

# Quality of life among caregivers of epileptic children with degree of controlling seizures in Aseer region

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## ABSTRACT

Epilepsy affects nearly 50 million people worldwide. Epilepsy can affect the quality of life of both the child and the caregiver leaving them unable to function in other areas of life. This quality of life is highly dependent on treatment adherence and how individuals feel about taking their medication. In our study, we aimed to investigate the frequency of medication adherence and the quality of life of caregivers of children with epilepsy. For this purpose, we conducted a cross-sectional survey at the Abha Maternity and Children's Hospital. We enrolled 133 consecutive participants and asked them to complete a questionnaire. The results showed that 37.6% of the participants forgot to take their medications, 9.8% of the participants reported that they were sometimes careless about giving their children medications and sometimes stopped giving them when the children were feeling better, 15.8% of the participants indicated that they sometimes stopped giving the medication when they felt that their children were getting worse when they took the medication., and 26.3% of the participants agreed that they only administered the medication when the children were sick. It was also found that the quality of life of the caregivers decreased when they forgot to give their children the medication and the quality of life of the caregivers increased when they continued to take the medication. In conclusion, quality of life increases as adherence to treatment increases, indicating that more intervention programs are needed to improve the adherence of epilepsy patients.

**Keywords:** Caregivers, epileptic children, quality of life

## Introduction

Epilepsy is the most frequent chronic neurologic condition in childhood. It has a significant effect on the lives of epileptic children, their families, and society. It affects about 50 million individuals worldwide, 0.5–1% of the children, and about 80% of the cases occur in developed countries.<sup>[1]</sup> Quality of life is an important priority for an epileptic patient, where a cure is

unachievable, and treatment can be extended.<sup>[2]</sup> Quality of life may be affected by several factors, including felt and enacted stigma, the severity of epilepsy, antiepileptic drug treatment as well as the type of epilepsy. For example, intractable epilepsy in children and their caregivers brings greater morbidity than controlled epilepsy impacting the functioning domains of life rendering a poor quality of life.<sup>[2-4]</sup> Children with epilepsy and their parents share the same family environment and experience together the process of living with epilepsy with all its associated challenges and concerns.<sup>[5]</sup> Various aspects of family life can be altered and affected indirectly due to epilepsy as it has been associated with

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loss of control, independence, fear, confusion, discrimination, problems related to the side effects of antiepileptic drugs, depression, and stigmatization.<sup>[1,6,7]</sup> Studies show that having a child with epilepsy produces an elevated stress level on the caregiver that is greater than that noted with other chronic conditions.<sup>[8]</sup> They are subjected to long-term stressors, which affect their daily lives and health such as disrupted sleep patterns and sleep deprivation, high rates of depression for both mothers and fathers of children with epilepsy increasing the risk for the poor quality of life (QOL).<sup>[1,9,10]</sup>

This QOL is also affected by the frequency of medication intake. Nonadherence to medication is a big problem. Some studies show that antiepileptic medication nonadherence ranges from 10 to 30%.<sup>[11]</sup> Most patients with epilepsy can control their epilepsy with antiepileptic medication, still, more than one-third of them cannot control it even with an optimal antiepileptic regimen.<sup>[12]</sup> A hospital-based cross-sectional study conducted in 2017 showed that 34.1% of the patients were nonadherent, 80.7% missed their medication, 53.5% revealed that forgetfulness was the cause. Among the determinants of adherence assessed in the study the educational level and medication side effects were significant statistically.<sup>[12]</sup> A systematic review was done in 2016 and showed an elevated frequency of nonadherence, which was related to special thinking and beliefs regarding antiepileptic medication which, in consequence, caused impaired control of seizures.<sup>[13]</sup> In 2013, a study found that more than 36% had some concerns regarding the negative effects of antiepileptic medication.<sup>[14]</sup> Whereas antiepileptic medication adherence had a positive impact on the QOL of an epileptic patient.<sup>[15]</sup> A cross-sectional study involved a total of 292 patients to assess their beliefs and adherence, which showed that most of them were nonadherent, and more than one-third had a negative belief.<sup>[16]</sup>

The adherence to antiepileptic medication and the overall QOL is directly related.<sup>[17]</sup> A prospective cross-sectional study to determine adherence to treatment and factors influencing epileptic patient adherence was performed from 9 to 22 February, 2015. The study showed the rate of adherence observed was poor. Forgetfulness was the most common nonadherence cause.<sup>[18]</sup> Such outcomes warrant new research and the development of new strategies which can only be achieved when the underlying cause and risk factors are properly identified.

## Materials and Methods

The objective of the study was to assess the degree to which the patient adhered to antiepileptic medication and the effect it had on the QOL of the caregivers. A descriptive-analytic cross-sectional survey was conducted in the Abha Maternity and Children Hospital, Abha city, Saudi Arabia.

