



# Anxiety and Depression among Family Caregivers of Children with Epilepsy in Burkina Faso

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## Abstract

**Background** Epilepsy is a common and chronic neurological disorder influencing children's cognitive and behavioral performance. Primary caregivers of children with epilepsy (CWE) report high levels of depression and anxiety.

**Patients and Methods** We performed a cross-sectional study on caregivers of CWE in the Neurology Department of Yalgado Ouédraogo University Teaching Hospital from May 7, 2020 to August 18, 2020. The State-Trait Anxiety Inventory scale and Beck Depression Inventory scale were assessed to screen anxiety and depression.

**Results** One hundred caregivers with a mean age of  $37.75 \pm 10.69$  years were included in the study. The majority of them were female gender (73%), aged <40 years (59%), and residing in rural areas (79%). Most of caregivers were female gender (73%) and the mothers of children (67%). The majority of CWE were boys (55%), having generalized epilepsy (55%) and epilepsy duration less than 6 years (74%). Anxiety was observed in 56%, depression in 27%, and both anxiety and depression in 23% of caregivers. The factors influencing anxiety among caregivers were female gender ( $p = 0.04$ ), being patient's mothers ( $p = 0.04$ ), and caring male patients ( $p = 0.04$ ). The factors associated with caregiver's depression were being married ( $p = 0.03$ ) and caring patients with five seizures per year ( $p = 0.04$ ).

**Conclusion** Our study revealed very high rates of anxiety and depressive disorder among caregivers of CWE in Burkina Faso.

## Keywords

- ▶ depression
- ▶ anxiety
- ▶ caregivers
- ▶ children with epilepsy
- ▶ Burkina Faso

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## Background

Epilepsy is a common and chronic neurological disorder influencing children's cognitive and behavioral performance.<sup>1</sup> Recurrent seizures may lead to irreversible effects on family members, especially parents.<sup>2</sup> Diagnosis of epilepsy in a child brought with it a series of consequences for the family, and most parents got affected by it: the loss of a perfect child and the realization that the child might always be different from other children because of their illness.<sup>3</sup> Primary caregivers of children with epilepsy (CWE) report high levels of depression and anxiety.<sup>4,5</sup> Compared with families of healthy children, caregivers of CWE have been found to have significantly higher levels of depression and anxiety.<sup>6</sup> The number of research done on the effects of epilepsy on family members and other caregivers are so few.<sup>7</sup> In sub-Saharan Africa, there are few studies regarding the prevalence of anxiety and depression among caregivers of patients with epilepsy.<sup>8,9</sup> In Burkina Faso, to our knowledge, there is no study on anxiety and depression among caregivers of people with epilepsy. The only study performed concerns the depression of adult patients with epilepsy, with a high prevalence of depression symptoms among adult patients with epilepsy attending in a tertiary hospital of Ouagadougou (56%).<sup>10</sup> The objective of this study was to determine the prevalence of anxiety and depression among caregivers of CWE in Burkina Faso.

## Patients and Methods

This study was approved by the Ethical Board of Medical School of Joseph Ki Zerbo University and the Local Ethical Committee of Yalgado Ouédraogo University Teaching hospital.

### Study Profile

This cross-sectional study was performed in the Department of Neurology of Yalgado Ouédraogo University Teaching Hospital during the period from May 7th to August 18th, 2020.

### Study Location

Burkina Faso is a French speaking country located in West Africa without access to the sea. Its population was estimated in 2016 as 19,034,397 inhabitants. Ouagadougou is its capital and the largest city of the country. The city has public health infrastructures such as the Yalgado Ouédraogo University Hospital, Tengandogo University Hospital, Charles De Gaulle Pediatric University Hospital, Bogodogo Hospital and many private health infrastructures. The department of neurology belongs to the department of medicine. It has been into existence since March 2003. It provides care for patients with neurological pathologies and pathologies with neurological repercussions. The neurology department has 23 inpatient beds spread over five wards.

