Global Scientific JOURNALS

GSJ: Volume 10, Issue 5, May 2022, Online: ISSN 2320-9186
www.globalscientificjournal.com

PSYCHOSOCIAL BURDEN AND ASSOCIATED FACTORS AMONG PRIMARY CAREGIVERS OF EPILEPTIC PATIENTS IN KAYONZA, RWANDA

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Key Words: Associated factors, Burden, Epilepsy, Primary caregivers, Psychosocial burden

ABSTRACT

Background: Worldwide, epilepsy affects around 50 million of people. More than 85% of epileptic cases are found in low and middle income countries especially in Africa. In Rwanda, the prevalence of epilepsy was estimated to be 49 per 1000 people or 41 per 1000 for active epilepsy. This study was to assess psychosocial burden and associated factors among primary caregivers of epileptic patients in Kayonza district, Rwanda.

Methods: This was a cross-sectional study and quantitative in nature. This study target population was all primary caregivers of epileptic patients in Kayonza District. A sample size of 246 caregivers was randomly selected. A structured questionnaire was used to collect data and all interviews were conducted face to face. The study questionnaire included the 22-questions adopted from Zarit Burden Interview that were used to collect data on the caregiver's psychosocial burden. The collected data was directly recorded into REDCap forms before being exported to Stata v15.1 for analysis. Caregiver and patient's characteristics were described using frequency and percentages for categorical data and median and interquartile range for continuous data. The overall score on the ZBI's 22 items was categorized as high level of burden when greater than mean score (50.1) or as low burden otherwise. Chi-squared and Wilcoxon rank sum tests and logistic regression were used to identify factors associated with the level of psychosocial burden.

Results: Of the caregivers, 83% were female. The caregivers aged between 19-34 years old were 19. 1% and 15% aged ≥65 years. Of the respondents, 61% were in *Ubudehe* category I or II, while the monthly income was ≤10,000 (Rwf) for 73% of caregivers. For the patients' characteristics, the estimated duration of disease was less than a year for 13.4% patients, between 1-5 years for 31.7% patients and >10 years for 31.3% patients. About 25% of caregivers were providing care to patients with ≥ 11 seizures monthly and 21% reported that their patients were having poor medication adherence. In the bivariate analysis, factors associated with level of psychosocial burden were caregiver's age ($p<0.003$), family size ($p=0.006$), *ubudehe* category ($p=0.047$), monthly income ($p=0.014$), duration of epilepsy ($p=0.003$), patient's number of seizures per month ($p=0.001$) and adherence to medication ($p<0.001$). In the final multivariable logistic regression model, increased odds of high level of psychosocial burden were significantly associated with the increased caregiver's age and the caregiver reporting that her patient was not adhering to treatment (OR: 4.47; 95% CI: 2.01-9.93).

Conclusion: This study indicated that a big proportion of primary caregivers of epileptic patients in Kayonza district have high level of psychosocial burden. Thus, there should be system of screening psychosocial burden among caregivers of epileptic patients, introducing and strengthening patient's home visit and accompaniment interventions in Kayonza and close patient's follow up by their caregivers.

Introduction

Around 50% million people worldwide have epilepsy, which makes it one of the most common neurological diseases globally. About 80% of people that have epilepsy live in low-and middle income countries [1]. In Sub-Saharan Africa, active epilepsy is likely to affect 4.4 million of people while the lifetime epilepsy is expected to affect 5.4% million people [2]. In Rwanda, the prevalence of epilepsy was estimated to be 49 per 1000 people or 41 per 1000 for active epilepsy [3].

Epilepsy is worldwidely distributed and chronically affects Central Nervous System of people of all ages. The fundamental manifestations of epilepsy for people with condition are through epileptic seizures. Many underlying disease mechanisms may lead to epilepsy though the disease cause is still unknown in around 50% of global cases and many diseases and injuries are implicated in the groundwork of epileptic seizures with variable spreading worldwide [4]. The 94% of three quarters of 50 million people having epilepsy live in developing countries are untreated [5]. This big percentage brings up many problems associated to the treatment facilities as well as the negative attitudes of society towards the disorder. The developing countries experience high negative attitudes or behaviors, stigma and discrimination against epileptic patients and their primary caregivers compared to the developed countries [6]. People with epilepsy compared to the control group of patients with other chronic diseases are worse regarding the family dysfunction that contributes to behavioral, emotional and psychiatric problems which bring other family members to consider the ill relative as a burden to them since she/he needs food, health care, clothes and other everyday basic needs [7].

