
Psychosocial effects and wellbeing of caregivers of epileptic patients in Rwanda, A case of Rwinkwavu district hospital

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ABSTRACT

Caregiving places many psychological and social burdens on caregivers. The general objective of the study was to assess psychosocial effects and wellbeing of caregivers of epileptic patients in Rwanda. The findings have social, psychological and educational contribution. Cross-sectional design using quantitative approach was used to assess psychosocial effects and wellbeing of caregivers. Systemic sampling technique was used to select the respondents. A Sample of 381 was taken from 933 people using Fisher et al., 1998 formula. The study only considered respondents aged 18 years old and above. The primary data was collected from Caregivers attending mental health service of Rwinkwavu hospital by using semi-structured questionnaire. Questions were in respondent's native language. Data analysis was done using SPSS Version 21, and presented in form of frequencies, percentages and analyzed using descriptive and inferential statistics. Throughout the findings, it was revealed that majority of caregivers at Rwinkwavu hospital were female 72.7%, 36.2% had between 34-44 years of age 68.8 % of patients were children, 96.6% were Christians; 67.5% had primary level of education; 87.7% were farmers; 74.8% earned <10,000 as monthly income. On the first objective, it was concluded that lack of concentration on daily activities, sleeping difficulties, inability to take decisions, unhappy feeling, stress and loss of confidence were identified as psychological effects of caring to epileptic patients and that caring to epileptic patients has moderate psychological effects on caregivers at Rwinkwavu hospital as indicated by (44) 11.6% who strongly disagreed, (95) 24.9% disagreed, (91) 23.9% were neutral, (67)17.6% agreed and (84) strongly agreed on the overall statements. On the second objective, it was indicated that changing life conditions, tensions of conflicts, reduction of family relationship, reduction of leisure time and redaction of family incomes were revealed as socio-economic effects of caring to epileptic patients, and that caring to epileptic patients has several socio-economic effects on caregivers as indicated by (154) 40.5%. On the third objective, it was concluded that there is a strong positive degree of relationship between socioeconomic status and wellbeing of caregivers of epileptic patients as indicated by (189) 49.6% who strongly disagreed on the overall statements. The researcher recommends the management of Rwinkwavu hospital to put in place financial supports to the caregivers of epileptic patients, the government of Rwanda was also recommended to put in place socio-economic projects aimed to support people who are caring for epileptic patients and that family members of epileptic patients should share the responsibilities of caring the patient.

Introduction

Epilepsy stands among the common chronic illness characterized by repetitive loss of conscious and seizures. Globally, 70 million people live with epilepsy, 80% of the affected population resides in the underdevelopment countries. In United States of America, the epilepsy is estimated to be 2.2 million cases, children and youth aged 14 and younger are 316000 epileptic cases. Approximately 50,000 new epileptic children and youth below the age of 18 years old diagnosed of epilepsy every year [1].

According to Evangelia (2017), Epilepsy is a chronic condition that manifested by repetitive seizure to human of any age, gender and geographical area. In western societies, at least 10 percent of the population presented one epileptic seizure during their life time and 1 percent of the general population live with epilepsy. In European union, the people affected by epilepsy is estimated to 2,64 million which is 44 per 100.000 people, the cost of epilepsy treatment in Europe is uncalculated and it is still a stigmatizing condition with many negative social consequences. Epilepsy can change caregiving family and patients' daily life causing social difficulties and psychological distress.

In sub-Saharan Africa where 80 % of epileptic patients reside, the people are receiving inadequate treatment because of limited capacity of diagnosing epilepsy, shortages of trained health care providers, contribution of social stigma and cultural beliefs to the treatment gap [2].

In South Africa, Spangenberg (2014). Epilepsy is estimated to be 1 in every 100 children and this condition occur at young age before 15. The death related to Epilepsy in South African patients is two to three higher than the general population, which makes the diagnosis and treatment epilepsy essential. In Rwanda, WHO (2014) reported that epilepsy is among the common mental health conditions that occupy first place 52%, psychiatric problems 26%, neurological disorders are 12 % and other conditions [3].

MoH (2020), reported that epilepsy ranks the first among the reasons of our patients' neurological consultations in Rwanda where it represents 61.04%, headache syndrome 22.68%, Migraine is 8.20% and Parkinson disease of 5.25 percent. The survey conducted by Sebera et al. (2015), found out that the prevalence of epilepsy in Rwanda is 49 per 1000 people, which positions Rwanda among the top in Africa. This study concluded that having epilepsy is greatly linked with stigma, psychological difficulties, poverty and decrease of family income, which explain the existing treatment gap of epilepsy, [4].

Epilepsy is not only medical condition; it includes economic, cultural and sociological dimensions. In Africa where Rwanda is located, people living with epilepsy face many forms of discrimination and rejection that lead to daily frustration. The negative effect and long-term impacts of epilepsy, prognosis and mortality rate is not clearly recorded in Africa [5].

Epilepsy affects the caregiving family due to the increase and changes in the use of family incomes. These may cause stress and psychological disruption in the family. Epilepsy as chronic condition with unpredictable occurrence puts a family at high risk of poor integration, communication and cohesiveness. The caregivers time for the enjoyment may end, fearing that patient with epilepsy may

present seizure while enjoying with friends or in presence of visitors at home. For family living in rural area, many expenses incur because of medical consultation, medications and other medical investigation are costly. Money for transport to the hospital and caring to the children left at home are additional expenses to the family. Siblings may miss different opportunities since the epileptic brother cannot participate and it have been found that family members living with epileptic patient are at high risk of psychiatric problems than the control group [6].