### Study Population

This study included children and adolescents with epilepsy attending in neurology department outpatient's consultation of the Yalgado Ouédraogo University Teaching Hospital during the study period and their principle caregivers for

whom informed consent was obtained. The inclusion criteria were: (1) the child was less than 18 years old; (2) epilepsy was clinically diagnosed according to the International League Against Epilepsy (ILAE) 2017 criteria; (3) the caregivers were older than 18 years; and (4) the caregiver of the child with epilepsy was willing to participate in this study. Principle caregivers of CWE, defined as the individuals who had most responsibility for the child's care (sisters, brothers, fathers, mothers, grandfathers, grandmothers). The exclusion criteria were: (1) other chronic diseases in the child with epilepsy, which could affect the emotional states of caregivers (i.e., congenital heart disease, diabetes); (2) lack of consent, (3) caregivers with diagnosed psychiatric disorders.

### Sampling

Our sample was non-random with systematic recruitment of caregivers of children and adolescents with epilepsy followed on an outpatient basis in the neurology department during the study period.

### Procedure

The caregiver who came along with a child with epilepsy for outpatient consultation in the neurology department was recruited. When the child arrived at the Neurology Department for the regular follow-up appointments, the parents were approached about participating in the study. All caregivers agreed to participate and signed the informed consent. Each caregiver was matched to a child with epilepsy.

## Data Collection and Analysis

### Survey

The data were collected by using a hetero-administered anonymous questionnaire, containing information about CWE and their caregivers. Data were collected. The questionnaire was made by the first five authors of the article (D.A.A., K.J.M.A., R.B., D.A., and B.Z.). The questionnaire was divided into two sections. The first section was focused on the characteristics of CWE, including: (1) children's basic characteristics (age, gender, place of residence); (2) disease status (seizure type, duration of epilepsy, seizure frequency). The second section was focused on the caregivers, including: (1) basic characteristics (gender of caregivers, age of caregivers, caregivers "education level, caregivers" working status, place of residence, marital status) and their past medical status (anxiety, depression, or psychiatric diseases). The initial questionnaire was pre-tested in five caregivers of CWE to gauge the acceptability of the study and to assess their interest in the study. The questionnaire was validated by C.N., R.B., A.M., K.K., and J.K.

### Assessment of Anxiety and Depression

All the caregivers of CWE were assessed on their level of anxiety by the State-Trait Anxiety Inventory scale, French version comprising 20 items. Each item is rated from 1 to 4. The total score varies from 20 to 80. The level of anxiety was classified into five categories: greater than 65 = very high, between 56 and 65 = high, between 46 and 55 = medium,

between 36 and 45 = weak, less than 36 = no anxiety.<sup>11</sup> The depression was assessed using the Beck Depression Inventory-Fast Screen scale, a short version of the Beck Depression Inventory II composed of seven items.<sup>12</sup> The seven items include sadness, pessimism, feelings of failure in the past, loss of pleasure, low self-esteem, self-criticism, and suicidal thoughts.<sup>13</sup> Following the recommendations of the BDII manual, caregivers with a BDI-II score of  $\geq 4$  points were classified as having symptoms of depression.

### Data Analysis

Data collected were analyzed on microcomputer using Epidata software version 7.2.1.0. The quantitative variables were expressed by their mean  $\pm$  standard deviation, and the qualitative variables by number and percentage. For the comparison of proportions, the Chi-square test and Fischer's exact test were used. The threshold of statistical significance was defined for a probability  $p$  less than or equal to 0.05 for the Chi-square and Fischer's exact tests. The threshold of statistical significance was defined for a probability if  $p < 0.05$ .

## Results

### Sociodemographic and Clinical Characteristics of Participants

One hundred CWE were included in the study. The majority of them were boys (55%). Their mean age was 12.34 years, ranging from 4 to 17 years. Most of the children had generalized epilepsy (55%). The mean duration of epilepsy was 4 years. Forty-five percent of CWE had more than three seizures per month. In line with the number of patients, 100 caregivers were enrolled in this study. The mean age of caregivers was  $37.75 \pm 10.69$  years ranging from 20 to 69 years. Most of them were female gender (73%), aged  $< 40$  years (59%), not educated (37%), residing in rural areas (79%), and merchants (33%). The principle caregivers were mothers (67%), fathers (20%), and sisters (7%). The mean age of mothers and fathers was respectively  $36.05 \pm 8.24$  years and  $45.85 \pm 12.17$  years. ► **Table 1** gives the sociodemographic and clinical characteristics of participants to the study.