Adults with epilepsy live and manage their sickness on their own but large proportion depend on family members and partners for medical care. Caring for epileptic patient is emotionally demanding and their primary caregivers are always at high risk for depression and anxiety [8].The better care delivery for PWE needs better information, resources for primary caregivers and better knowledge and attitudes towards epilepsy [8]. Epilepsy affects the quality of life (QOL) of patients and indirectly for their primary caregivers in ways of losing control, independence, lifestyle, low self-esteem, fear, depression, social and employment restrictions, stigmatization and financial strains [9].

The care burden is an outcome of different factors including psychological, physical, emotional, social, economic as well as distressing moods notably embarrassment, anger, shame, self-blame and self-guilt [10].

Methods

Study disign

This study was a cross-sectional study using quantitative approach that investigated the psychosocial burden and associated factors among primary caregivers of epileptic patients in Kayonza district, Rwanda.

Target Population, sample size and procedures

The estimated target population for this study was 638 primary caregivers of epileptic patients in Kayonza district, Rwanda and the sample size was 246 caregivers selected by using simple random sampling technique. The study questionnaire included the 22-questions adopted from Zarit Burden Interview (ZBI) that were used to collect data on the caregiver's psychosocial burden, and social demographic factors and patients' clinical factors associated with psychosocial burden among primary caregivers of epileptic patients in Kayonza.

The community health workers (CHWs) helped in inviting primary caregivers at health facilities and the head of health facilities provided the private and silent rooms for interviews. Each participant was explained the purpose of this study and data collectors interviewed them and the collected data were directly recorded into REDCap forms before being exported to Stata v15.1 for analysis.

Data analysis and management

The data was collected using tablets with REDCap forms and exported to Stata version 15.1 for data cleaning, management and statistical analysis. Caregiver and patient's characteristics were described using frequency and percentages for categorical data and median and interquartile range for continuous data. The ZBI consists of 22 items rated on a 5-point Likert scale: 0 (never), 1 (rarely), 2 (sometimes), 3 (quite frequently) and 4 (nearly always) with the sum of scores ranging between 0–88. The overall score on these 22 items was categorized as high level of burden when greater than the mean score (50.1) or as low burden otherwise. Chi-squared and Wilcoxon rank sum tests and logistic regression were used to identify factors associated with the level of psychosocial burden. Only factors associated with the level of psychosocial burden in bivariate analyses at 0.20 level of significance were included in the full logistic regression model. The backward stepwise approach was used to eliminate non-significant variables and only variables with a p-value <0.05 were retained in the reduced logistic regression model.

Ethical consideration

The approvals to conduct the study were granted by Mount Kenya University, Partners In Health/*Inshuti Mu Buzima* and Gahini district hospital. Study participants were explained that the research was for academic purpose only and that, it was voluntary to participate. So, the consent forms were distributed and signed by the participants and assured them that their information will be confidential, nowhere that their names will appear on questionnaire. Furthermore, the data collectors explained to the participants that research will cause no harm to human, environment and the passwords for tablets will be used to genuinely keep and protect the data and the researcher highlighted to them the benefits of the study.

Results

Demographic characteristics of respondents

In total, 246 primary caregivers of epileptic patients participated in this study. Of the caregivers, 83% were female, the youngest caregiver's age was 19 years, with 47 (19.1%) caregivers aged between 19-34 years old and 35 (15%) were aged 65 years or older. About the caregivers' level of education, 81 (32.9%) did not attend any formal education, while 21 (8.5%) had secondary school or higher level of education. Thirty-three (13.4%) caregivers reported to be unemployed, while the majority of employed caregivers (n=175; 71.1%) were farmers. In addition, 180 (73.2%) caregivers reported a monthly income of ≤10,000 Rwf, with only 27 (11.0%) caregivers reporting to earn more than 20,000 Rwf per month (Table 1).