In low-income countries including Rwanda, 75% of epileptic patients in need of treatment they do not get it, however 70 % among patients living with epilepsy can become seizure free once the appropriate treatment is available, and this could reduce the treatment gap in the management of epilepsy [7]. Caregiving places many psychological and social difficulties on caregivers, and different researches confirm that caregivers are poorly rewarded, often loss their work, undergo poor health, and faces family conflicts. Counseling psychology literature is filled with scholars all over the world as well as Rwanda that have written a lot about treatment of people living with epilepsy but the psychological and social life of their caregivers has never identified as treatment gap to holistic care in Rwanda, therefore this study will establish the understanding of psychosocial effects and the wellbeing of caregivers of epileptic patients in Rwanda, using Rwinkwavu district hospital as a case study.

Research methodology

The aim of the study is to assess psychosocial effects and wellbeing of caregivers of epileptic patients in Rwanda. The study was cross-sectional using quantitative approach to assess psychosocial effects and wellbeing of caregivers. Systemic sampling technique was used to select the respondents. A Sample of 381 was taken from 933 people using Fisher et al., 1998 formula.

Study population and procedure of the study

The study took place in Rwinkwavu district hospital of Kayonza district in Rwanda. The target population was 933 caregivers of epileptic patients attending Rwinkwavu district hospital aged between eighteen years old and above who are accompanying or coming to pick anti-epileptic medications for epileptic patients on monthly basis. Rwinkwavu district hospital has been selected due to its highest numbers of caregivers of epileptic cases among mental health service users where 46% of caregivers are for epileptic patients [8]. Information that was used in this study were gotten from primary sources using approved semi structured questionnaire. The questionnaire was divided into four sections where part A focused on demographic characteristics of respondents, part B focused on the psychological effects, part C on the socio-economic effects to caregivers of epileptic patients and part D on the assessment of wellbeing of caregivers of epileptic patients in Rwanda.

Data Analysis

The mass of raw data collected from caregivers of epileptic patients using systematic sampling method was systematically organized according to the major variables to answer the three research questions raised. Analysis was done at almost every stage of research

process, from the day of data collection to presentation of results. After data was collected it was coded and analyzed for interpretation and discussion. Analysis of data were done by using SPSS statistics software of computer program version 21.0. Findings were presented using graphs and tables with frequency and proportions. Descriptive analysis was done to tabulate and describe the data. Inferential statistics was used to establish the association between age, gender, blood relationship with economic status and wellbeing of caregivers of epileptic patients by using Chi square tests and multivariable logistic regression models. Findings were presented at ratios of 95% confidence interval and the variable impact was set at $P < 0.05$.

Results

The study involved 381 active caregivers of epileptic patients who are aged between 18 years and above. Of which majority of the respondents were females, this was indicated 277 (72.7%) females and 104 (27.3%) males. Most of the respondents were more than 35 years of age, this was indicated by 138(36.2%) that varies between 35-44 years of age. Regarding relationship with care recipient that majority of them were parents caring to their children this was indicated by 262(68.8%) caregivers. As long as marital status gets considered, majority of the respondents were married. This was indicated by 63.3% of the respondents, 13.9% were single, whereas about 10.5% of the respondents were separated. Taking religion into consideration, majority of the respondents were christian 96.6%. Considering education, the findings revealed that majority of epileptic caregivers at Rwinkwavu district hospital have primary level of education, this was indicated by 257 (65.5%) who have primary level of education, 100 (26.2%) have never went to school, only 5.2 percent have secondary schools and only 1 percent attended university.

Table 1. Socio-Demographic Characteristics of Respondents

Variables	Indicators	Frequency (N:381)	Percentages (%)
Gender	Female	277	72.7
	Male	104	27.3
Age	18-24	21	5.5
	25-34	97	25.5
	35-44	138	36.2
	45-54	91	23.9
	55+	34	8.9
Relationship with care recipient	Child	262	68.8
	Parent	40	10.5
	Sibling	28	7.3
	Spouse	17	4.5
	Other	34	8.9
Marital Status	Single	53	13.9
	Married	241	63.3
	Separated	40	10.5
	Divorced	36	9.4

	Other	11	2.9
Religion	Christian	368	96.6
	Muslim	6	1.6
	Other	7	1.8
Education Level	None	100	26.2
	Primary	257	67.5
	Secondary	20	5.2
	University	4	1.0

Source: Primary Data, (2022)

Table 2. Distribution of Respondents by Socio-Economic Characteristics

Variables	Indicators	Frequencies	Percentages
Ubudehe Categories	Category I	116	30.4
	Category II	137	36.0
	Category III	128	33.6
Care giving role	Primary caregiver	340	89.2
	Secondary Caregiver	41	10.8
Caregiving period	1 to 6months	15	3.9
	6 to 12 months	43	11.3
	1 to 2 years	22	5.8
	3 to 4 years	106	27.8
	5 years and above	195	51.2
Living with other chronic illness	Yes	105	27.6
	No	276	72.4
Occupation	Farmer	334	87.7
	Casual Labor	19	5.0
	Employed	6	1.6
	Unemployed	20	5.2
	Student	2	.5
Monthly Income	Less than 10000 Frw	285	74.8
	10000 to 50000 Frw	84	22.0
	51000 to 100000 Frw	7	1.8
	110000 to 150000 Frw	3	.8
	160000 Frw and above	2	.5

Source: Primary Data, (2022)

Table 2 presents socio-economic characteristics of the respondents where majority of respondent found in category II of economic category (Ubudehe) indicated by 36.0% of respondents. When taking responsibilities of the caregivers into consideration, majority of them have primary responsibilities for caring the patients this was indicated by 89.2%, only 10.8% act as secondary caregivers. About the living with chronic conditions, it was indicated that 27.6% of the caregivers of epileptic patients at Rwinkwavu hospital live with other chronic diseases, whereas 72.4% were free from other chronic diseases. As long as occupation of the respondents get considered, the findings indicated that majority of the epileptic caregivers were farmers 87.7%. Last but not the least, when taking income levels of the respondents into considerations, from the results of this study, it was concluded that majority of caregivers earned lesser than 10,000 Rwandan francs, as

indicated by (285)74.8%.