**Table 1** Sociodemographic characteristics of participants to the study

Variable	Study population (N = 100)	Frequency (%)
Sociodemographic characteristics of caregivers		
Age (years)		
< 40	59	59
40–59	27	27
$\geq 60$	14	14
Gender		
Women	73	73
Male	27	27

**Table 1** (Continued)

Variable	Study population (N = 100)	Frequency (%)
Sociodemographic characteristics of caregivers		
Urban	79	79
Rural	21	21
Educational status		
Not scolarized	37	37
Primary	16	16
Secondary	26	26
University	20	20
Relationship with child		
Mothers	67	67
Fathers	20	20
Sisters	7	7
Grandparents	6	6
Marital status		
Married	89	89
Single	11	11
Occupation		
Merchants	33	33
House women	32	32
Civil servant	23	23
Students	6	6
Famer	3	3
Retired	3	3
Characteristics of CWE		
Age (years)		
0–5	54	54
6–11	24	24
12–17	17	17
> 17	5	5
Gender		
Boys	45	45
Girls	55	55
Sixteen types		
Generalized	45	45
Focal	55	55
Epilepsy duration (years)		
0–5	74	74
6–11	17	17
$\geq 12$	9	9
Seizures frequency per month		
1	19	19
2–3	36	36
> 3	45	45

**Prevalence of Anxiety and Its Risk Factors**

The mean STAI YB score of  $37.73 \pm 9.11$  ranging from 21 to 60. Fifty-six percent of parents were found to be anxious. Of them, 33 (58.9%) had fair anxiety, 18 (32.1%) moderate anxiety, and five (8.9%) severe anxiety. The mean age of caregivers with anxiety was  $37.37 \pm 11.27$  years. The symptoms of anxiety were nervousness (98.2%), feelings of vulnerability (87.5%), feelings of failure and worry (55.3%), feelings of insecurity (42.85%), and a lack of confidence in self (39.28%). The factors influencing anxiety among caregivers was female gender ( $p = 0.04$ ), being patient's mothers ( $p = 0.04$ ), and caring male patients ( $p = 0.04$ ). **Table 2** shows the factors associated or not with caregiver's anxiety.

**Prevalence of Depression and Its Risk Factors**

Twenty-seven percent of caregivers had depression symptoms with a mean BDI-FS score of  $2.92 \pm 4.11$  with extremes

**Table 2** Factors associated with anxiety of caregivers of CWE

Variable	Study population	With anxiety	Without anxiety	p-Value
Sociodemographic characteristics of caregivers				
Age (years)				
< 40	59	34 (57.6%)	25	0.59
40-59	27	19 (70.4%)	8	
≥60	14	3 (75%)	11	
Gender				
Women	73	46 (63%)	27	0.48
Male	27	10 (37%)	17	
Residence				
Urban	79	44 (55.7%)	35	0.48
Rural	21	12 (57.1%)	9	
Educational status				
Not scolarized	37	16 (43.2%)	21	0.18
Primary	16	9 (56.2%)	7	
Secondary	26	18 (69.2%)	8	
University	20	12 (60%)	8	
Type of family caregivers				
Mothers	67	43 (64.2%)	24	0.04
Fathers	20	6 (30%)	14	
Sisters	7	3 (57.1%)	4	
Grandparents	6	4 (66.7%)	2	
Marital status				
Married	89	48 (53.9%)	41	0.34
Single	11	8 (72.7%)	3	
Occupation				
Merchants	33	14 (42.4%)	19	0.31
House women	32	21 (65.6%)	11	
Civil servant	23	13 (56.5%)	10	
Students	6	5 (83.3%)	1	
Famer	3	2 (66.7%)	1	
Retired	3	2 (66.7%)	1	

(Continued)

