

# Quality of life among caregivers of children with epilepsy: A cross-sectional study at Eastern Nepal

Rita Pokharel<sup>1</sup>  | Prakash Poudel<sup>2</sup>  | Sami Lama<sup>1</sup>

<sup>1</sup>Department of Psychiatric Nursing,  
BP Koirala Institute of Health Sciences,  
Dharan, Nepal

<sup>2</sup>Department of Paediatrics and Adolescent  
Medicine, BP Koirala Institute of Health  
Sciences, Dharan, Nepal

## Correspondence

Rita Pokharel, Department of Psychiatric  
Nursing, B.P. Koirala Institute of Health  
Sciences, Koshi, Dharan-18, 56700, Nepal.  
Email: rpokharel35@gmail.com

## Abstract

**Objective:** To assess the quality of life among caregivers of children with epilepsy in a tertiary care center of eastern Nepal.

**Methods:** A cross-sectional study was conducted among primary caregivers of children with epilepsy, who accompanied their child in child neurology clinic. Consecutive sampling was done, and 106 respondents were interviewed. Data were collected using World Health Organization Quality of Life-BREF (WHOQOL-BREF) scale and analyzed using Statistical Package for the Social Sciences. Descriptive and Inferential statistics were applied.

**Results:** Mean WHOQOL-BREF score was 82.25 {standard deviation (SD)  $\pm 12.11$ }. Transformed scores (0-100) for each domain were  $57.98 \pm 14.55$  in physical,  $55.87 \pm 13.16$  in psychological,  $53.12 \pm 13.42$  in social, and  $52.52 \pm 13.04$  in environmental domain. Mean score for overall perception of quality of life (QOL) was  $2.71 \pm 0.79$  and was  $3.12 \pm 0.75$  for overall perception of health. Living below poverty line ( $P = .03$ ) and poor seizure control status of children ( $P = .46$ ) were significantly associated with lower total QOL score. Living below poverty line was significantly associated with low social relationship ( $P = .003$ ) and environment domain ( $<0.001$ ) scores.

**Significance:** Epilepsy has a multifaceted impact on the lives of affected people. Caring children with epilepsy is associated with enormous psychosocial effects on parents and family members. Caregivers' QOL may affect the treatment and outcome of epilepsy in children. Given the consideration to scarcity of this kind of literature in Nepalese context, this study was conducted.

## KEY WORDS

caregivers, child, epilepsy, Quality of Life

## 1 | BACKGROUND

Epilepsy is one of the most common brain disorders around the world with a reported frequency of four to eight cases per 1000 children.<sup>1</sup> Nearly 80% of the people with epilepsy

live in low- and middle- income countries, and epilepsy is linked with impaired quality of life (QOL).<sup>2-4</sup> Epilepsy has negative impacts on affected person, caregivers, and family. Some of those impacts are burden, stigma, deprivation from education, problems related to side effects of antiepileptic

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drugs, and poor QOL. QOL among parents of children with epilepsy was found to be lower as compared to parents of healthy children.<sup>5</sup> In children, epilepsy can be associated with developmental problems such as developmental delay, poor academic performance, inadequate social skills, and psychosocial problems such as attention-deficit/hyperactivity disorders, intellectual disability, poor self-esteem. In addition to their routine activities, caregivers have to manage time for care and treatment of their children with epilepsy and associated comorbidities that contribute to carers' poor QOL. The impact may depend upon the severity of epilepsy, intricacy of management, coping ability, accepting the condition, and the level of social support from significant others.<sup>6</sup> Many times, family caregivers have difficulties to accept the fact that their children have epilepsy, generally because of stigma.<sup>7</sup> Many similar studies have been done in other countries of the world. As mentioned above, various studies have reported poor QOL among caregivers of patients with epilepsy.<sup>4-8</sup> There is scantiness of literature regarding psychosocial aspects including QOL among caregivers of children living with epilepsy in Nepal where optimum resources are not available for managing childhood epilepsy. Therefore, the present study was conducted with the aim of assessing QOL among caregivers of children with epilepsy in Nepal.