Table 3. Psychological Effects of Caregivers of Epileptic Patients at Rwinkwavu District Hospital

STATEMENTS	Never		Rarely		Sometime s		Frequently		Always		Mea n	St.d
	F	%	F	%	F	%	F	%	F	%		
I'm able to concentrate on my usual activities.	58	15.2	144	37.8	116	30.4	35	9.2	28	7.3	2.55	1.08
I experience sleep difficulties over worry of my epileptic patient.	36	9.4	42	11.0	184	48.3	38	10.0	81	21.3	3.22	1.17
I feel that I'm an important person to the patient.	4	1.0	93	24.4	38	10.0	58	15.2	188	49.3	3.87	1.28
I feel capable to make decision about patient's conditions.	13	3.4	109	28.6	66	17.3	102	26.8	91	23.9	3.39	1.22
I feel able to overcome my difficulties.	83	21.8	149	39.1	58	15.2	60	15.7	31	8.1	2.49	1.22
I experience unhappy or depressed feeling.	30	7.9	95	24.9	117	30.9	48	12.6	91	23.9	3.19	1.26
I feel myself worthless person due to my epileptic patient.	69	18.1	110	28.9	95	24.9	43	11.3	64	16.8	2.79	1.32
I experienced stressful period due to caregiving to an epileptic patient.	44	11.5	38	10.0	63	16.5	123	32.3	113	29.1	3.57	1.31
I lost confidence in myself due to caregiving to an epileptic patient.	62	16.3	68	17.8	85	22.3	98	25.7	68	17.8	3.11	1.33

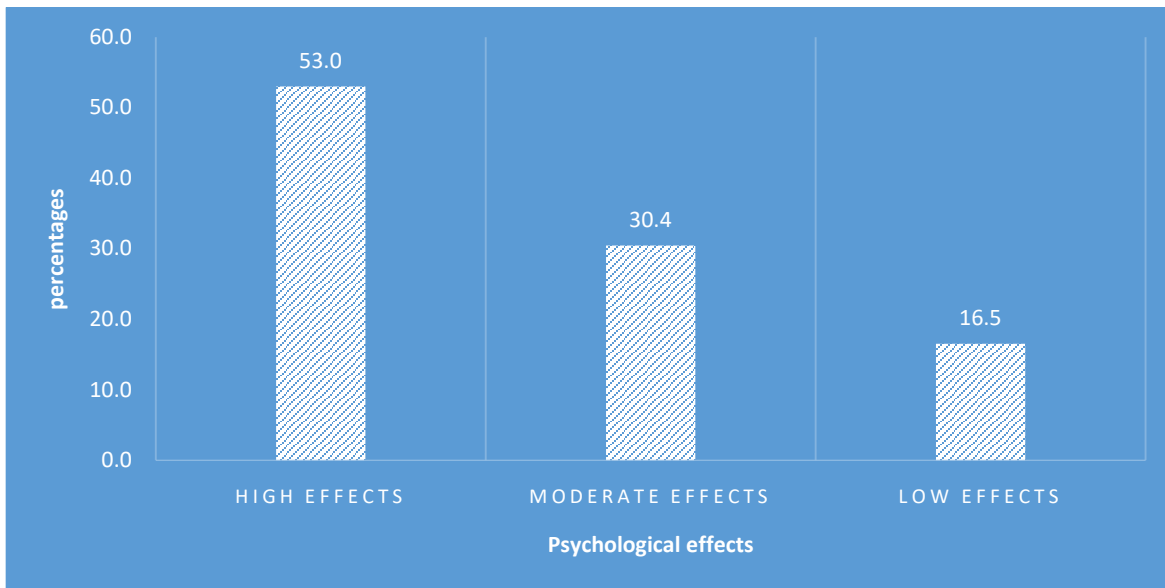
Source: Primary Data (2022)

Table 3 present psychological effects among caregivers of epileptic patients attending Rwinkwavu District Hospital. The presentation and analysis followed the provided statement. On the first statement the findings indicated that majority of caregivers were unable to concentrated on their usual activities. This was indicated by (144) 37.8% who rarely concentrated on their activities, (116) 30.4% sometimes got time to concentrate on their work. In similar vein, the second statement majority of the respondents indicated that (184) 48.30% sometimes experienced sleep difficulties over worry of my epileptic patient and (81)21.3% always experienced sleeping difficulties as results of worries caused by his/ her epileptic patient. On the thirst statement majority of the respondents (188) 49.3% always felt that they are an important person to the patient. To the same extent, the fourth statement, majority of the respondents (109) 28.6% rarely and (66) 7.3% some time felt incapable to make decision about patient's conditions, this affects their psychological feeling. On the fifty statements, the results on this statement indicated that majority of the participants said that they felt unable to overcome their difficulties. This was indicated by (83) 21.8% who said never, (149) 39.1% who said rarely and (58) 15.2% who said that sometimes they are unable to overcome the difficulties caused by their patients. On the sixth statement the findings indicated that majority of the caregivers of epileptic patients at Rwinkwavu hospital were experienced in many cases unhappy or depressed feeling. This was indicated by (117)30.9% who sometimes express sadness feeling, 48 (12.6%) did it frequently and (91)23.9% who always express that feeling of unhappiness and sadness as results of caring for epileptic patient. On the seventh statement, (93) 24.9% some times and (43)11.3% frequently and (64) 16.8% always felt themselves worthless people due to their epileptic patients. Whereas on the eighth statements, the findings on this point indicated that

(123) 2.3% frequently and (113) 29.1% they always experienced stressful period due to caregiving to an epileptic patient and on the ninth statement the findings from participants for this study indicated that they lost confidence as results of caregiving to the epileptic patients 25.7%.

The overall psychological effects were calculated and the summarized data was presented in the figure 1.

Figure 1. Overall psychological effects of caregivers of epileptic patients attending Rwinkwavu district hospital



Source: Researcher (2022)

Throughout the findings, it was indicated that majority experienced higher effects. This was indicated by 53.0% of the participants.