**Table 2** (Continued)

Variable	Study population	With anxiety	Without anxiety	p-Value
Sociodemographic characteristics of caregivers				
Characteristics of CWE				
Age (years)				
0-5	54	29 (53.7%)	25	0.77
6-11	24	15 (62.5%)	9	
12-17	17	10 (58.8%)	7	
> 17	5	2 (40%)	3	
Gender				
Boys	45	26 (57.8%)	19	0.006
Girls	55	30 (54.5%)	25	
Sixteen types				
Generalized	45	29 (64.4%)	16	0.52
Focal	55	27 (49.1%)	28	
Epilepsy duration (years)				
0-5	74	40 (54%)	34	0.09
6-11	17	8 (47%)	9	
≥12	9	8 (88.9%)	1	
Seizures frequency per year				
0-5	19	13 (68.4%)	6	0.64
5-30	36	20 (55.5)	16	
> 30	45	23 (51.1%)	22	

of 0 and 10. The mean age of depressed caregivers was  $37.51 \pm 12.29$  years. The symptoms of depression were mood sadness (92.6%), pessimism (55.5%), past failure (74.1%), negative self-criticism (74.1%), and desire for suicide (41.7%). The factors associated with caregivers depression was being married ( $p = 0.03$ ) and having children with less seizures per month ( $p = 0.04$ ). **Table 3** shows the factors associated or not with caregivers depression.

**Discussion**

We conducted a cross-sectional study to evaluate anxiety and depression status among caregivers of CWE in Burkina Faso, and examined which factors were associated with anxiety and depression. The caregivers included in the study were parents (87%), female gender with majority of mothers (73%). Similar studies conducted across different countries had found that most of the caregivers were female and mothers of CWE.<sup>14-17</sup> The prevalence of anxiety in this study was 56%, in line with the literature in which its value varied from 9 to 58%.<sup>18</sup> However, the high prevalence was also similar to those observed in China (56.2%),<sup>4</sup> Saudi Arabia (55%),<sup>19</sup> and United States (64.20%).<sup>20</sup> In contrast, lower prevalence was observed in Iran (46.7%),<sup>21</sup> Nigeria (12 and 38.6%),<sup>8,9</sup> and China (25.7%).<sup>22</sup> Regarding depression, its prevalence (27%) was lower than that observed in Saudi Arabia (38.7%),<sup>19</sup> China (38.40%),<sup>23</sup> Nigeria (50.5%),<sup>8</sup> and Hussain in United States (46.91%)<sup>20</sup> but higher than those observed in another studies in China (21.67%),<sup>23</sup> and Nigeria (18.7%).<sup>9</sup> Twenty-two percent of caregivers had

**Table 3** Factors associated with depression of caregivers of CWE

Variable	Study population	With depression	Without depression	p-Value
Sociodemographic characteristics of caregivers				
Age (years)				
< 40	59	18 (36%)	41	0.82
40–60	27	7 (18.9%)	20	
≥60	14	2 (50%)	12	
Gender				
Men	73	21 (28.8%)	52	0.34
Women	27	6 (22.2%)	21	
Educational status				
Out of school	37	10 (27%)	27	0.48
Primary	16	3 (18.7%)	13	
Secondary	27	10 (37%)	17	
University	20	4 (20%)	16	
Residence				
Rural	21	4 (19%)	17	0.51
Urban	79	23 (29.1%)	56	
Marital status				
Married	89	26 (37.7%)	63	0.03
Single	11	1 (9.1%)	10	
Family caregivers				
Mothers	67	19 (28.3%)	48	0.23
Fathers	20	5 (25%)	15	
Sisters	7	0	7	
Grandparents	6	3 (50%)	3	
Occupation 0.73				
Merchants	33	11	22	
House women	3	1	2	
Civil servant	6	0	6	
Students	23	7	16	
Farmer	32	7	25	
Retired	3	1	2	
Children (n = 100)				
Age group (years)				
0–5	54	15 (27.8%)	39	0.36
6–11	24	4 (16.7%)	20	
12–17	17	7 (41.2%)	10	
> 17	5	1 (20%)	4	
Gender				
Female	45	14 (31.1%)	31	0.07
Male	55	13 (23.6%)	42	
Sixteen types				
Generalized	45	11 (24.4%)	34	0.43
Focal	55	16 (29.1%)	39	
Epilepsy duration				
0–5	74	18 (24.3%)	56	0.08
6–11	17	5 (29.4%)	12	
12–17	35	4 (11.4%)	31	

