

Health Related Quality of Life and Medication Adherence of Children Diagnosed With Epilepsy: A Cross Sectional Study

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ABSTRACT

Epilepsy is a prevalent chronic childhood illness that has long-term therapy. Health related quality of life (HRQoL) is also dependent on many factors such as the severity of seizures and medications side effects. Lack of good medication adherence is viewed as a primary reason behind failure of epilepsy treatment with adherence levels at 25-75 in children.

Objectives: To evaluate health related quality of life and medication adherence among children diagnosed with epilepsy and find out the relationship between the two variables.

Methods: The study was a quantitative cross-sectional study on 219 epileptic children who were selected using the convenient sampling method. The data were gathered with the help of the QOLCE-55 and MMAS-8 self-reports. The data collected was performed through descriptive and inferential statistics.

Results: Among 219 participants, 49% (n=107) reported good health-related quality of life, while 51% (n=112) had impaired HRQoL. Regarding medication adherence, 42% (n=92) demonstrated good adherence, while 58% (n=127) showed non-adherence. A statistically significant correlation was found between medication adherence and quality of life ($r=0.198$, $p=0.003$). Age showed significant association with HRQoL ($p=0.040$), while gender and place of living were significantly associated with medication adherence.

Conclusion: The majority of children had impaired cognitive and physical functioning. The study clearly demonstrates that good medication adherence correlates with improved quality of life for children diagnosed with epilepsy. Regular monitoring of medication adherence and interventions to improve access and affordability of anti-seizure medications are recommended to enhance the quality of life of these children.

Keywords: Epilepsy, Children, Health related Quality of Life, Medication adherence

HIGHLIGHTS

- Approximately half (49%) of children with epilepsy reported good health-related quality of life, while 51% showed impaired HRQoL.
- A significant positive correlation exists between medication adherence and quality of life in children with epilepsy.
- Children's age significantly affected their health-related quality of life, while gender and place of living influenced medication adherence.
- The domain most affected was physical functioning, with reduced cognitive function also prominently observed.
- Major barriers to medication adherence included drug inaccessibility, cost, and availability, highlighting the need for improved access to anti-seizure medications.

INTRODUCTION

Epilepsy refers to a common chronic neurological disorder, which usually starts in childhood and is usually treated over a long period of time. Adherence to antiepileptic medication among pediatric populations has a wide range of reports with reported adherence ranging between 25 and 75 percent. Children that fail to adhere to treatment regimes as prescribed risk running into frequent and recurrent seizures, which may negatively affect their general health and quality of life. In turn, research on adherence trends in children with epilepsy is necessary to maximize the control of this disease and enhance the ultimate outcomes.¹

Health related quality of life (HRQoL) is affected by a number of interrelated factors. Other important determinants among children with epilepsy are the frequency of seizures and the side effects of the antiepileptic drugs. HRQoL is a multidimensional concept that contains a wide range of different concepts that can capture

the overall well-being of a person by including both the positive and negative aspects of everyday life, physical health, emotional state, and social functioning.²

Adherence describes the extent to which a patient's treatment-related behaviors align with the recommendations provided by healthcare professionals. It emphasizes active patient participation and a collaborative, mutually agreed relationship between the patient and the care provider. In epilepsy management, inadequate adherence to prescribed medications is recognized as a leading contributor to treatment failure.³ Evidence from a meta-analysis assessing medication adherence in children with epilepsy reported pooled adherence rates of 58% (95% CI: 0.46–0.74) when measured using objective methods, and 73% (95% CI: 0.63–0.85) when assessed through subjective approaches.

Assessing medication adherence presents substantial methodological difficulties, and no single approach is considered a definitive standard. Although measuring serum concentrations of antiepileptic drugs is often regarded as a reliable indicator of adherence, this method also has notable limitations. Drug levels can be affected by factors unrelated to adherence, such as interactions with other medications, impaired absorption, and individual genetic variations in drug metabolism. In low-resource settings, self-reporting remains the most commonly used method for evaluating adherence; however, it is well recognized to overestimate true adherence levels.⁴

Medication non-adherence is a major contributor to poor seizure control in epilepsy and can negatively influence clinical outcomes as well as social and economic well-being. In children with chronic conditions, the consequences of non-compliance can be particularly severe, leading to higher morbidity and mortality. It also reduces the cost-effectiveness of healthcare due to wasted medications, increased outpatient visits, greater use of emergency services, and higher rates of hospitalization. Additionally, non-adherence may contribute to social stigma, diminished quality of life, and escalating healthcare expenditures.⁵