Table 4. Socioeconomic Effects among Caregivers of Epileptic Patients at Rwinkwavu District Hospital

STATEMENTS	SDA		Disagree		Neutral		Agree		SA		Mean	St.D
	F	%	F	%	F	%	F	%	F	%		
The disorder that my patient is suffering from seems to me something very serious.	7	1.8	25	6.6	18	4.7	64	16.8	256	69.6	4.61	2.28
The patient's illness changed my family life conditions.	24	6.3	28	7.3	21	5.5	149	39.1	159	41.7	4.02	1.15
There is a conflict or tension in my life.	128	33.6	65	17.1	48	12.6	63	16.5	77	20.2	2.93	3.36
I'm more worry of what is happening.	13	3.4	67	17.6	47	12.3	91	23.9	163	42.8	3.85	1.24
The patient's conditions caused changes for the worse in my work.	11	2.9	77	20.2	44	11.5	113	29.7	136	35.7	3.75	1.21
Caregiving to an epileptic patient worsened my leisure activities.	42	11.0	59	15.5	46	12.1	117	30.7	117	30.7	3.54	1.35
My extra family relationship became worse.	60	15.7	63	16.5	19	5.0	126	33.1	113	29.7	3.44	1.45
The patient's epileptic conditions have caused economic difficulties to my family.	27	7.1	42	11.0	13	3.4	93	24.4	206	54.1	4.07	1.28

Source: Primary Data (2022)

Table 4 shows findings about socio-economic challenges caused by caregiving to epileptics patients. Questions were in form of statements organized in Likert scale format. The findings analysis and presentations were also followed the provided statements. On the first statement, many respondents at (257) 69.6% indicated that the disorder that their patients were suffering from were something very serious to them. On the second statement, (149) 39.1% agreed and (159) 41.7% strongly agreed that patient’s illnesses changed their family life conditions. On the third statement, majority of the respondents disagreed that caring to epileptic patients caused conflict or tension in their life this was indicated by (128) 33.6% who strongly disagreed with the statements, significant number of respondents agreed on the statement (63)16.5% and (77) 20.2% strongly agreed that caring for epileptic patients have caused tension of conflict in their life. This tells us that caring for epileptic patients is a threat to caregivers’ social life. Majority of the respondents on the fourth statements indicated that (163) 42.8% strongly agreed that they more worried about what was happening. On the fifth statements majority of the participants indicated that the patient’s conditions have caused changes for the worse in their works. This was indicated by (113) 29.70% who agreed and (136) 35.7% who strongly agreed on the statement. As long as sixth statement get considered, the findings have indicated that (117) 30.7% agreed and (117) 30.7% strongly agreed that caregiving to an epileptic patient worsened their leisure activities. In this vein seventh statement was also considered and the answers on this statement shows that most of the participated agreed that their extra family relationship have become worse as results of caring to epileptic patients. This was indicated by 126 (33.1%) and 113 (29.70%) who strongly agreed. On the eighth statement, many caregivers indicated that patients’ epileptic conditions have caused economic difficulties to their families, as indicated by (206) 54.1% who strongly agreed on the statements. In summary, there was also a need to present the overall socioeconomic effects of caring to epileptic patients among caregivers attending Rwinkwavu hospital. The collected were presented in figure 2.

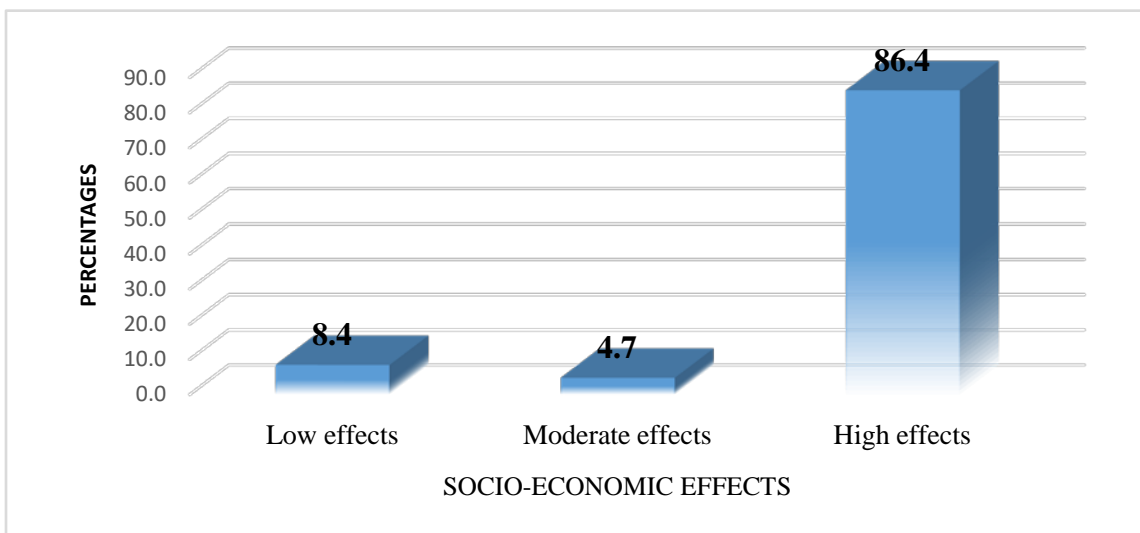


Figure 2. Socioeconomic effects of caring to epileptic patients

Source: Primary data (2022)

Throughout the findings it was revealed that majority of caregivers have experienced higher socioeconomic effects as results of caring to epileptic patients. This was indicated by 86.4% of the participants.