## 2 | METHODS

### 2.1 | Design

A cross-sectional study was conducted among caregivers of children with epilepsy attending a child neurology clinic. Caregivers were selected using purposive sampling technique.

### 2.2 | Study site

Nepal is a low-middle income and land-locked country situated in South Asia. Nepal has seven provinces. Study site is located in Province 1 at eastern part of Nepal. BP Koirala Institute of Health Sciences is a 750-bedded tertiary care university hospital at eastern Nepal providing health services to people from eastern Nepal belonging to Province 1 and Province 2. A small number of patients are also from central Nepal and neighboring districts of India. Child neurology clinic is run once a week. There are about a 1000 follow-up patients currently receiving treatment from the clinic. More than 80% of them are diagnosed with epilepsy. There are many ethnic groups (castes) in Nepal. Nepalese caste system is the traditional classification of birth-ascribed social stratification and ranking of people based upon occupation of their family during ancient times. The caste system is linked with education, occupation,

### Key Point

- There is scarce literature regarding quality of life among caregivers of children with epilepsy in Nepal.
- Poorly controlled seizure in children was significantly associated with poor quality of life among caregivers.
- Income below poverty line was associated with poor quality of life in social relationship and environmental domain.

and overall socioeconomic status of people. Janajati is considered as a relatively disadvantaged group.

### 2.3 | Sample population

Caregivers were either parents or other family members of the children. Other family members were second-degree and third-degree relatives, few of them were step parent or distant relatives who were taking care of patients with full responsibility. Caregivers who denied informed consent, who were under treatment for psychiatric problems, and who could not communicate in Nepali language were excluded. All caregivers presenting to pediatric neurology clinic for treatment of their children during the study period were screened for eligibility. A total of 200 caregivers were screened during the data collection period (from October 2018 to October 2019). Among them, 94 caregivers were excluded. Twenty-three caregivers reported psychiatric problems, 51 caregivers denied consent to participate, and 20 caregivers were unable to communicate in Nepali language because they were exclusively using traditional ethnic language. Remaining eligible consenting caregivers were further interviewed to collect data.

### 2.4 | Data collection and analysis

Principal investigator collected data by interview method using World Health Organization Quality of Life-BREF (WHOQOL-BREF).<sup>9</sup> Four domains (physical, psychological, social, and environmental) and two items (overall perception of QOL (Q1) and health (Q2)) were the primary outcomes of this study. WHOQOL-BREF questionnaire consists of 26 items. Items 1 and 2 assess individual's overall perception of quality of life and health, respectively. The remaining items are categorized under physical, psychological, social, and environmental domains. Scores range from 1 to 5 on each item. Raw scores obtained in this study were then transformed into

a 0-100 scale using a transformation formula.<sup>9</sup> WHOQOL-BREF is frequently used tool in Nepal to measure QOL in different conditions.<sup>10-12</sup> In one of the Nepalese studies using this tool, Joshi U. Et al reported internal consistency in different domains ranging from 0.66 in social relationship to 0.84 in physical domain.<sup>11</sup> Anxiety and depression were measured using a Nepali version of the Hospital Anxiety Depression Scale.<sup>13</sup>

Data were analyzed using the Statistical Package for the Social Sciences v. 16 (SPSS Inc, Chicago, IL, USA). Data were presented as descriptive and inferential statistics. Independent *t* test and analysis of variance (ANOVA) statistics were used to compare mean scores. The Pearson correlation coefficient test was applied to test the relationship of WHOQOL-BREF score with other continuous variables. Confidence interval for all tests was 95%.

Details of methodology and socio-demographic information have been published in another article elsewhere.<sup>14</sup>

## 2.5 | Ethical consideration

Study was approved by the institutional review committee of BP Koirala Institute of Health Sciences, Dharan, Nepal (IRC/0951/017). All participants provided informed consent.

## 3 | RESULTS

There were 106 participants. Mean raw score of WHOQOL-BREF was 82.25 (SD ± 12.11). Table 1 shows WHOQOL-BREF score in each domain. The highest score was observed in physical domain followed by psychological domain. The lowest score was observed in environmental domain.