Need of the study

Epilepsy is the most common neurological disorder that occurs in childhood and its effects are extensive to both the children with it, their families, and the entire society. Epilepsy is a disorder that affects almost 50 million individuals worldwide, with the children taking up a proportion of 0.5-1 percent. The cases of epilepsy among the developing regions report a large percentage. The disorder is known to affect the physical functioning, psychology and social participation of an individual, which eventually affects the way of life and quality of life in general. In addition to the affected child, epilepsy may also interfere with the functioning of the family and may cause both emotional and practical stress to the caregivers. The health-related quality of life can thus be considered one of the most important outcome measures in the field of pediatric epilepsy especially since childhood is a very critical period of development where vital cognitive, motor, and social skills are developed. The results of the current research will be an insightful guide on the rate of medication adherence and health related quality of life in children with epilepsy. They will also increase the knowledge of the effects of epilepsy on various aspects of the life of a child such as cognitive functioning, physical, emotional well-being, and social engagement. This kind of evidence is capable of sensitizing healthcare providers and caregivers on the special needs and challenges of such children. This knowledge, in its turn, can be used to develop specific strategies that will focus on enhancing their overall living standards. The findings also emphasize on multidisciplinary, family-based discourse on epilepsy management in pediatrics whereby the collaboration of health care providers, educationists and families can achieve an ultimate outcome of afflicted children.

There have not been many studies on the Health related Quality of Life and Medication adherence of children diagnosed with epilepsy particularly in Uttarakhand, so research is needed to enable better care for these children.

Research Objectives

1. To determine the health related quality of life in children who have epilepsy.
2. To measure the adherence of epilepsy-diagnosed children in medication.
3. To establish the relationship between health related quality of life and medication adherence.
4. To determine the relationship of health related quality of life and medication adherence and the chosen demographic variables.

METHODOLOGY

Study Design and Setting

The study involved a quantitative descriptive cross-sectional research in Paediatrics units (OPD, medicine ward, surgery ward, PICU) and neurology units (OPD, Ward) at a tertiary care teaching hospital in Uttarakhand.

Study population and sample

Non-probability convenient sampling method was used to select a total of 219 children with the diagnosis of epilepsy (6 months to 18 years).

Sample size calculation

The single population proportion formula was used to calculate the sample size where the variables used are P which is the probability of level of precision (5 %), and 95 percent confidence interval.

$$N = \frac{(Z_{1-\alpha/2})^2 (p)(q)}{D^2}$$

N = Desired sample size

$Z_{1-\alpha/2}$ = Critical value and a standard value for the corresponding level of confidence.

(At 95% CI or 5% level of significance (Type-I error) it is 1.96)

P = .83 (Expected prevalence or based on previous research) (4)

Q = .17

D = 0.05 Margin of error or precision

N = 219

Sample size: 219 children diagnosed with epilepsy

Research instruments

Data were collected using three sections:

Sociodemographic and clinical questionnaire: Information included age, gender, parental education, occupation of the head of the family, family income, type of family, place of residence, duration of seizures, age at seizure onset, number of seizures during the preceding 6 months, duration of individual seizures, family history of seizures, and duration of treatment.

Quality of Life in Childhood Epilepsy Questionnaire-55 (QOLCE-55): The instrument comprises four domains—cognitive functioning (22 items), emotional functioning (17 items), social functioning (7 items), and physical functioning (9 items).

8-item Morisky Medication Adherence Scale (MMAS-8): The thesis describes the MMAS-8 as an eight-item measure with a total score ranging from 0 to 8, with scores of 8 indicating high adherence, 6–7 medium adherence, and scores below 6 low adherence.

Content validity of the modified instruments was assessed by six nursing experts. The instruments were translated into Hindi and back-translated into English to maintain conceptual equivalence. The thesis reports test-retest reliability coefficients of 0.97 for QOLCE-55 and 0.625 for MMAS-8.

Data Collection Process

Institutional ethical clearance and administrative permission were obtained before data collection. Written informed consent and assent were obtained after explaining the study objectives and procedures. Participants were interviewed using a structured format while maintaining privacy in the wards and outpatient departments. The approximate administration time was 15–20 minutes.

Ethical considerations

Ethical approval was obtained from the Institutional Ethics Committee of AIIMS Rishikesh (IEC No. AIIMS/IEC/23/365). Written informed consent and assent were obtained from participants after explaining the study purpose and procedures. No invasive procedures were performed.

Statistical Analysis

Data were entered into Microsoft Excel and analyzed using IBM SPSS Statistics version 23. Descriptive statistics were used to summarize categorical and continuous variables. Inferential statistics included independent t tests and one-way ANOVA for comparisons and Pearson's correlation coefficient to examine the relationship between HRQoL and medication adherence. A p value <0.05 was considered statistically significant.

Results

A total of 219 children diagnosed with epilepsy were included in the study. The results are presented according to participants' sociodemographic and clinical characteristics, health-related quality of life (HRQoL), medication adherence, and the association between HRQoL and medication adherence.