Table 5. Wellbeing of Caregivers of epileptic patients at Rwinkwavu hospital

STATEMENTS	SDA		Disagree		Neutral		Agree		SA		Mean	Std.d
	F	%	F	%	F	%	F	%	F	%		
I have an ability to work regularly and productively.	171	44.9	143	37.5	17	4.5	41	10.8	9	2.4	1.88	1.06
I do have social and financial support.	253	66.4	101	26.5	6	1.6	21	5.5	0	0.0	1.46	.78
I have enjoyment time with my family and peer.	224	58.8	120	31.5	13	3.4	19	5.0	5	1.3	1.58	.87
I have stable social and financial status.	243	63.8	94	24.7	6	1.6	35	9.2	3	0.8	1.58	.96
I'm able to enjoy my daily activities.	183	48.0	107	28.1	17	4.5	52	13.6	22	5.8	2.01	1.26
I'm satisfied with my monthly income.	189	49.6	133	34.9	14	3.7	26	6.8	19	5.0	1.82	1.10
I feel mentally and emotionally healthy	105	27.6	147	38.6	27	7.1	79	20.7	23	6.0	2.39	1.25
I feel having a happy life.	147	45.7	89	23.4	23	6.0	76	19.9	19	5.0	2.15	1.32
My living conditions sweet me and my family.	185	48.6	108	28.3	22	5.8	47	12.3	19	5.0	1.96	1.22

Source: Primary Data (2022)

Table 5. Shows the wellbeing of the caregivers to epileptic patients in Rwinkwavu district hospital. Questions were in form of statements organized in Likert scale format. The findings analysis and presentations were also followed the delivered statements. Making a case on the first statement, majority indicated that they don't have ability to work regularly and productively due to being caregivers to epileptic patients. This was indicated by (171) 44.9% who strongly disagreed and (143) 37.5% who disagreed on the statement. On the second statement majority of the respondents indicated that they don't have social and financial support. This was indicated by (253) 66.4% strongly disagreed and (101) 26.5% who disagreed. On the third statement, most of the participants revealed that they don't have time to enjoy life with their family and peers. This was indicated by (224) 58.8% who strongly disagreed; (120) 31.5% who disagreed on the statement.

As long as fourth statement get considered majority of the respondents who were caregivers indicated that caring to epileptic patients have destabilize social and financial status of care givers. This was indicated by (243) 63.8% who strongly disagreed and (97) 24.7% who disagreed on the statement. Fifth statement, many respondents indicated that they are unable to enjoy their daily activities as results of being caregivers to epileptic patients. This was indicated by (183) 48.0%, who strongly disagreed and (107) 28.1% who disagreed that they are able to enjoy my daily activities. On the sixth statement majority of the respondents have also indicated that they are not satisfied with their monthly income. This was indicated by (189) 49.6% who strongly disagreed and (133) 4.9% who disagreed that they are satisfied with

their monthly income.

In similar vein, seventh statement was considered, in this concern majority of the respondents have indicated that they are mentally and emotionally not feeling healthy. This was indicated by (105) 27.6% strongly disagreed and (147) 38.6% disagreed that they feel mentally and emotionally healthy. On eighth statement, many of the respondents have indicated that they are feeling having bad life. This was indicted by (147) 45.7% who strongly disagreed and 89 (23.4%) who disagreed that they feel having a happy life. On the ninth statement, majority of the respondents disagreed that their living conditions sweet them and their families. This was indicated by (185) 48.6% strongly disagreed and (108) 28.3% agreed on the provided statement.

The overall wellbeing state of caregivers of epileptic patients attending Rwinkwavu hospital were computed and the findings were presented in the figure 3.

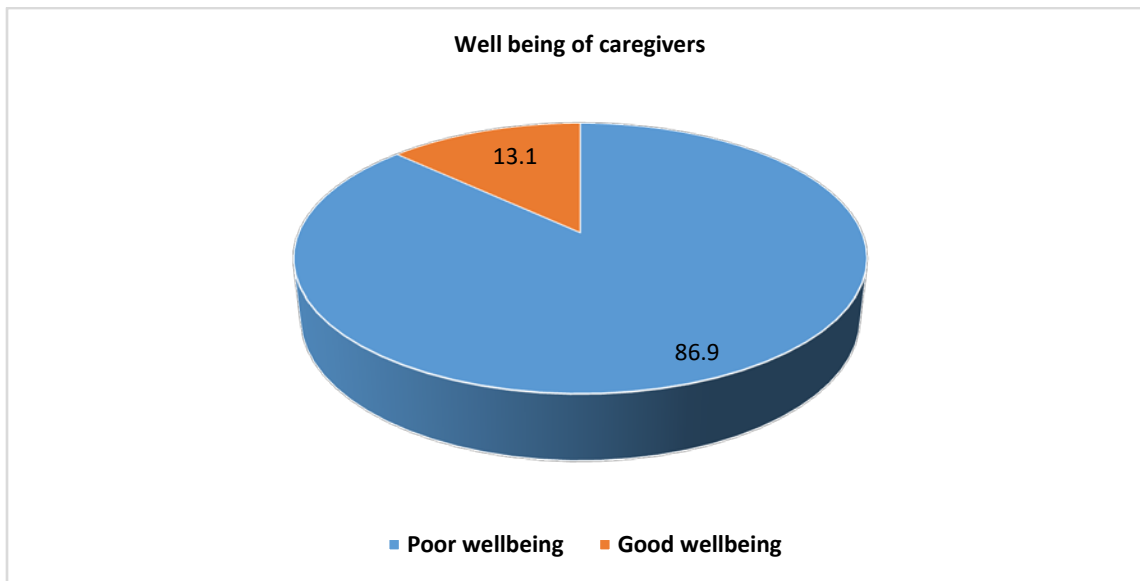


Figure 3. The overall wellbeing state of caregivers of epileptic patients attending Rwinkwavu district hospital.

Source: Primary Data (2022)

The majority of the participants in this study had poor wellbeing. This was indicated by 86.9 percent of the participants.

Relationship between Socio-demographic characteristics and wellbeing of caregivers to epileptic patients at Rwinkwavu District Hospital.

There was also a need to establish relationship between social demographic status and wellbeing of the caregivers to epileptic patients at Rwinkwavu district hospital. To achieve this, structured questionnaires organized in Likert scale format were distributed to 381 caregivers who were participants at that hospital. Throughout the analysis researcher wanted to know if there was a change of wellbeing in relation to socio-demographic characteristics (age, gender, education level, Ubudehe category, marital status and monthly income). To achieve this chi-square tests was computed and the data was organized in the tables below.