Table 2 illustrates the comparison of WHOQOL-BREF mean raw score with different variables. Poverty and poorly controlled seizure in children were significantly associated with lower scores among caregivers.

Table 3 depicts the comparison of mean domain scores with different variables. Poverty was significantly associated with lower score among caregivers in social and

environmental domain. Other variables were not significantly associated with QOL.

Duration of epilepsy was not significantly correlated with total QOL score ( $r = .11$ ,  $P = .2620$ ) and domain scores (physical:  $r = .12$ ,  $P = .209$ ; psychological,  $r = .05$ ,  $P = .551$ ; social:  $r = .11$ ,  $P = .236$ ; and environmental:  $r = .12$ ,  $P = .221$ ).

## 4 | DISCUSSION

This study evaluated the QOL among primary caregivers of children with epilepsy, who accompanied their children to the child neurology clinic. In present study, mean WHOQOL-BREF score in all 26 items was 82.25 (SD ± 12.11). The mean scores of the overall perception of QOL and perception of health were 2.71 and 3.12, respectively. The transformed mean scores of each four domains were within the range of 52.5-57.8, which is lower as compared to caregivers of adult patients with epilepsy, but the score was comparable to adult patients of epilepsy in Sudan<sup>15</sup> and adult patients undergoing hemodialysis in Nepal.<sup>11</sup> The mean domain scores in this study were also similar to the scores of patients with epilepsy in India.<sup>4</sup> The mean score in physical domain was highest followed by psychological domain. The mean scores in social relationship and environment domains were lower as compared to physical and psychological domains. This finding is also similar to the finding of one study done in India among patients with epilepsy.<sup>4</sup> Children may not understand the disease condition, and they are dependent on their primary caregivers. So, caregivers of children may face the same situation as adult patients. This may be the reason of the similar QOL score in caregivers of children of this study with the adult patients of other studies.<sup>4,11,15</sup>

Previous studies found lower QOL score with the increasing age group, but present study did not find any differences in QOL scores with the age of caregivers.<sup>7,15</sup> In this study, score of total QOL and scores in different domains of QOL were not significantly different between mother and the other caregivers. However, a study in Egypt found that mothers had significantly diminished QOL score as compared to fathers as

**TABLE 1** WHOQOL-BREF Score among caregivers of children with epilepsy (n = 106)

Domain	Mean ± SD Raw score	Mean ± SD Transformed score (0-100)	Mean ± SD Transformed score (4-20)
Q1	2.71 ± 0.79	NA	NA
Q2	3.12 ± 0.75	NA	NA
Physical	23.24 ± 4.05	57.98 ± 14.55	13.26 ± 2.33
Psychological	19.41 ± 3.12	55.87 ± 13.16	12.00 ± 2.11
Social	24.41 ± 1.58	53.12 ± 13.42	12.50 ± 2.14
Environmental	9.38 ± 14.55	52.52 ± 13.04	12.39 ± 2.09

Abbreviations: NA, not applicable; Q1, overall perception of QOL; Q2, overall perception of health.