The inclusion criteria were primary caregivers of epileptic children who were willing to participate, and their children had been diagnosed with epilepsy and were on treatment for at least 6 months. Non-primary caregivers, people whose children had been on treatment for less than 6 months, and people who were unwilling to participate were excluded.

After the attainment of informed consent, every participant was provided with a validated questionnaire formed by combining the clinical characteristics, age, and educational level from the World Health Organization Quality of Life – BREF (WHOQOL-BREF) is a self-report questionnaire which assesses 4 domains of quality of life (QOL): physical health, psychological health, social relationships, and environment and Medication Adherence Rating Scale (MARS).

Ethical approval was obtained from the IRB in King Khalid University.

## Results

A total of 133 participants were enrolled in the study by surveying the caregivers of children with epilepsy who accompanied their children to the pediatrics neurology clinic and were willing to participate in the study.

### Demographic characteristics

From Table 1, most of the children with epilepsy who participated in the study were females (51.9%) and aged between 10 and 15 years (34.6%). Most of the children were not yet in school (48.1%), followed by 45.9% in primary school and only one child in high school.

### General history

Only 24% of our samples had a family history of epilepsy and the vast majority (38%) had been diagnosed with the condition between 1 and 3 years ago. When we asked the caregivers about the type of seizures their children had, 73% reported not knowing the type of seizure and 7.5% mentioned different types of seizures that we did not specify. Regarding the types of seizures we previously identified, we found that absence seizures accounted for more than 13% of the total.

**Table 1: Demographic characteristics of epileptic children with degree of controlling seizures in the Aseer region during 2021**

	n	%
Age of the patient:		
Less than one year	3	2.3%
1-3	26	19.5%
4-6	31	23.3%
7-9	27	20.3%
10-15	46	34.6%
Gender:		
Female	69	51.9%
Male	64	48.1%
Educational level:		
Not in school yet	64	48.1%
Illiterate	0	0.0%
Primary school	61	45.9%
Secondary school	7	5.3%
High school	1	0.8%

In 74% of our patients, the seizure lasted for less than 5 min, most epileptic seizures occurred in 66 (49.6%) of them while they were awake, 23 (17.3%) when they were asleep, 17 (12.8%) caregivers could not determine exactly when the seizures occurred, 40% considered their children's epilepsy well-controlled and 30.8% not well-controlled, and the rest were not sure. Further descriptive details are given in Table 2.

### Degree of antiepileptic medication adherence

As shown in Table 3, 37.6% of the participants forgot to give their children medication. About 9.8% of the participants reported that they were sometimes careless about giving their children the medication and sometimes stopped giving it when the children felt better. About 15.8% of the parents indicated that they sometimes stopped giving the medication when they felt that their children were getting worse when taking the medication. About 26.3% of the participants agreed that they only give the medication when the children were sick. About 77.4% of the respondents said that their children's thoughts were clearer when they were on the medication. About 91.0% of the participants agreed that taking medication prevented their children from getting sick. About 70.7% of the caregivers did not see their children feeling weird while on medication and only 39% of the participants said their children felt sluggish while on medication.

**Table 2: General history of epileptic children with degree of controlling seizures in the Aseer region during 2021**

	n	%
Do you have family history of epilepsy		
Yes	32	24.1%
No	101	75.9%
Time since diagnosis:		
Less than 6 months	30	22.6%
6-12 months	16	12.0%
1-3 years	51	38.3%
More than 3 years	36	27.1%
What type of epilepsy have you been diagnosed with?		
Absence Seizures	18	13.5%
Atonic seizure	1	0.8%
Generalized tonic - clonic	5	3.8%
I don't know	98	73.7%
Myoclonic seizures	1	0.8%
Other	10	7.5%
Usually for how long the seizure last?		
Less than five min	98	73.7%
More than five min	35	26.3%
I tend to have seizures when?		
Awake	66	49.6%
Asleep	23	17.3%
Both	27	20.3%
Unsure	17	12.8%
Perception of epilepsy as well-controlled		
Yes	52	39.1%
No	41	30.8%
Unsure	40	30.1%

### Impact of medication adherence on the caregivers' quality of life

We used the WHOQOL-BREF scale to rate the caregivers of epileptic children. The total range of the scores was calculated in four domains from 4 to 20. Physical health was scored as  $12.20 \pm 2.42$ , psychological domain as  $14.88 \pm 2.57$ , social relationships as  $14.74 \pm 3.37$ , and environment as  $14.23 \pm 3.51$  [Table 4].

Ordinal logistic regression was performed to determine the impact of medication adherence on the caregivers' quality of life. The model of fitting is shown in Table 5.

The model fitting information indicated that the Chi-square was significant ( $P < .001$ ). This was an indication that the final model significantly improved the baseline intercept-only model. As such, our model significantly fitted our data.

