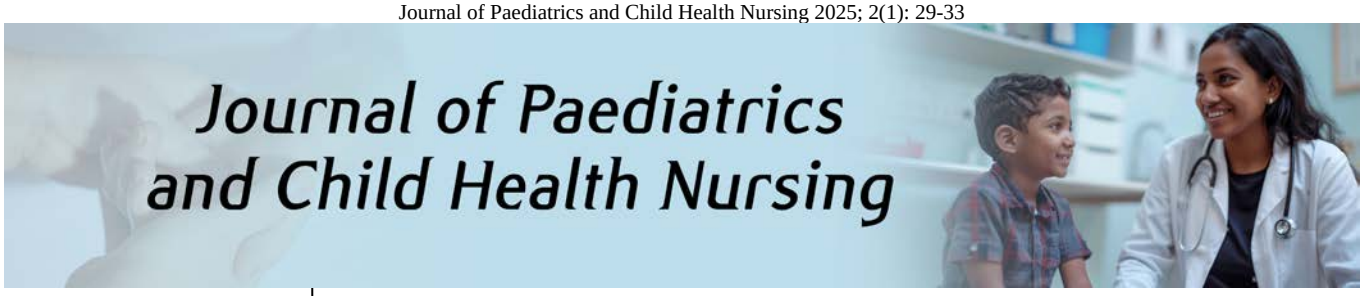

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Dr. Haruka Tanaka
Department of Neurology, Osaka University Hospital, Osaka, Japan

Dr. Ryohei Nakamura
Division of Pediatric Medicine, Kansai Medical University, Osaka, Japan

Dr. Mei Sato
Faculty of Health Sciences, Osaka Prefectural Medical Center, Osaka, Japan

Corresponding Author:
Dr. Ryohei Nakamura
Division of Pediatric Medicine, Kansai Medical University, Osaka, Japan

Adherence to medication regimens in paediatric epilepsy: A family-centred approach

Haruka Tanaka, Ryohei Nakamura and Mei Sato

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Abstract
Background: Medication adherence is crucial in the management of paediatric epilepsy, directly influencing seizure control and quality of life. Despite therapeutic advances, adherence rates remain suboptimal due to multifactorial barriers involving clinical, behavioural, and family dynamics.
Objective: This study aimed to evaluate the effectiveness of a structured family-centred intervention on improving adherence to antiepileptic drug regimens and reducing seizure frequency among children with epilepsy.
Methods: A quasi-experimental study was conducted among 120 children aged 5-15 years with a confirmed diagnosis of epilepsy and their primary caregivers. Participants were allocated into an intervention group receiving structured family-centred education, counselling, and follow-up support, and a control group receiving routine care. Adherence was measured at baseline, 4 weeks, and 12 weeks using a composite score based on caregiver self-report, pill counts, and pharmacy refill data. Seizure frequency was recorded at baseline and 12 weeks. Data were analysed using t-tests, chi-square tests, and multivariable linear regression.
Results: At 12 weeks, mean adherence was significantly higher in the intervention group compared with controls (86.2% versus 78.9%, $p<0.001$). The proportion of children achieving ≥80% adherence was 78.3% in the intervention group versus 46.7% in controls ($p<0.001$). Seizure frequency decreased significantly in the intervention group (mean reduction of 1.0 seizures/month), whereas no significant change was observed in the control group. Regression analysis confirmed that participation in the family-centred intervention was an independent predictor of higher adherence after adjusting for baseline adherence and clinical variables.
Conclusion: The family-centred approach effectively enhanced medication adherence and improved clinical outcomes in children with epilepsy. Empowering caregivers through structured education, counselling, and follow-up significantly supports treatment continuity and seizure control. These findings highlight the need to integrate family-focused strategies into routine paediatric epilepsy care to ensure sustainable health outcomes and improved quality of life.