Table 1: Social-economic and demographic factors of primary caregivers

Variables	n	median (IQR)	%
Caregiver's gender			
Female	204		82.9
Male	42		17.1
Caregiver's age (years)			
19-34	47		19.1
35-44	55		22.4
45-54	65		26.4
55-64	42		17.1
65+	37		15.0
Marital status			
Married/Cohabiting	144		58.5
Single	14		5.7
Separated/Divorced	23		9.4
Widow/Widower	65		26.4
Educational level			
None	81		32.9
Primary	144		58.5
Secondary	21		8.5
Employed			
Yes	213		86.6
No	33		13.4
Occupation			
Farmer	175		71.1
Other	27		11.0
Unknown/Missing data	44		17.9
Family size		5(4-6)	
***Ubudehe* category**			
Category I	57		23.2
Category II	94		38.2
Category III	95		38.6

Caregiver's monthly income (RWF)		
≤10,000	180	73.2
11,000-20,000	39	15.9
>20,000	27	11.0
Religion		
Catholic	98	39.8
Protestant	91	37.0
Muslim/other	32	13.0
None	25	10.2

Table 2 below presents the patients' clinical characteristics as reported by their caregivers. At the time of epilepsy onset, 62 (25.2%) patients were under 5 years of age, 107 (43.5%) aged between 5-14 years and 77 (31.3%) patients were aged 15 years or older. The estimated length of time between when the patient was diagnosed with epilepsy and the survey date was less than a year for 33 (13.4%) caregivers, between one and five years for 78 (31.7%) caregivers and more than ten years for 77 (31.3%) caregivers. The reported monthly frequency of seizure was 10 times or less for the majority (n=185, 75.2%) of patients, while it was 11 or more times of seizure for about a quarter of patients (n=61, 24.8%). In addition, 51 (20.7%) caregivers reported that their patients were not adhering to medication.

Table 2: The epileptic patient's clinical characteristics as reported by their caregivers

Variables	**n**	**%**
Age (years) of the patient at the time of epilepsy onset		
<5	62	25.2
5-14	107	43.5
≥15	77	31.3
Number of months since the patient was diagnosed with epilepsy.		
<12	33	13.4
12-60	78	31.7
61-120	58	23.6
>120	77	31.3
Patient's monthly frequency/times of seizures		
0-10	185	75.2
≥11	61	24.8
Patient's reported adherence to medication.		
Yes	195	79.3
No	51	20.7

The study findings describes the research results organized according to the research objectives. The findings were presented using tables and figures and comprises the level of psychosocial burden as well as social demographic and patient's clinical factors associated with psychosocial burden.

Table 3: The level of psychosocial burden among primary caregivers of epileptic patients

#	QUESTION	Never (s=0), n (%)	Rarely (s=1), n (%)	Sometimes (s=2), n (%)	Quite Fre-quently (s=3), n (%)	Nearly Always (s=4), n (%)	Mean score, mean (SD[a])
1	More help than she/he needs	30 (12.2)	26 (10.6)	67 (27.4)	79 (32.2)	43 (17.6)	**2.3 (1.2)**
2	No time for yourself because of her/him?	21 (8.5)	26 (10.6)	53 (21.5)	94 (38.2)	52 (21.1)	**2.5 (1.2)**
3	Feeling stressed due to your daily work and caring for her/him	21 (8.5)	24 (9.8)	68 (27.6)	88 (35.8)	45 (18.3)	**2.5 (1.2)**
4	Embarrassed of his/her behavior	51 (20.7)	42 (17.1)	62 (25.2)	57 (23.2)	34 (13.8)	**1.9 (1.3)**
5	Angry when you are with your relative	24 (9.8)	29 (11.8)	71 (28.9)	72 (29.3)	50 (20.3)	**2.4 (1.2)**
6	Affecting your relationship with your family	34 (13.8)	36 (14.6)	75 (30.5)	81 (32.9)	20 (8.1)	**2.1 (1.2)**
7	Afraid about your relative's future	0 (0.0)	14 (5.7)	31 (12.6)	83 (33.7)	118 (48.0)	**3.2 (0.9)**
8	Your relative is dependent upon you	14 (5.7)	13 (5.3)	31 (12.6)	63 (25.6)	125 (50.8)	**3.1 (1.2)**
9	Strained when you are with your relative	29 (11.8)	21 (8.5)	95 (38.6)	87 (35.4)	14 (5.7)	**2.1 (1.1)**
10	Your health suffered because of your relative	27 (11.0)	27 (11.0)	74 (30.1)	94 (38.2)	24 (9.8)	**2.2 (1.1)**
11	Not having privacy because of him/her	34 (13.8)	33 (13.4)	75 (30.5)	80 (32.5)	24 (9.8)	**2.1 (1.2)**
12	Social life suffered due to caring him/her	31 (12.6)	25 (10.2)	94 (38.2)	76 (30.9)	20 (8.1)	**2.1 (1.1)**
13	Uncomfortable to receive your friends because of your relative	72 (29.3)	42 (17.1)	62 (25.2)	53 (21.5)	17 (6.9)	**1.6 (1.3)**