**TABLE 2** Comparison of total mean score of WHOQOL-BREF with different variables (n = 106)

Variables	Category	Frequency	Mean ± SD	t-value	95%CI	P-value
Age of caregiver (years)	≤34	53	82.26 ± 13.74	0.08	−4.674 to 4.712	.994
	>34	53	82.25 ± 10.35			
Sex of caregiver	Female	76	82.34 ± 12.82	0.129	−4.458 to 5.076	.907
	Male	30	82.03 ± 10.30			
Religion	Hindu	82	82.98 ± 12.00	1.134	−2.383 to 8.751	.259
	Others	24	79.79 ± 12.42			
Ethnicity	Janajati	43	84.67 ± 12.81	1.715	−0.637 to 8.779	.089
	Others	63	80.60 ± 11.41			
Relationship with child	Mother	68	81.94 ± 12.62	0.355	−5.760 to 4.011	.723
	Others	38	82.82 ± 11.27			
Family type	Nuclear	59	82.54 ± 12.59	0.273	−4.068 to 5.366	.786
	others	47	81.89 ± 11.60			
Poverty line <sup>a</sup>	Below	38	77.95 ± 9.71	−3.046	−11.091 to −2.338	.003
	Above	68	84.66 ± 12.70			
Depression in caregiver	No	90	82.04 ± 12.41	F = 0.234	NA	.792 <sup>b</sup>
	Borderline	9	84.89 ± 10.70			
	Yes	7	81.57 ± 10.81			
Anxiety in Caregiver	No	91	82.63 ± 12.30	F = 0.331	NA	.719 <sup>b</sup>
	Borderline	8	80.75 ± 13.45			
	Yes	7	79.14 ± 8.37			
Onset of seizure in child	Focal	50	81.92 ± 13.08	−0.268	−5.328 to 4.061	.790
	others	56	82.55 ± 11.28			
Seizure control in child	Yes	67	83.93 ± 12.97	2.018	0.074-9.008	.046
	No	39	79.38 ± 9.97			
Comorbidities in child	Yes	20	82.25 ± 13.46	−0.406	−7.214 to 5.494	.685
	No	86	82.02 ± 11.85			

Abbreviations: CI, confidence interval; NA, not applicable.

<sup>a</sup>Categorized on the basis of world bank definition of absolute poverty (per capita income below \$ 1.90 per day)

<sup>b</sup>One-way ANOVA.

caregivers.<sup>16</sup> In contrast to the study done by Ohaeri et al and Karakis et al, this study did not find any significant difference in QOL scores between men and women. Those studies reported better QOL scores in male caregivers.<sup>7,15</sup> Ohaeri et al highlighted the importance of social support for better QOL.<sup>15</sup> The concept of joint family is linked with better social support in eastern culture. However, this study did not find any difference in QOL scores between caregivers living in nuclear families and joint families. Living below absolute poverty was significantly associated with poor QOL scores in caregivers, especially in social relationship and psychological domains. Another study done among Nepalese patients undergoing hemodialysis also found a significant positive correlation of income with social relationship and environment domain of QOL.<sup>11</sup> However, studies done in India and Malaysia among adult patients with epilepsy and caregivers of epileptic patients found no association of QOL with economic condition.<sup>4,17</sup> Some studies have linked QOL with the

rank of employments, which is directly related to income or financial condition of the patients and the families.<sup>7,15</sup> The WHOQOL-BREF social relationship and environment domains assess feelings of being supported by others, personal security, financial adequacy, etc These factors are related to income. A study highlighted that psychology of social rank had a protracted impact on perception of personal identity and the environment.<sup>18</sup> Therefore, social rank psychology may influence the perception of own situation and QOL of a person. Hence, income could be one of the important factors in improving QOL while managing the chronic conditions such as epilepsy. At the same time, it also depends upon individual perception of the situation.

This study did not find a significant difference in QOL score between caregivers of children with comorbidities and without comorbidities. This finding is contradictory to the results of one study done in Saudi Arabia, which found significantly poor QOL level in caregivers of children having

TABLE 3 Comparison of mean WHOQOL-BREF score with variables (n = 106)