Table 3. Association between Gender and Wellbeing of caregivers

Gender * Wellbeing Crosstabulation				
		Wellbeing		Asymp.sig-(2 sided)
		Poor wellbeing	Good wellbeing	
Gender	Count	246	31	.000
	Female % within Gender	88.8%	11.2%	
	% within Well being	74.3%	62.0%	
	Count	85	19	
	Male % within Gender	81.7%	18.3%	
	% Within Well being	25.7%	38.0%	
Total	Count	331	50	
	% within Gender	86.9%	13.1%	

Significant was at $p \leq .05$

Source: Primary data (2022)

Table 6. Shows that majority of respondents female had poor wellbeing. This was indicated by (246) 88.8% of the respondents. It was also indicated that there is an association between gender and wellbeing as indicated ($p.000 < .05$).

Table 7. Association between Age and Wellbeing of caregivers

Age * Wellbeing Crosstabulation					
		Wellbeing		Asymp.sig-(2 sided)	
		Poor	Good		
Age	Lesser than 20yrs	Count	2	2	.002
		% within Age	50.0%	50.0%	
		% within Well being	.6%	4.0%	
	21-25yrs	Count	17	5	
		% within Age	77.3%	22.7%	
		% within Well being	5.1%	10.0%	
	26-30 yrs	Count	19	1	
		% within Age	95.0%	5.0%	
		% within Well being	5.7%	2.0%	
	31-35yrs	Count	122	17	
		% within Age	87.8%	12.2%	
		% within well being	36.9%	34.0%	
>35yrs of age	Count	171	25		
	% within Age	87.2%	12.8%		
	% within Well being	51.7%	50.0%		

Significant was at $p \leq .05$

Source: Primary data (2022)

Majority of poor wellbeing was observed among caregivers whose age was more than 35 years. This was indicated by 51.7 percent of the participants. It was also revealed that there is a strong degree of association between age and wellbeing as indicated by $P.002 < .05$.

Table 8. Association between occupations of caregivers and their wellbeing

Occupation of the respondents * Wellbeing Crosstabulation			Well being		Asymp.sig- (2 sided)
			poor wellbeing	Good wellbeing	
Occupation of the respondents	Farmer	Count	295	39	.004
		% within Well being	89.1%	78.0%	
	Casual Labor	Count	13	6	
		% within Well being	3.9%	12.0%	
	Employed	Count	4	2	
		% within Well being	1.2%	4.0%	
	Unemployed	Count	17	3	
		% within Well being	5.1%	6.0%	
	Student	Count	2	0	
		% within Well being	0.6%	0.0%	

Significant was at $p \leq .05$

Source: Primary data (2022)

Poor wellbeing was identified among caregivers who were farmers. This was indicated by (295)89.1 percent. It was also indicated that there is a major association between occupations and wellbeing as indicated by ($P.004 < .05$).

Table 4. Association between education level of caregivers and wellbeing

Education level of the participants * Wellbeing Crosstabulation			Well, being		Asymp.sig-(2 sided)
			Poor wellbeing	Good wellbeing	
Education levels	None	Count	91	9	.022
		% within Well being	27.5%	18.0%	
	Primary	Count	220	37	
		% within Well being	66.5%	74.0%	
	Secondary	Count	16	4	
		% within Well being	4.8%	8.0%	
	University	Count	4	0	
		% within Well being	1.2%	0.0%	

Significant was at $p \leq .05$

Source: Primary data (2022)

The quality of wellbeing was poor among caregivers who had primary level of education. This was indicated by (220) 66.5%. It also shows that there is an important correlation between education level and wellbeing of caregivers as indicated by ($P.022 < .05$).

Table 10 Association between Marital status and wellbeing of caregivers

		Well, being		Asymp.sig-(2 sided)	
		poor wellbeing	Good wellbeing		
Marital status	Single	Count	47	6	.000
		% within Well being	14.2%	12.0%	
	Married	Count	205	36	
		% within Well being	61.9%	72.0%	
	Separeted	Count	38	2	
		% within Well being	11.5%	4.0%	
	Divorced	Count	33	3	
		% within Well being	10.0%	6.0%	
	Other	Count	8	3	
		% within Well being	2.4%	6.0%	

Significant was at $p \leq .05$

Source: Primary data (2022)

The higher poor wellbeing was identified among caregivers who were married. This was indicated by (205) 61.9 percent and there is a significant association between marital status and wellbeing of caregivers to epileptic patients as indicated ($P.000 < .05$).

Table 5. Association between Monthly income and wellbeing

Respondent's monthly income * Wellbeing crosstabulation			Well being		Asymp.sig-(2 sided)
			poor wellbeing	Good wellbeing	
Monthly income	Less than 10000	Count	253	32	.000
		% within Well being	76.4%	64.0%	
	10000 to 50000	Count	68	16	
		% within Well being	20.5%	32.0%	
	51000 to 100000	Count	5	2	
		% within Well being	1.5%	4.0%	
	110000 to 150000	Count	3	0	
		% within Well being	.9%	0.0%	
	160000 and above	Count	2	0	
		% within Well being	.6%	0.0%	
Total		Count	331	50	
		% within Well being	100.0%	100.0%	

Significant was at $p \leq .05$

Source: Primary data (2022)

This indicated that there a significant association between income levels of the caregivers and their wellbeing.

There was also a need to examine the extent to which caregiving responsibilities to epileptic patients correlated with well-being of caregivers. To achieve this Karl Pearson correlational coefficients of determination was computed. After computation analyzed data

presented in the table 12.

