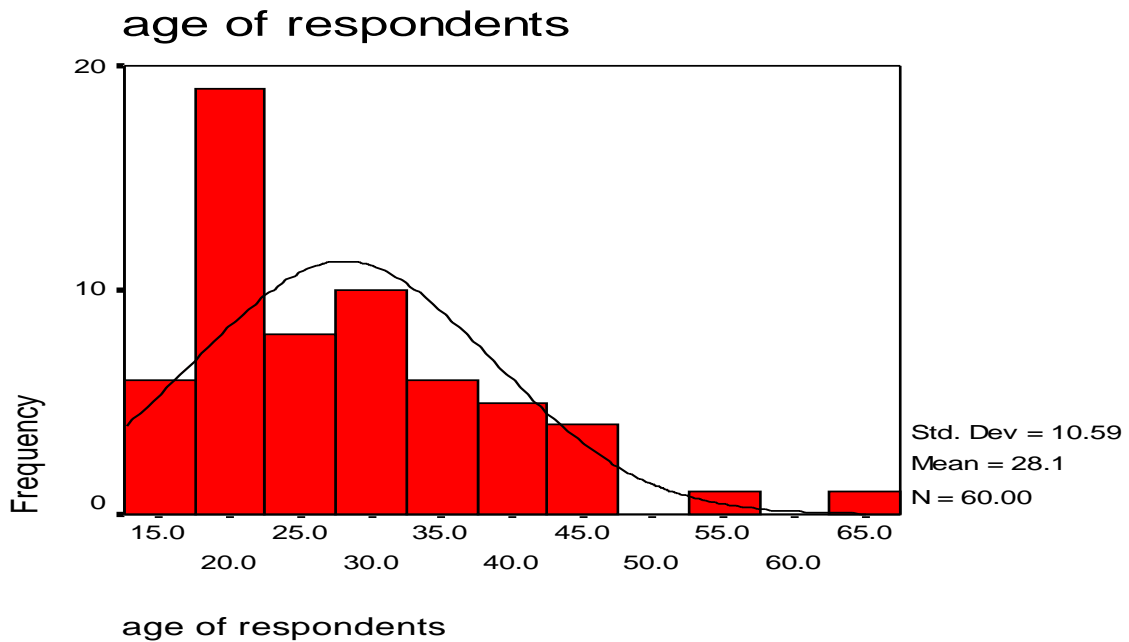


Figure 1: Age of respondents

The majority of respondents confirmed that the cure of epilepsy is achieved by different therapies including modern and both traditional and modern (**Table 1**). This have been shown in other studies [3,5,10] where respondents confirmed the use of several types of treatment that vary between the traditional, medical, educational, and religious treatment. This finding shows the reason why people in this country turn to traditional healers. Even if this study shows that the cure of epilepsy is achievable by modern medication (38.3%), a strong network of traditional and modern medication (28.3%) was found, this means that traditional healers may be found providing a parallel system of health care in Rwanda due to the belief in supernatural causes of epilepsy [10,14]. Although 76.7% of family caregivers said that patients should not miss even one dose of antiepileptic drugs, more than 30% believed that taking antiepileptic drugs will impair memory. This may be attributable to some antiepileptic drugs causing drowsiness, leading to the conclusion that antiepileptic drugs have a harmful effect on brain function, particularly on memory [5,7,11,13].

**Table 1 Knowledge of family caregivers about treatment of epilepsy**

The treatment of epilepsy	Frequency	Percentage
It is a fatal disease, there is no treatment	4	6.70%
Cure is achievable by magic/religious practices	15	25%
Cure is achievable by traditional medication	1	1.70%
Cure is achievable by modern medication	23	38.30%
Cure is achievable by modern and traditional	17	28.30%
<b>Total</b>	<b>60</b>	<b>100%</b>

Few of respondents in this study believed that antiepileptic drugs destroy the liver and kidneys. Considering that person with epilepsy (PWE) have to take antiepileptic drugs(AEDs) for an extended period, it is quite possible for family caregivers to have misconceptions regarding their side effects [5,7]. It is also likely that in Kirehe(Kibungo), which is still strongly influenced by traditional remedies, respondents believe that antiepileptic drugs damage the liver and kidneys in a way similar to herbal medicine. These results imply that the respondents are less well informed on certain important issues, but still have specific misconceptions [2,5]. The practices of family care givers to face an epileptic attack (**Table 2**), the majority of respondents promptly move the patient away from immediate danger (78.3%) which is consistent with the study done in Sudan [17]. Around 73.3% of the respondents in this study indicated the appropriateness of putting an object into the patient's mouth to prevent tongue biting when seizure occurs, which is lower than in other studies carried out in China [8],in Pakistan [1] , in Sudan [17]. Regrettably, this misconception is still publicized by the mass media.