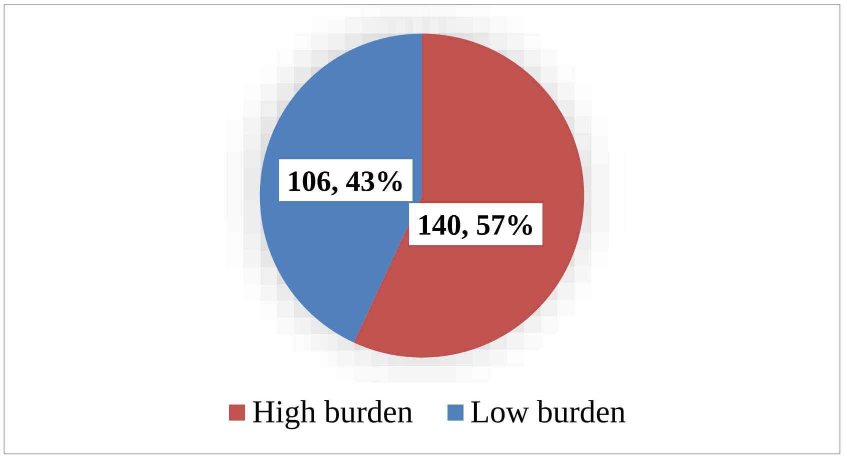
Table 3 continued

14	Expected as single source for her/his help	12 (4.9)	15 (6.1)	37 (15.0)	90 (36.6)	92 (37.4)	**3.0 (1.1)**
15	Not having enough money to care for your relative	9 (3.7)	19 (7.7)	39 (15.9)	100 (40.7)	79 (32.1)	**2.9 (1.1)**
16	Filling unable to take care of your relative much longer	40 (16.3)	33 (13.4)	76 (30.9)	76 (30.9)	21 (8.5)	**2.0 (1.2)**
17	Losing life control since your relative's illness	42 (17.1)	49 (19.9)	72 (29.3)	65 (26.4)	18 (7.3)	**1.9 (1.2)**
18	Wish to leave his/her care to someone else	162 (65.9)	29 (11.8)	34 (13.8)	15 (6.1)	6 (2.4)	**0.7 (1.1)**
19	Not sure of what to do about your relative	22 (8.9)	32 (13.0)	116 (47.2)	64 (26.0)	12 (4.9)	**2.0 (1.0)**
20	Willing of doing more for your relative	4 (1.6)	14 (5.7)	44 (17.9)	122 (49.6)	62 (25.2)	**2.9 (0.9)**
21	Doing better job in caring for your relative	39 (15.9)	82 (33.3)	64 (26.0)	39 (15.9)	22 (8.9)	**1.7 (1.2)**
22	Overall burden of caring for your relative	2 (0.8)	28 (11.4)	57 (23.2)	97 (39.4)	62 (25.2)	**2.8 (1.0**

Table 3 illustrates the level of psychosocial burden among primary caregivers of epileptic patients. For individual items, caregivers reported that they were afraid of what the future holds for the patient nearly always (48%), quite frequently (34%) and none of the caregivers reported that she had never been worried about the future of her patient (0%). On the item of feeling that the relative (patient) depends upon the caregiver, more than a half (51%) responded nearly always whereas (26%) responded quite frequently. For the item of feeling that the relative (patient) seems expecting the caregiver as single source of his/her help, (37%) of the respondents responded nearly always, (37%) responded quite frequent and (5%) responded never.