**Table 3** (Continued)

Variable	Study population	With depression	Without depression	p-Value
Epilepsy frequency per year				
0–5	19	8 (42.1%)	11	0.040
6–30	36	5 (13.9%)	31	
> 30	45	14 (31.1%)	31	

both anxiety and depression, in lower prevalence than that observed in Saudi Arabia (32%).<sup>19</sup> The differences in levels of anxiety, depression, and both anxiety and depression among different studies might be because of socio-economic and cultural differences, differences in availability of treatment options, age of patients and differences in resilience of people across different study settings. However, this current study suggest that neurologists as psychiatrics should pay more attention to psychoemotional symptoms among caregivers of CWE. The second objective of this study was to examine the factors associated with anxiety and depression of caregivers of CWE. Being a women and mother of a child with epilepsy was associated with anxiety of caregivers. In several studies, mothers are significantly affected by anxiety as evidenced by several studies.<sup>4,19,24,25</sup> Mothers plays a pivotal role in the provision of health care services to children.<sup>26,27</sup> Women are usually more closely and emotionally involved in caregiving, and are traditionally expected to be involved with household work than men; thus bringing them into more contact with the patients.<sup>28</sup> The caregivers of boys with epilepsy were significantly affected by anxiety, unlike the study of Yusuf et al in Nigeria<sup>9</sup> who found that caregivers of girls with epilepsy were mostly affected. A study from Saudi Arabia had found that parental anxiety was not linked to the sex of the child with epilepsy.<sup>19</sup> This situation could be explained by the fact that the majority of CWE were of male gender. Moreover, in the African context, parents give more interest to the education of boys than that of girls. In the present study, caregivers who were married were significantly affected by depression than single (23 vs. 9%). This may be due to the majority of caregivers in the current study being married, which induces family burden in addition to special care for an epileptic child which affect mother and may lead to depression. Similar results were found by Rehab in Egypt where 81.0% of married mothers were depressed and there was a statistically significant relationship between marital status and depression.<sup>29</sup> Our study found that lower seizures frequency in child with epilepsy was significantly associated with 'caregiver's depression. Riechmann et al in Germany<sup>30</sup> observed a significantly higher frequency of depression in parents with children having active epilepsy than those with remission, respectively. As for Babalola et al in Nigeria,<sup>8</sup> they observed significantly more depression in parents whose children had more seizures. The fact that parents of children with fewer seizures are more affected by depression could be explained by the fact that the majority of patients (74%) had a short duration of disease (less than 6 years). Therefore, this did not allow the caregivers to adapt to the unpredictability of seizures.



## Study Limitations

This study provided insight into the impact of epilepsy on the health status of caregivers of CWE. However, it has several limits. In addition, several data relating to the caregivers which could better analyze the factors of risk of anxiety and depression (duration of caring of child; presence of other pathologies in the family, income of caregivers, their responsibilities and knowledge and attitudes of caregivers about epilepsy) could not be included in this present study.

## Conclusion

The study revealed very high rates of anxiety and depressive disorders among caregivers of CWE in Burkina Faso. The presence of anxiety and depressive disorder was significantly associated with gender of caregivers, relation to patient, marital status, gender of patients, and frequency of epilepsy seizure.

### Ethical Approval and Consent to Participate

The confidentiality of patients data was taken into account and the informed oral consent of the parents was obtained before the start of the interview. Parents suspected of having generalized anxiety or depressive disorder were referred to the psychiatric department of management

### Authors' Contributions

A.A.D., B.B., A.D., Z.B., and J.M.A.K. had contributed to the data collection or processing, analysis or interpretation, literature research and writing. C.N., K.K., and J.K. had contributed to concept and design of the study. All the authors read and approved the final manuscript.

### Conflict of Interest

None declared.

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