**Table 2 Distribution of family caregivers by their practices towards epileptic attack**

Practices towards epilepsy	Answers	Frequency	Percentage
Have ever helped or seen an epileptic while convulsing	Yes	59	98.3%
	No	1	1.7%
Attach the patient	Yes	28	46.7%
	No	32	53.3%
Avoid touching patients during seizures	Yes	15	25%
	No	45	75%
Avoid touching patient's saliva.	Yes	16	26.7%
	No	44	73.3%
Bind the patient or keep hold of the patient's limbs	Yes	17	28.3%
	No	43	71.7%
Try to push drugs into the patient's mouth	Yes	21	35%
	No	39	65%

Promptly move the patient away from immediate danger	Yes	47	78.3%
	No	13	21.7%
Lay the patient on his or her side.	Yes	41	68.3%
	No	19	31.7%
Remove food from mouth	Yes	35	56.7%
	No	25	41.7%
Prevent tongue biting	Yes	44	73.3%
	No	16	26.7%

The majority of the negative attitudes toward epilepsy were significantly associated with the misunderstanding of epilepsy (**Table 3**). The negative attitude seemed to be similar with other reported studies in USA and China [8], in Pakistan [1,3]. This negative attitude towards epilepsy appears to be universal. In the USA, 18 states prohibited people with epilepsy from marrying and ,United Kingdom a law prohibiting people with epilepsy from marrying was not repealed until 1970 [8], and in some parts of the world where epilepsy is still generally viewed as a reason for concealing marriages [7,14,20].

**Table 3 Distribution of family caregivers by their attitudes towards epilepsy**

Attitudes towards epilepsy	Answers	Frequency	Percentage
Epilepsy is a hindrance to a happy life	Yes	59	98.3%
	No	1	1.7%
It is not possible for an epilepsy patient to lead a married life	Yes	30	50%
	No	30	50%
Epilepsy affects the education of a person.	Yes	51	85%
	No	9	15%
Epilepsy patients cannot work like other people	Yes	19	31.7%
	No	41	68.3%
Do you think society discriminates against persons with epilepsy?	Yes	18	30%
	No	42	70%
Would you allow your child to play with a child with epilepsy	Yes	39	65%
	No	21	35%
Would you allow your child to marry a person with epilepsy	Yes	33	55%
	No	27	45%

This study shows also a discrimination against epileptic patients in the society. Of 60 respondents, 31.7% of respondents said that an epileptic cannot work like other people while 55% of respondents said that they would

not allow their children to marry an epileptic patient. This may be due to the society that believe the epilepsy to be high contagious [2,18] and shameful disease in the eyes of the public [2,14], because of these factors persons with epilepsy may be shunned and discriminated against in the society and consequently remain in the shadow of the treatment gap [2,14,21].

The comparison between the practices and the level of education was performed using the Pearson chi-square ( $\chi^2$ ) test which was significant ( $\chi^2=0.001$ ) among family caregivers who attach the patient to avoid injury and their level of education, and among family caregivers who promptly move the patient from immediate danger and their level of education, however the test was slightly significant ( $\chi^2=0.04$ ) among family caregivers who prevent tongue biting and their level of education.

#### 4. Conclusion

The results of the present study indicate that epilepsy is still not well known among family caregivers who assist and give the first care in their communities to epileptic patients attending the chronic care clinic at district hospital level. The majority lacks correct information on the causes, contagiousity, nature and treatment of the disease. In this study, it was shown that positive attitudes and practices were related to the level of education and knowledge of the disease. Therefore, one can conclude that attitudes and practices towards people with epilepsy depend on the knowledge of this disease and the level of education. The findings of this study show that health promotion interventions could aim at increasing awareness and knowledge of epilepsy and its management among family care givers of epileptic patients.

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