There was a statistically significant result for "Do you ever forget to give your child his medication? =1" ( $P = 0.008$ ), "By staying on medication, I can prevent my child from getting sick. =1" ( $P = 0.021$ ), and "Medication makes me feel tired and sluggish = 1" ( $P = 0.000$ ). The value of the "Do you ever forget to take your medication? =1" coefficient was negative (-1.079) suggesting that the caregivers forgetting to give medication to their children caused their QOL to decrease. The value of "By staying on medication I can prevent getting sick = 1" was positive (1.656) indicating that staying on medication increased the QOL for the caregivers. In addition, the respondent agreeing with "Medication makes my child feel tired and sluggish." had a negative coefficient (-1.562) suggesting that the participants agreed with medication making their children tired and sluggish negatively affected their QOL.

### Discussion

This article examined how adherence to antiepileptic medication affected the QOL of the caregivers of epileptic children finding a positive association. It was found that the majority of the patients did not have epilepsy in their family, and in the majority of the patients, the seizures lasted less than 5 min. The seizures occurred more frequently when the patient was awake. The seizures were usually found to be well-controlled. A disturbing finding was that almost 37% of the caregivers forget to give their children medication. This may be the reason for uncontrolled or prolonged seizures. It also indicates mental exhaustion of the caregivers to some extent. It has also been found that caregivers stopped administering medication to children at their discretion which can be fatal, while a majority of the caregivers believed that the children behaved and felt better when they took medication but a study in the United States found that there was no relationship between caregiver belief and medication adherence.<sup>[19]</sup> The QOL of the caregivers was better in those whose children took medication. This could be due to the fact that the children felt better and functioned better when they were taking the correct medication, which in turn made the caregivers feel relieved and have a sense of peace.

**Table 3: Degree of antiepileptic medication adherence of epileptic children with degree of controlling seizures in the Asir region during 2021**

	n	%
Do you ever forget to give your child his medication?		
Yes	50	37.6%
No	83	62.4%
When you feel your child is better, do you sometimes stop giving the medication?		
Yes	13	9.8%
No	120	90.2%
Sometimes if you feel your child is worse when he takes the medication, do you stop giving it?		
Yes	21	15.8%
No	112	84.2%
I give my child his medication only when he is sick		
Yes	35	26.3%
No	98	73.7%
My child thoughts are clearer on medication		
Yes	103	77.4%
No	30	22.6%
By staying on medication, I can prevent my child from getting sick.		
Yes	121	91.0%
No	12	9.0%
My child feels weird, like a 'zombie' on medication.		
Yes	39	29.3%
No	94	70.7%
Medication makes my child feel tired and sluggish.		
Yes	52	39.1%
No	81	60.9%

**Table 4: Caregiver's quality of life on the WHOQOL-BREF Scale**

	Mean	SD	Maximum	Minimum
Physical health	12.70	2.42	20.00	6.86
Psychological	14.88	2.57	20.00	4.67
Social relationships	14.74	3.37	20.00	4.00
Environment	14.23	3.51	20.00	4.00

**Table 5: Model of fitting**

Model	-2 Log Likelihood	Chi-square	df	Sig.
Intercept only	185.434			
Final	149.617	35.817	8	0.000

These findings are consistent with the study by Buck *et al.*,<sup>[11]</sup> which found a nonadherence rate of almost 30%. Moreover, nonadherence was found to be related to lower QOL, which was also found earlier.<sup>[13]</sup> Although most studies focus on the QOL of the patients,<sup>[2,15,17,20]</sup> there are a few studies reporting on the QOL of the caregivers.<sup>[8,21-23]</sup> According to these, caring for a child with epilepsy results in significantly higher levels of stress and anxiety than caring for other chronic illnesses.<sup>[8,21-23]</sup> These findings raise an alarming issue of nonadherence leading to poor QOL for both the patient and the caregiver. This may

also have implications on a broader level as caregivers and patients with poor QOL also fail to perform in other areas of life such as work or school. Medication nonadherence results in nearly 1,25,000 deaths annually.<sup>[24]</sup>

It is also important to acknowledge the limitation of the study. We had a limited sample size and the study was conducted in a single location, so the result may not be as generalizable and there may be community influence.

New strategies and interventions are urgently needed to improve this problem. Although complete medication adherence is not practically possible, it is recommended that new strategies be introduced and educational programs be initiated to promote adherence. Services can also be provided in the epilepsy clinic to improve adherence. With these interventions, we can greatly improve the lives of many patients and their caregivers.

## Conclusions

In summary, the main reason for nonadherence to intake is forgetfulness, caregiver discretion, and fear of side effects. It was also found that nonadherence to medication is significantly associated with poor QOL of the caregivers and patients.

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Nil.

## Conflicts of interest

There are no conflicts of interest.

## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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