Regarding the item of feeling not having enough money to care for the relative (patient), (32%) responded nearly always, (41%) responded quite frequently whereas (4%) responded never. Despite the psychosocial burden that these primary caregivers face; on the item of wishing to leave the care of the relative (patient) to someone else, more than a half 66% responded never, 7% responded quite frequently whereas 2% responded nearly always. For the item of overall caregiver burden in caring for a relative (patient), (25%) of respondents responded nearly always, (39%) responded quite frequently and (1%) responded never.

The mean score was (50.1) and the overall total score was categorized as high level of burden when greater than the mean score or as low burden otherwise



This study found out that the level of psychosocial burden increased with the caregiver's age where the lowest prevalence of high burden (42.6%) was observed among the youngest caregivers with age between 19-34 years compared to 70.3% of high psychosocial burden among caregivers aged 65 years or older (p=0.003). Caregivers from big families were more likely to have high level of psychosocial burden with caregivers with the high burden reporting an average of 6 people (IQR: 4-7) in their families compared to an average of 5 people (IQR: 4-6) in families of caregivers with low burden (p=0.006).

Table 4: Social demographic factors associated with psychosocial burden among primary caregivers of epileptic patients

Variables	Psychosocial burden High, n (%)	Psychosocial burden Low, n (%)	p-value
Gender			0.499
Female	114 (55.9)	90 (44.1)	
Male	26 (61.9)	16 (38.1)	
Caregiver's age (years)			**0.003**
19-34	20 (42.6)	27 (57.4)	
35-44	23 (41.8)	32 (58.2)	
45-54	41 (63.1)	24 (36.9)	
55-64	30 (71.4)	12 (28.6)	
65+	26 (70.3)	11 (29.7)	
Caregiver's marital status			0.159
Married/Cohabiting	76 (52.8)	68 (47.2)	
Single	9 (64.3)	5 (35.7)	
Separated/Divorced	11 (47.8)	12 (52.2)	
Widow/Widower	44 (67.7)	21 (32.3)	
Caregiver's level of education			0.418
None	49 (60.5)	32 (39.5)	
Primary	77 (53.5)	67 (46.5)	
Secondary	14 (66.7)	7 (33.3)	
Employed			0.346
Yes	124 (58.2)	89 (41.8)	
No	16 (48.5)	17 (51.5)	
Occupation, N=202			0.679
Farmer	93 (53.1)	82 (46.9)	
Other	16 (59.3)	11 (40.7)	
Family size, median [IQR]	5.5 [4-7]	5 [4-6]	**0.006**
***Ubudehe* category**			**0.047**
Category I	34 (59.7)	23 (40.3)	
Category II	61 (64.9)	33 (35.1)	
Category III	45 (47.4)	50 (52.6)	
Caregiver's monthly income (RWF)			**0.014**
≤10,000	104 (57.8)	76 (42.2)	
11,000-20,000	27 (69.2)	12 (30.8)	
>20,000	9 (33.3)	18 (66.7)	
Religion			0.777
Catholic	54 (55.1)	44 (44.9)	
Protestant	50 (55.0)	41 (45.0)	
Muslim/other	20 (62.5)	12 (37.5)	
None	16 (64.0)	9 (36.0)	

This study revealed out that the caregiver's level of psychosocial burden was also associated with the duration of disease, where the proportion of caregivers with high level of psychosocial burden increased with the duration of disease (39.4% for a disease duration of <12 months versus 50.0%, 67.2% and 63.6% for a duration of disease of 12-60 months, 61-120 months and more than 120 months, respectively; p=0.023). Caregivers of patients with a severe disease in terms of the monthly frequency of seizure were also more likely to have the high psychosocial burden (75% for patients with ≥11 number of monthly seizures vs. 51% for patients with ≤10 number of monthly seizures; p=0.001). In addition, a significantly higher prevalence of high psychosocial burden was observed among caregivers who reported that the patient was not taking medication as prescribed (82% vs. 50% among caregivers of patients with medication adherence; p<0.001).