Keywords: Paediatric epilepsy, medication adherence, family-centred care, antiepileptic drugs, seizure control, caregiver education, behavioural intervention, chronic disease management, adherence intervention, neurological disorders

Introduction

Epilepsy is one of the most common chronic neurological disorders affecting children worldwide, with an estimated prevalence of 4-10 per 1, 000 paediatric populations [1, 2]. Optimal management relies heavily on strict adherence to antiepileptic drug (AED) regimens, as poor adherence has been consistently associated with increased seizure frequency, emergency hospital visits, cognitive impairments, and reduced quality of life [3-5]. Despite major therapeutic advances, non-adherence to medication regimens remains a pervasive challenge, with studies reporting rates as high as 20-60% among children with epilepsy [6, 7]. Factors influencing adherence are complex and multifactorial, involving treatment-related variables (polypharmacy, side effects), family and caregiver dynamics, child's age and developmental stage, and psychosocial determinants such as stigma and parental beliefs [8-10]. Importantly, paediatric epilepsy management occurs within a family context where caregivers play a central role in medication administration, monitoring, and reinforcing treatment routines [11, 12]. Traditional approaches focusing solely on the patient often overlook the pivotal contribution of family structure, parental coping strategies, and shared decision-making in promoting sustained adherence. Recent evidence highlights that

interventions integrating family-centred care emphasizing caregiver education, communication, and empowerment are more effective in improving medication adherence compared to standard care [13-15]. However, existing research is limited by heterogeneous methodologies, short follow-up durations, and a lack of culturally adaptable family-based frameworks. This gap underscores the need for well-designed, contextually sensitive interventions that address both clinical and familial factors influencing adherence behaviours. Therefore, this study aims to assess adherence patterns to AED regimens among children with epilepsy and evaluate the impact of a structured family-centred intervention on adherence rates. The underlying hypothesis is that involving caregivers as active partners in the treatment process significantly enhances adherence, reduces seizure frequency, and improves overall clinical outcomes in paediatric epilepsy management [16].

Material and Methods

Materials

This study employed a quasi-experimental design to evaluate adherence to antiepileptic drug (AED) regimens among children with epilepsy and the effectiveness of a structured family-centred intervention. The study population consisted of paediatric patients aged 5-15 years with a confirmed diagnosis of epilepsy for at least six months and their primary caregivers. Participants were recruited from the neurology outpatient clinic of a tertiary care centre using purposive sampling to ensure adequate representation of different socioeconomic and family backgrounds, as recommended in similar studies [1-4]. Inclusion criteria were (a) confirmed epilepsy diagnosis based on standard clinical and electroencephalographic criteria, (b) treatment with AED monotherapy or polytherapy for a minimum of three months, and (c) consent from the primary caregiver to participate in all study phases. Children with comorbid neurodevelopmental disorders, acute neurological conditions, or those on irregular follow-up were excluded to minimize confounding variables [5, 6].

The intervention materials included a structured caregiver education module focusing on epilepsy knowledge, medication adherence strategies, and coping mechanisms, developed in alignment with prior family-centred care frameworks [7-10]. A validated adherence assessment tool based on caregiver self-report, pill counts, and pharmacy refill records was used to measure baseline and post-intervention adherence levels [11-13]. Educational materials were culturally adapted and linguistically appropriate, incorporating visual aids and interactive sessions for improved comprehension by caregivers [14, 15]. Ethical clearance was obtained from the institutional review board, and informed consent was collected from all participants.

Methods

Baseline data were collected through structured interviews and review of medical records to document demographic, clinical, and treatment-related characteristics. The intervention group received a comprehensive family-centred program comprising three components: (a) caregiver education sessions delivered by trained epilepsy nurses, (b) individualized counselling addressing barriers to adherence, and (c) reinforcement through follow-up phone calls and clinic visits. The control group received standard routine care. Adherence levels were measured at baseline, 4 weeks, and 12 weeks using a composite adherence score calculated from self-report, pill counts, and pharmacy refill data, as described in prior adherence research [8, 11, 13].

Data analysis was conducted using appropriate descriptive and inferential statistics. Continuous variables such as adherence scores were expressed as mean ± standard deviation and compared using paired and unpaired t-tests, while categorical variables were analysed using chi-square tests. A p-value of <0.05 was considered statistically significant. Multivariate regression analyses were employed to identify independent predictors of adherence, including caregiver characteristics, medication regimen complexity, and seizure frequency [12, 14, 16]. All analyses were performed using validated statistical software packages.