Variables	Category	Frequency	Q1	Q2	Physical	Psychological	Social	Environmental
Age of caregiver (Years)	≤34	53	2.68 ± 0.85	3.18 ± 0.70	57.89 ± 14.74	56.36 ± 15.09	52.72 ± 13.88	52.36 ± 14.76
	>34	53	2.74 ± 0.73	3.05 ± 0.79	58.08 ± 14.49	55.38 ± 11.02	53.53 ± 13.08	52.68 ± 11.20
	<i>P</i>		.715	.369	.947	.703	.757	.900
Sex of caregiver	Female	76	2.74 ± 0.78	3.11 ± 0.74	58.16 ± 14.44	56.04 ± 13.99	53.71 ± 14.32	52.41 ± 13.60
	Male	30	2.63 ± 0.80	3.13 ± 0.77	57.53 ± 15.05	55.43 ± 10.99	51.63 ± 10.91	52.80 ± 11.70
	<i>P</i>		.547	.929	.843	.814	.424	.890
Religion	Hindu	82	2.68 ± 0.81	3.07 ± 0.73	59.05 ± 14.84	56.71 ± 13.45	53.74 ± 13.04	53.38 ± 12.99
	Others	24	2.79 ± 0.72	3.29 ± 0.80	54.33 ± 13.14	53.00 ± 11.92	51.00 ± 14.76	49.58 ± 14.76
	<i>P</i>		.557	.212	.164	.227	.381	.211
Ethnicity	Janajati	43	2.81 ± 0.69	3.16 ± 0.69	59.67 ± 14.20	58.21 ± 13.92	54.35 ± 14.30	55.00 ± 13.24
	Others	63	2.63 ± 0.84	3.09 ± 0.72	56.83 ± 14.78	54.27 ± 12.48	52.29 ± 12.84	50.83 ± 12.73
	<i>P</i>		.255	.652	.325	.131	.440	.106
Relationship with child	Mother	68	2.71 ± 0.79	3.10 ± 0.75	57.54 ± 14.34	55.37 ± 13.83	53.60 ± 14.25	52.40 ± 13.34
	Others	38	2.71 ± 0.80	3.15 ± 0.75	58.76 ± 15.08	56.76 ± 12.00	52.26 ± 11.95	52.74 ± 12.65
	<i>P</i>		.977	.720	.681	.603	.625	.898
Family type	Nuclear	59	2.64 ± 0.78	3.15 ± 0.73	58.88 ± 15.77	55.85 ± 13.79	52.32 ± 14.34	53.36 ± 13.66
	Others	47	2.79 ± 0.86	3.08 ± 0.77	56.85 ± 12.92	55.89 ± 12.47	54.13 ± 12.26	51.47 ± 12.27
	<i>P</i>		.358	.649	.478	.986	.494	.462
Poverty line <sup>a</sup>	Below	38	2.55 ± 0.82	3.10 ± 0.86	55.00 ± 13.75	53.37 ± 12.18	48.00 ± 12.21	46.00 ± 10.42
	Above	68	2.79 ± 0.76	3.13 ± 0.68	59.65 ± 14.816	57.26 ± 13.56	55.99 ± 13.30	56.16 ± 12.99
	<i>P</i>		.133	.860	.115	.145	.003	<.001
Depression in caregiver	Normal	90	2.73 ± 0.77	3.14 ± 0.74	57.00 ± 14.59	55.63 ± 12.87	53.12 ± 13.68	52.60 ± 13.06
	Borderline	9	2.78 ± 0.83	3.22 ± 0.66	65.44 ± 11.59	62.00 ± 13.66	52.78 ± 15.32	50.11 ± 13.43
	Abnormal	7	2.29 ± 0.95	2.71 ± 0.95	61.00 ± 16.12	51.00 ± 15.53	53.57 ± 7.95	54.57 ± 13.71
<i>P</i>		.345	.320	.216	.232	.993	.788 <sup>b</sup>	
Anxiety in Caregiver	Normal	91	2.71 ± 0.79	3.14 ± 0.72	57.88 ± 14.96	55.99 ± 12.75	53.85 ± 13.69	53.20 ± 12.65
	Borderline	8	2.75 ± 0.88	3.37 ± 1.06	58.88 ± 15.15	57.12 ± 17.78	51.50 ± 11.97	45.38 ± 15.72
	Abnormal	7	2.57 ± 0.78	2.57 ± 0.53	58.29 ± 8.75	52.86 ± 14.53	45.57 ± 9.96	51.86 ± 14.49
<i>P</i>		.891	.093	.982	.803	.276	.266 <sup>b</sup>	

(Continues)

TABLE 3 (Continued)