Table 5: Patients clinical factors associated with psychosocial burden among primary caregivers of epileptic patients

	Psychosocial burden		
Variables	**High, n %**	**Low, n %**	**P-Value**
Age (years) of the patient at the time of epilepsy onset			0.300
<5	30 (48.4)	32 (51.6)	
5-14	64 (59.8)	43 (40.2)	
≥15	46 (59.7)	31 (40.3)	
Number of months since the patient was diagnosed with epilepsy			**0.023**
<12	13 (39.4)	20 (60.6)	
12-60	39 (50.0)	39 (50.0)	
61-120	39 (67.2)	19 (32.8)	
>120	49 (63.6)	28 (36.4)	
Patient's monthly frequency/times of seizures			**0.001**
0-10	94 (50.8)	91 (49.2)	
≥11	46 (75.4)	15 (24.6)	
Patient's reported adherence to medication.			**<0.001**
Yes	98 (50.3)	97 (49.7)	
No	42 (82.3)	9 (17.7)	

Of the factors found to be significant at 0.20 level of significance in bivariate analysis, logistic regression was done and the findings were as follow:

Table 6: Factors associated with high psychosocial burden among caregivers of epilepsy patients

	Full model			**Final model**		
Variables	**OR^a**	**95% CI***	**p-value**	**OR^a**	**95% CI***	**p-value**
Caregiver's age (years)			**0.136**			**0.009**
19-34	**ref**			**ref**		
35-44	**1.13**	**[0.44-2.90]**		**1.04**	**[0.46-2.36]**	
45-54	**2.30**	**[0.87-6.09]**		**2.67**	**[1.20-5.91]**	
55-64	**3.90**	**[0.95-8.84]**		**3.25**	**[1.30-8.14]**	
65+	**3.20**	**[0.99-10.36]**		**2.70**	**[1.04-7.00]**	
Caregiver's marital status			0.647			
Married/Cohabiting	ref					
Single	1.84	[0.44-7.67]				
Separated/Divorced	0.74	[0.27-2.03]				
Widow/Widower	1.32	[0.61-2.86]				
Family size, median	1.20	[0.99-1.46]	0.068			
***Ubudehe* category**			0.169			
Category I	ref					
Category II	1.96	[0.90-4.28]				
Category III	1.20	[0.55-2.62]				
Caregiver's monthly income (RWF)			0.183			
≤10,000	ref					
11,000-20,000	1.52	[0.64-3.65]				
>20,000	0.47	[0.16-1.39]				
Number of months since the patient was diagnosed with epilepsy			0.236			
<12	ref					
12-60	0.72	[0.26-2.00]				
61-120	1.63	[0.55-4.83]				
>120	0.85	[0.28-2.56]				
Patient's monthly frequency/times of seizures			0.112			
0-10	ref					
≥11	1.95	[0.86-4.45]				
Patient's reported adherence			**0.152**			**<0.001**

to medication.				
Yes	**ref**		**ref**	
No	**2.11**	**[0.76-5.85]**	**4.47**	**[2.01-9.93]]**

^{a}OR, Odds ratio
***CI,** Confidence interval
Ref, Reference

In the final model, increased caregiver's age and the patient's non-adherence to medication were significantly associated with higher odds of the high level of psychosocial burden. Compared to young caregivers aged between 19-34 years old, the odds of high level of psychosocial burden were 2.67 times (95% CI: 1.20-5.91) for caregivers aged 45-54 years, 3.25 times (95% CI: 1.30-8.14) for caregivers aged 55-64 years and 2.70 times (95% CI: 1.04-7.00) for caregivers aged 65 years or older. In addition, caregivers who reported that their patients were not adhering to medication had 4.47 times odds of high level of psychosocial burden (OR: 4.47; 95% CI: 2.01-9.93) compared to their counterpart caregivers whose patients were adhering to medication as prescribed.