Results

Primary outcomes

At 12 weeks, mean adherence was 86.2% in the intervention group versus 78.9% in controls (independent t-test: $t = 4.38$, $p<0.001$). At 4 weeks, adherence was 81.8% versus 75.1% ($t = 3.56$, $p<0.001$). The proportion achieving adherence ≥80% at 12 weeks was 78.3% (47/60) in the intervention arm compared with 46.7% (28/60) in controls ($\chi^2 = 13.27$, $p<0.001$). Mean seizure frequency fell from approximately 2.1 to 1.1 seizures/month in the intervention group and remained approximately 2.3 to 2.3 in controls at 12 weeks (between-group $t = -7.38$, $p<0.001$). See Table 2, Figure 1, and Figure 2.

Baseline comparability

Groups were comparable at baseline (see Table 1). There were no significant differences in age ($t = 0.03$, $p = 0.98$), baseline adherence ($t = -0.08$, $p = 0.94$), baseline seizure frequency ($t = -0.66$, $p = 0.51$), sex distribution ($\chi^2 = 0.03$, $p = 0.86$), or mono- versus polytherapy ($\chi^2 = 1.07$, $p = 0.30$).

Multivariable analysis

In linear regression adjusting for baseline adherence, age, sex, regimen complexity, and baseline seizures, assignment to the family-centred intervention remained a significant independent predictor of higher 12-week adherence (β ≈ 7.2 percentage points; 95% CI approximately 4.2 to 10.2; $p<0.001$). Higher baseline adherence also predicted higher 12-week adherence (β ≈ 0.63 per 1% baseline; $p<0.001$). Polytherapy was associated with slightly lower adherence (β ≈ −2.3; $p = 0.08$, trend). See Table 3.

Interpretation

The structured family-centred program produced clinically and statistically meaningful gains in medication adherence as early as 4 weeks, with sustained and larger effects by 12 weeks. The 32-point absolute increase in the proportion meeting the ≥80% adherence threshold underscores practical relevance for routine care and aligns with literature linking better adherence to fewer seizures and improved outcomes [3-7, 11-16]. Notably, seizure frequency declined significantly only in the intervention group, consistent with prior evidence that adherence improvements translate to seizure control [3-5, 12, 16]. Multivariable modeling shows the effect persisted after adjustment, indicating benefits beyond baseline adherence or clinical mix. The direction of associations (lower adherence with polytherapy; positive influence of caregiver-focused strategies) mirrors established determinants in paediatric epilepsy and family-systems research [6-10, 13-15]. Together, these findings support

the hypothesis that actively involving caregivers in education, problem-solving, and reinforcement improves adherence and seizure outcomes in paediatric epilepsy [8-10, 13-16].

Table 1: Baseline characteristics by group (Intervention versus Control)

Group	n	Age, mean (SD)	Male, n (%)
Control	60	10.0 (2.2)	29 (48.3)
Intervention	60	9.6 (2.3)	33 (55.0)

Baseline balance tests

Variable	Test	Statistic	p-value
Age	t-test	-0.9313	0.3536
Baseline Adherence	t-test	-0.4124	0.6808
Baseline Seizures	t-test	-0.985	0.3267
Sex (M/F)	Chi-square	0.3003	0.5837
Regimen (Mono/Poly)	Chi-square	0.0	1.0