Table 6. Correlation between Independent and dependent variables

Correlations			
n°	Independent Variables	Statistical test	Caregivers well being
1	Social Factors	Pearson Correlation Sig.(2-tailed)	.194 .000
2	Economic factors	Pearson Correlation Sig.(2-tailed)	.251 .035
3	Psychological factors	Pearson Correlation Sig.(2-tailed)	.153 .000
4	Demographics	Pearson Correlation Sig.(2-tailed)	.336 .001

** . Correlation is significant at the $p \leq .05$ level (two-tailed).

Listwise N=381

Computation was based on the confidence level of 95%

Source: Primary data (2022)

Table 4.12 shows relationship between caring epileptic patients' responsibilities and caregiver's wellbeing. Based on the sample variables tested, it was revealed that there is low positive degree of relationship between caregiver's wellbeing and social factor. This was indicated by ($r = .194$; $P = .000$; $N = 381$). On the point of economic factors, it was also revealed that there is a low positive degree between the two variables. This was indicated by ($r=.251$; $P= .035$; $N 381$). The findings have revealed lower positive degree of relationship. This was indicated by ($r = .153$, $p= .000$; $N = 381$). Last but not the least, it was also revealed that there is low positive degree of relationship between demography and wellbeing. This was indicated ($r= .336$, $P= .001$; $N= 381$)

A regression analysis was performed to produce a model summary, analysis of variance and coefficient model for all dependent variables.

Table 7. Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.399 ^a	.159	.155	.45216

a. Predictors: (Constant), wellbeing of care givers.

Source: Primary data (2022)

Table 13 shows model summary indicates that $R = 0.399$, R - square = 0. 159, adjusted R - square= 0.155, and the $SE = 0.45216$. The coefficient of determination also called the R square is 0.159. This shows that the effects of caregiving service to epileptic patients, explains 15.9% of the variations on the quality of caregivers' wellbeing in Rwinkwavu hospital. This implies that a change in independent variables has a strong and a positive effect on quality of life.

Table 8. Analysis of Variance

Model		Sum of Squares	Df	Mean Square	F	Sig.
1	Regression	14.662	2	7.331	35.857	.000 ^b
	Residual	77.281	372	.204		
	Total	91.94	380			

a. Predictors: (Constant), social demographic factors

b. Dependent Variable: quality of well being

Source: Primary data (2022)

The significance of the regression model was tested using Analysis of Variance (ANOVA). Table14 indicated that regression was significant at ($p = .000$), this explains that correlation and significant was not happened by chance, this was because the significance value is 0.000 which is less than 0.05. This made the results of the regression model credible and reliable.

Table 9. Regression summary coefficient Analysis

Model	Unstandardized Coefficients		Standardized Coefficients		Sig.	
	B	Std. Error	Beta	T		
1	(Constant)	.569	.165		3.443	.001
	Socioeconomic status	.521	.042	.557	12.458	.000
	Psychological factor	.063	.040	.083	1.585	.011
	Demographics	.018	.032	.029	.553	.005

a. Dependent Variable: Wellbeing

Source: Primary data (2022)

Table15 shows regression coefficient findings of key variables under investigation (socioeconomic variables, psychological factors and demographics). It was indicated that epileptic caregiving effect is statistically significant in explaining the poor wellbeing among caregivers attending Rwinkwavu hospital. This was shown by epileptic caregiving service which is statistically significant to affect quality of living among caregivers attending Rwinkwavu hospital ($B = 0.557$, p value = 0.000). This tells us that improve in socioeconomic status by one unit can lead to the improve of 0.557 on the quality of living among caregivers attending Rwinkwavu health centers. On the case of psychological factors, it was indicated that psychological factors are statistically significant in explaining the poor wellbeing of the caregivers. This was indicated by ($B = 0.063$, $P = 0.011$). This means that improve of psychological factor by one unit will lead to the improve of 0.036 on the wellbeing of the caregivers.

Discussions

The prevalence of caregivers of epileptic patients in mental health service of Rwinkwavu district hospital is 46%. This study concluded that caring to an epileptic patient greatly linked with poor wellbeing, psychological and social difficulties, this explained by the following results from this study. On the point gender, majority of the respondents were females indicated by 72.7%, these findings were in line with findings published by NISR [9] that female account 52% of the total population of Rwanda. About 68.8% were children who were being cared by their parents. These findings were not far from the reports published by the Ministry of gender and family promotion [10], that parents have primary responsibilities of caring to their children. In addition, these findings were also supported by the findings of the study conducted in five low middle-income countries (Tanzania, Uganda, Ghana, South Africa and Kenya) with aim to ascertain the clinical

features, consequences and the causes of active cases of epilepsy in the region, it found out that 51% of epileptic patients were children and study reveal out 69% of epilepsy cases started in childhood.

Focusing on caregivers' occupations, majority of caregivers were farmers (87.7%). These findings were not far from the current health and demographic survey (DHS, 2020), which concluded that about 58% of Rwandese live in farming. It was also revealed that 74.8% of cares earned lesser than 10000 Frw as monthly salary. These findings were against the findings presented by the ministry of finance and economic planning (MINICOFIN, 2018; World Bank, 2019), that Rwanda have been able to reduce extreme poverty from 78% in 1998 to 38% in 2018. Furthermore, it was also reported that in the countries with low income, the socio-demographic profile of the epileptic patients is characterized by unemployment, single status and low level of education and more likely to divorce [11].

Throughout the findings, it was revealed that, as results of being caregiver to epileptic patients 37.8% of caregivers were unable to concentrate on their usual activities, about 48.30% sometimes experienced sleep difficulties over worries of their patients. These findings were similar to the findings presented by Cianchetti et al., (2014), that caring for epilepsy patients caused serval psychological problems like stress, sadness and warries of the future. These was supported by Saada, 2015 who confirmed that epileptic sickness caused psychological stress to the caregivers [12].

As long as social economic effects of epilepsy get considered, about 69.6% indicated that the disorder that their patients were suffering from were something very serious to them. These findings were very close the findings presented by World Health organization (2019) that across the world people with epilepsy and their families, face different form of human right violation. These were supported by the study conducted in rural region of Tanzania by Goodall et al., (2018), revealed that YPWE has poor social outlook than people with no epilepsy.