Discussion

According to this study, more than a half (57%) of caregivers had a high psychosocial burden. The findings of this study are similar to what was reported by [11] that the primary caregivers of people with epilepsy experience high level of psychological stress, worries of what will happen to the patients when the caregivers will not be available to take care of them in the future. The family members who take care of epileptic patients experience greater burden of care; anxiety, depression.

The findings of this study were also similar with what were revealed out in a study entitled "patient, caregiver, and health care practitioner knowledge of beliefs and attitudes toward epilepsy", Elliott and Shneker that caring for epileptic patient is emotionally demanding and their primary caregivers are always at high risk for depression and anxiety [8]. Epilepsy constitutes high social and psychological burden to caregivers of epileptic patients worldwide [1].

This study showed that the caregivers with ≥65 years old 26 (70.3%) had high level of psychosocial burden. These findings are not far from what was found by [12] that there is association of epileptic patient caregivers' psychosocial burden with age. Although, in a cross-sectional study conducted in Brazil by [13], they identified that there is an association of caregivers burden with being aged more than 60 years of age.

This study agreed with some other previously published findings which revealed that the caregiver's quality of life was negatively associated with age, since the younger caregivers understand better their relatives' illnesses and positively respond in terms of providing needed support to the challenges experienced [14].

The family size was associated with caregivers' psychosocial burden as also reported by [12] in a study named "Perceived burden and social support of caregivers in early onset psychosis & epilepsy: a comparative study" where they revealed out that there in association between caregivers' psychosocial burden and size of family.

Furthermore, this study found out that caregivers with low income have high level of psychosocial burden. It is not also different to what was reported by [12] that there is association of epileptic patients' caregivers' psychosocial burden with income level.

It was revealed out that epileptic patients' large proportion depend on family members and partners for medical care since caring for epileptic patient is economically and emotionally demanding and their primary caregivers are always at high risk for depression and anxiety [8] which is not far from the findings of this study.

It was also revealed out by [9] that bad adherence to medications affects patients health and their primary caregivers as showed by this study as well.

The poor adherence to anti-epileptic drugs as poor patient's behavior that results into seizures could further worsen the patient's QOL and increase the burden on the caregivers as reported by [15] in their study entitled

'Behavioral and psychiatric comorbidities in pediatric epilepsy: toward an integrative model'. It is not different from what this study revealed out. These study findings also are similar to what [16] reported regarding the repetitive or prolonged seizures that are unpredictable and occur at any time to the epileptic patients, the repeated use of emergency health facilities is costly and creates financial strain to their caregivers. They also added that different factors affect the quality of life of people that have epilepsy and their families notably the repetitive seizures as long as people fear seizure recurrence and the caused patients' loss of control that usually generates anxiety and worry to the patients themselves, their caregivers and other individuals around them. This was also revealed out by [9] that seizure severity, seizure type affect patients' health and their primary caregivers. Furthermore, in a study entitled burden in caregiving of adults with epilepsy in Asian families [17], they reported that primary caregivers of people with epilepsy experience psychosocial burden caused by their patient's clinical factors especially frequent seizures.

This study showed that the duration of of epilepy causes the pychosocial burden to the caregivers as reported by [18] in a study called "The burden experienced by family caregivers of patients with epilepsy attending the government psychiatric hospital, Kaduna, Nigeria" that poor seizure control and long duration of epilepsy increase the epileptic patients' caregivers' psychosocial burden.

These study findings also are similar to what [16] reported regarding the prolonged seizures which are mostly unpredictable to the patients with epilepsy, the conditional and emergent health facilities visits are costly and cause financial burden to their caregivers.

Conclusion

Generally, this study revealed that the primary caregivers of epileptic patients in Kayonza district had high level of psychosocial burden. The mental health care providers should continuously sensitize, educate and encourage primary caregivers to help patients to adhering to medications.

Acknowledgement

I would also like to thank all primary caregivers who accepted to participate in this study. And also, express gratitude to Dr Jean Damascene Iyamuremye and Mr. Habtu Michael who supervised this thesis.

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