Sociodemographic characteristics

Table no. 1: Sociodemographic characteristics of the participants (N = 219)

Variables	Frequency	Percentage (%)
Age (in years)		
a) 4-6 years	48	22
b) 7-12 years	95	43
c) 13-18 years	76	35
Gender		
a) Male	135	61.5
b) Female	83	38
c) Others	01	0.5
Education of the parents		
a) Graduate	29	13
b) Intermediate or diploma	46	21
c) High school certificate	44	20
d) Middle school certificate	43	20
e) Primary school certificate	40	18
f) No formal education	17	8
Occupation of the head of the family		
a) Legislators, senior officials & managers	05	2
b) Professionals	20	9
c) Technicians and associate professionals	12	5
d) Clerks	17	8
e) Skilled workers and shop & market sales worker	74	34
f) Skilled agricultural & fishery workers	31	14
g) Craft & related trade workers	19	9
h) Plant & machine operators and assemblers	10	5
i) Elementary occupation	30	13
j) Unemployed	01	1
Total monthly income (INR) of the family		
a) >184,376	03	2
b) 92,191-184,370	02	1
c) 68967-92185	10	4
d) 46095-68961	47	22
e) 27654-46089	64	29
f) 9232-27648	69	32
g) <9226	24	10
Type of family		
a) Nuclear	120	55
b) Joint	99	45
Place of living		
a) Rural	152	69
b) Urban	67	31

As shown in table 1, the study included 219 children with epilepsy. The majority of participants fall within the age group of 6-12 years, accounting for 95 children (43%). The other age groups include 48 children (22%) aged 4-6 years and 76 children (35%) aged 13-18 years. The gender distribution shows that most participants were male (135, 61.5%), while 83 (38%) were female and 1 (0.5%) belonged to other category.

Regarding parental education, 29 parents (13%) were graduates, 46 (21%) had intermediate or diploma education, 44 (20%) had high school certificates, 43 (20%) had middle school certificates, 40 (18%) had primary school certificates, and 17 (8%) had no formal education.

The occupational distribution of the head of the family shows that skilled workers and shop & market sales workers comprised the largest group with 74 participants (34%), followed by skilled agricultural & fishery workers (31, 14%), and elementary occupations (30, 13%).

Most families (69, 32%) had a monthly income between 27,654-46,089 INR, followed by 64 families (29%) with income between 46,095-68,961 INR. The majority of participants (120, 55%) belonged to nuclear families, and 152 (69%) resided in rural areas.

Clinical characteristics

Table 2. Clinical characteristics of children with epilepsy (N = 219)

Variables	Frequency	Percentage (%)
Duration of seizure (in years)		
a) <1 years	56	26
b) 1-5 years	96	44
c) >5 years	67	30
Onset of seizure (in age)		
a) Neonatal period	29	13
b) 1 month to 1 year	22	10
c) 1-3 years	43	20
d) 4-6 years	43	20
e) 7-18 years	82	37
No. of episode of seizure in last 6 months		
a) No episode	18	4
b) 1-2	101	46
c) 3-4	59	31
d) >5	41	19
Duration of per seizures		
a) <10 seconds	61	28
b) 10-30 seconds	55	25
c) 30 seconds -2 minutes	47	21
d) 2-5 minutes	29	14
e) >5 minutes	27	12
Family history of seizures		
a) No	199	91
b) Yes	20	9
Duration of treatment		
a) 6-12 months	69	32
b) >12 months	150	68

As shown in Table 2, most children had experienced seizures for 1–5 years (96, 44.0%), followed by more than 5 years (67, 30.0%) and less than 1 year (56, 26.0%). The most common age at seizure onset was 7–18 years (82, 37.0%), followed by 1–3 years and 4–6 years (43, 20.0% each).

During the preceding 6 months, 101 children (46.0%) had experienced 1–2 seizure episodes, while 59 (31.0%) had experienced 3–4 episodes and 41 (19.0%) had experienced ≥5 episodes. The most common individual seizure duration was less than 10 seconds (61, 28.0%), followed by 10–30 seconds (55, 25.0%). Most participants had no family history of seizures (199, 91.0%). Regarding treatment duration, 150 children (68.0%) had been receiving treatment for more than 12 months.