Variables	Category	Frequency	Q1	Q2	Physical	Psychological	Social	Environmental
Type onset of seizure in child	Focal	50	2.68 ± 0.768	3.04 ± 0.78	57.30 ± 14.59	54.58 ± 14.37	53.74 ± 14.09	52.58 ± 13.72
	Others	56	2.73 ± 0.820	3.19 ± 0.72	58.59 ± 14.61	57.02 ± 12.00	52.57 ± 12.90	52.46 ± 12.51
Seizure control in child	P		.737	.287	.651	.344	.657	.964
	Yes	67	2.76 ± 0.83	3.10 ± 0.74	59.48 ± 16.03	57.55 ± 14.13	54.76 ± 14.33	54.40 ± 13.34
Comorbidities in child	No	39	2.62 ± 0.71	3.15 ± 0.77	55.41 ± 11.29	52.97 ± 10.86	50.31 ± 11.33	49.28 ± 11.96
	P		.363	.746	.130	.065	.081	.051
Comorbidities in child	No	86	2.79 ± 0.738	3.12 ± 0.74	57.19 ± 14.22	55.66 ± 13.27	53.50 ± 13.22	52.21 ± 12.46
	Yes	20	2.35 ± 0.93	3.10 ± 0.78	61.40 ± 15.82	56.75 ± 12.98	51.50 ± 14.93	53.85 ± 15.57
	P		.060	.882	.245	.741	.551	.615

<sup>a</sup>Categorized on the basis of world bank definition of absolute poverty (per capita income below \$ 1.90 per day).

<sup>b</sup>One-way ANOVA.

cerebral palsy as a comorbidity, but not in caregivers of children with intellectual disability.<sup>5</sup> Inconsistencies in findings between this study and Saudi study may be the result of differences in sample size of children having comorbidities. Few studies reported longer duration of epilepsy in children and adults was associated with lower QOL in caregivers. However, present study did not reveal any significant correlation between caregivers' QOL and age of onset, and duration of epilepsy in children.<sup>17,19</sup> Good seizure control has been found to be associated with good QOL among adult patients of epilepsy and caregivers of children with epilepsy.<sup>4,14,18</sup> Raw QOL score was significantly higher among caregivers of children having good seizure control in this study as well. While comparing seizure control status of the children with QOL scores in each domain, QOL score in this study was low with poor seizure control in each domain, but statistical significance was not observed. Similar to the finding of a study from the Netherlands, this study did not find an association between QOL and type of onset (focal and others) of epilepsy.<sup>20</sup>

A study done in Jordan revealed statistically significant association of QOL scores with the caregivers having anxiety or depression.<sup>21</sup> In the present study, QOL scores were lower among the caregivers having anxiety or depression, but there was no statistically significant association. Statistical non-significance might be because of small number of respondents having anxiety or depression.

### 4.1 | Strength and limitation of the study

This study added an evidence in an overlooked area of epilepsy care and management, especially in a resource-limited setting such as Nepal. Results from this study have shed light on need of care for the carers. The limitation of the study is WHOQOL-BREF scale is rated on the basis of subjective response of the respondents. Therefore, recall bias of respondents might have affected the scores. The modest sample size of caregivers could have underpaid us for the uncovering of additional associations and hindered us from applying regression model, limiting our analysis to bivariate analysis.

### 4.2 | Policy implication and future direction

This study revealed that QOL among caregivers of children and adolescent with epilepsy is comparable with adult epileptic patients but not with caregivers of adult patients. Present study shows the requirement of multidisciplinary approach policy for managing the epilepsy of children and adolescents in order to improve QOL among caregivers of epileptic children.

## 5 | CONCLUSION

On assessment of QOL among caregivers of children with epilepsy using WHOQOL-BREF scores, poverty was associated with poor QOL in terms of social relationship and environmental perception. Poor seizure control in children was also associated with poor overall QOL among their caregivers.

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### CONFLICT OF INTERESTS

None. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

### AUTHORS' CONTRIBUTIONS

RP conceptualized and designed the study. PP and SL helped in concepts and design. RP collected data, analyzed it, and prepared manuscript. PP edited and revised manuscript. SL revised manuscript. All authors approved the manuscript.

### CONSENT TO PUBLISH

All authors consented to publish the manuscript.

### DATA AVAILABILITY STATEMENT

The datasets generated and/or analyzed during the current study will be available from the corresponding author on reasonable request.

### ORCID

Rita Pokharel  <https://orcid.org/0000-0001-5873-4638>

Prakash Poudel  <https://orcid.org/0000-0002-9375-2847>

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