About 39.1% agreed and 41.7% strongly agreed that patient's illnesses changed their family life conditions. About 16.5% agreed and 20.2% strongly agreed that caring for epileptic patients have caused tension of conflict in their life. These findings were in line with the findings presented by the study conducted by Simms et al., (2008) who find out that the prevalence of epilepsy in Rwanda is 0.7 % and due to the lack of appropriate medical help, epilepsy affects the quality of life of people living with epilepsy and their caregiving families. In support to this, [13] and [4], in the study conducted in Rwanda, they have concluded that having epilepsy is heavily associated with stigma, psychological distress, poverty and decrease of family income, which explain the existing treatment gap of epilepsy and social difficulties to caregivers. Furthermore, in the study conducted by Irafan et al., (2017) concluded that negative social effect of caregiving was witnessed among caregivers due to wide demands of caregiving role and inadequate resources.

Focusing on the relationship between socioeconomic status and wellbeing of caregivers of epileptic patients attending Rwinkwavu District Hospital. The findings have showed that there is a low positive degree of relationship between caregiver's wellbeing and Ubudehe category ($r = .194$; $P = .000$; $N = 381$), that there is a low positive degree of relationship between caregivers' monthly income and their well-being ($r = .25$; $P = .035$; $N = 381$), and that there is a lower negative degree of relationship between caregiving period and wellbeing, $r = -.153$, $p = .000$;

N= 381). These findings were in line with the findings presented in Malaysia by Siew-Tim Lai et al (2019) confirmed that socio-demographic factors: Factors like age, gender and family relationship influence psychosocial effects among caregivers of epileptic patients. It was further reported that female was highly affected than men, data showed that 58% female and 42% of male affected with justification that female plays many roles in the family including to caring sick family members. In addition, the study showed that aging people with no occupation are more like to get affected, more than 55% of aged people reported psychosocial effects related to caring epileptic family members [14]. These findings were supported by the findings of the study conducted in Nigeria by AJ Yusuf et al., (2013) high level of emotional pain was observed among siblings that are caregivers, this explained that play a role of nuclear family and caregivers is huge responsibility. In addition to this, Thompson, et al., (2014), carried out a study and concluded that caring to epileptic patients significantly impact the caregiver's employment status, and some respondents reported to stop working in order to meet epileptic patient's care needs, all these worsen the economic status of the entire family. Last but not the least, in the study conducted by Siew-Tim Lai et al., (2019), Sabo 2020 have concluded that caregivers with financial and family support reported to have few psychosocial effects, while caregivers with less family support reported to highly affected. In support to the raised point, it was also found that low education and several seizures was associated with negative impacts experienced by caregivers of pediatric epilepsy.

Conclusion

Based on the findings presented it was concluded that lack of concentration on daily activities, sleeping difficulties, inability to take decisions, unhappy feeling, stress and loss of confidence were identified as psychological effects of caring to epileptic patients and that caring to epileptic patients has moderate psychological effects on well-being of caregivers. It was also indicated that changing life conditions, tensions of conflicts, reduction of family relationship, reduction of leisure time and reduction of family incomes were revealed as socio-economic effects of caring to epileptic patients, and that caring to epileptic patients has several socio-economic effects on well-being of caregivers and it was determined that there is a strong positive degree of relationship between sociodemographic characteristics and wellbeing of caregivers to epileptic patients in Rwanda. The researcher recommends the management of Rwinkwavu district hospital to put in place financial supports to the caregivers of epileptic patients, the government of Rwanda was also recommended to put in place socio-economic projects aimed to support people who are caring for epileptic patients and that family members of epileptic patients should share the responsibilities of caring to the patients.

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REFERENCES

- [1] EpilepsyFoundationofAmerica, "Epilepsy & My Child Toolkit: A Resource for Parents with a Newly Diagnosed Child," *National center for project acces*, p. 9, 2018.
- [2] J. Chin, "Epilepsy treatment in sub-Saharan Africa: closing the gap," *African Health Sciences*, p. vol 12, 2 June 2012.
- [3] WHO, "WHO COUNTRY COOPERATION STRATEGY 2014/2018," WHO regional office for Africa, Kigali, 2014.
- [4] F. Sebera, M. Naasson , E. T. Dirk , N. . P. Ibrahim, A. . G. Diop, A. Tofighy, P. Boon and P. Dedeken, "Addressing the treatment gap and societal impact of epilepsy in Rwanda," *www.researchgate.net*, p. 7, 27 March 2015.
- [5] WHO, "Epilepsy in the WHO African Region: Bridging the Gap," WHO Regional Office for Africa, Brazzaville, 2010.
- [6] N. L. & J. Spangenberg, "Children with Epilepsy and their families: psychosocial issues," *tandfonline.com*, p. 60, 15 August 2014.
- [7] WHO, "Epilepsy: a public health imperative," World Health Organization, Geneva, 2019.
- [8] HMIS, "Rwinkwavu district hospital annual HMIS report," MoH, Kigali city, 2020.
- [9] NISR, "National Institute of Statistics of Rwanda," NISR, Kigali city, 2020.
- [10] MIGEPROF, "national gender statistics report," NISR, Kigali city, 2016.
- [11] C. E. Jevela, "Epidemiological profile of epilepsy in low income populations," *Elsevier*, p. 56, February 2018.
- [12] F. Saada, "The everyday lives of families of adult individuals with epilepsy," *www.elsevier.com*, vol. Epilepsy & Behavior 50 , pp. 10-13, 17 June 2015.
- [13] S. Victoria , "Prevalence of epilepsy in Rwanda: a national cross-sectional," *Tropical Medicine and International Health*, p. 6, August 2008.
- [14] S.-T. Lai, W. Y. Tan, M. . C.-M. Wo, K.-S. Lim , S. B. Ahmad and C.-T. Tan , "Burden in caregivers of adults with epilepsy in Asian families," *European Journal of Epilepsy*, pp. 7-8, 2019.