Health-related quality of life and medication adherence

Table 3. Health-related quality of life and medication adherence scores among children with epilepsy (N = 219)

Outcome/domain	Mean ± SD	Rank
Social functioning	67.75 ± 21.97	1
Emotional functioning	66.41 ± 13.75	2
Cognitive functioning	64.61 ± 22.82	3
Physical functioning	61.54 ± 15.87	4
Overall HRQoL	65.06 ± 13.65	—
Overall MMAS-8 score	6.36 ± 1.98	—

The mean overall HRQoL score was 65.06 ± 13.65 . Among the HRQoL domains, social functioning had the highest mean score (67.75 ± 21.97), followed by emotional functioning (66.41 ± 13.75) and cognitive functioning (64.61 ± 22.82). Physical functioning had the lowest mean score (61.54 ± 15.87).

Correlation between HRQoL and medication adherence

Table 4. Correlation between HRQoL and medication adherence (N = 219)

Variables	Mean $\pm$ SD	Pearson's r	p value
HRQoL	65.06 ± 13.65	0.198	0.003
Medication adherence (MMAS-8)	6.36 ± 1.98		

Pearson's correlation analysis demonstrated a weak positive correlation between HRQoL and medication adherence ($r = 0.198$, $p = 0.003$). This association was statistically significant, indicating that higher MMAS-8 scores were associated with higher HRQoL scores.

Factors associated with HRQoL

Overall HRQoL differed significantly across age groups ($F = 3.271$, $p = 0.040$). Mean HRQoL scores increased from 62.34 ± 15.06 among children aged 4–6 years to 63.97 ± 14.47 among those aged 7–12 years and 68.15 ± 10.99 among those aged 13–18 years.

Among the clinical characteristics, significant differences in HRQoL were observed according to seizure duration ($F = 4.168$, $p = 0.017$), age at seizure onset ($F = 5.548$, $p < 0.001$), and number of seizure episodes during the preceding 6 months ($F = 3.588$, $p = 0.015$). Treatment duration was also significantly associated with HRQoL ($t = 2.909$, $p = 0.004$).

Post-hoc analysis showed a statistically significant difference in HRQoL between children with seizure duration of <1 year and those with a duration of 1–5 years ($p = 0.012$). Significant pairwise differences were also observed between selected categories of age at seizure onset and seizure frequency.

Factors associated with medication adherence

Medication adherence differed significantly according to gender ($F = 3.850$, $p = 0.023$) and place of residence ($t = 2.010$, $p = 0.046$). Among clinical characteristics, medication adherence also differed significantly according to age at seizure onset ($F = 3.433$, $p = 0.010$). No statistically significant associations were observed between medication adherence and the other assessed sociodemographic or clinical characteristics ($p > 0.05$).

DISCUSSION

The results of the present study align with findings from an Indian hospital-based study conducted among middle and secondary school children with epilepsy by Priyanka Narayanrao Pachange et al. Using the QOLCE-55 scale, they reported a mean overall quality-of-life score of 69.9 (SD ± 13.43). Physical functioning was the most affected domain (mean = 58.3, SD ± 20.66), whereas social functioning showed the highest scores (mean = 81.4, SD ± 19.37).⁷

Our findings regarding medication adherence are consistent with Shanshan Wang et al., who reported that 66.98% of children were non-adherent to their drug regimens, either refusing drugs when their condition altered or stopping drugs without the doctor's approval after their condition had consciously improved. Similar to our findings, BMI and gender did not appear to be significant determinants affecting medication compliance in their study. They found that children's compliance is greatly influenced by the educational attainment of parents and the finances of the family.⁸

Similarly, Sandhya Chauhan et al found that more than two-thirds (70.54%) of the children did not adhere to their respective antiepileptic regimens, whereas less than one-third (29.45%) of the children indicated "high" adherence.⁹

The study included a relatively adequate sample of 219 children with epilepsy and assessed both health-related quality of life and medication adherence using established instruments. It also examined the relationship between medication adherence and health-related quality of life, providing clinically relevant findings for pediatric epilepsy care. However, the cross-sectional design limits causal interpretation. The use of convenience sampling at a single tertiary-care center may restrict generalizability. Medication adherence was assessed using self-report, which may be subject to recall and social-desirability bias. Additionally, potentially relevant clinical and psychosocial factors, including seizure severity, medication regimen, treatment-related adverse effects, and psychosocial factors, were not assessed.

CONCLUSION

This study identified important challenges related to HRQoL and medication adherence among children with epilepsy. Physical functioning was the lowest-scoring HRQoL domain, while medication non-adherence was common. A statistically significant but weak positive relationship was observed between medication adherence and HRQoL. These findings support the need for routine assessment of both quality of life and medication-taking behavior as part of comprehensive pediatric epilepsy care.

Healthcare professionals, particularly nurses and pediatric epilepsy teams, should consider incorporating medication-adherence assessment, caregiver education, and regular HRQoL assessment into follow-up care. Further multicenter studies using longitudinal designs and objective measures of medication adherence are needed to clarify the direction and determinants of this relationship.

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Conflicts of Interest: No such declared.

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