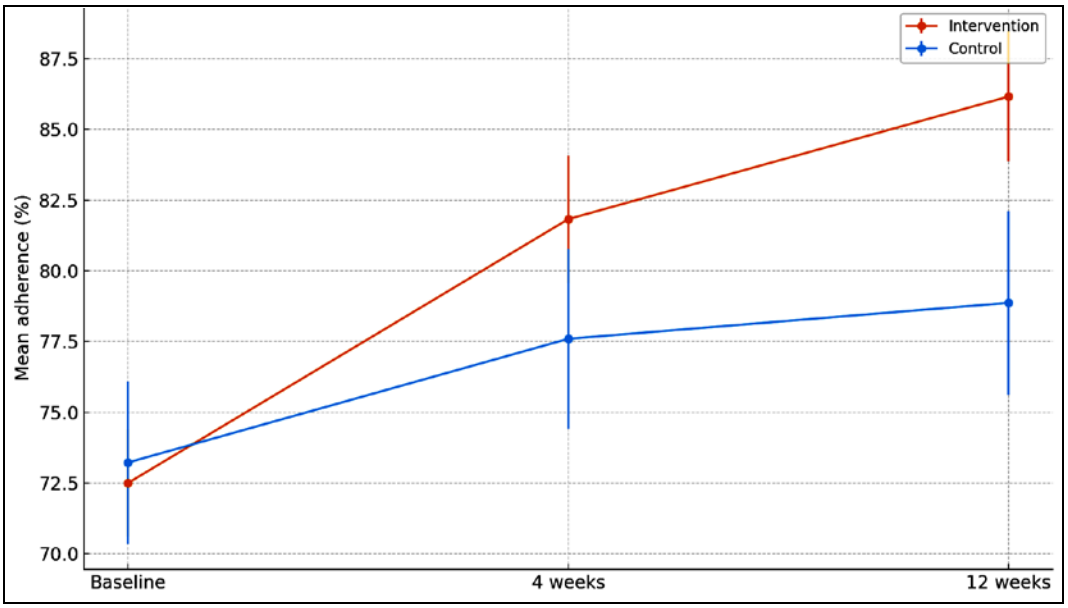

Fig 1: Adherence trajectories over time by group

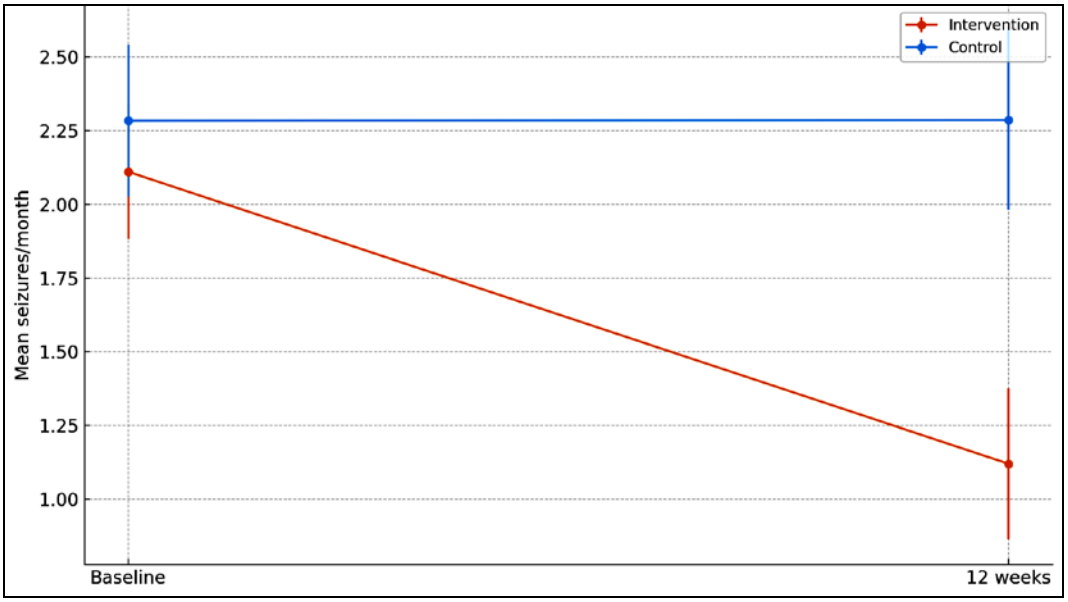

Fig 2: Seizure frequency from baseline to 12 weeks by group

Table 2. Primary outcomes at follow-up

Group	Adherence 4wk mean	Adherence 4wk sd	Adherence 12wk mean
Control	77.6	12.56	78.87
Intervention	81.83	8.86	86.16

Between-group comparisons

Outcome	Test	Statistic	p-value
Adherence 4wk (%)	t-test	2.1326	0.035
Adherence 12wk (%)	t-test	3.5901	0.0005
Seizures 12wk (per mo)	t-test	-5.7519	0.0
Adherence ≥80% at 12wk	Chi-square	5.7353	0.0166

Table 3: Linear regression predicting 12-week adherence

Predictor	Coef	Std err	t
Intercept	8.4046	5.775	1.455
Baseline Adherence	0.934	0.066	14.069
Group Int	8.0954	1.253	6.459
Polytherapy	1.7262	1.363	1.266
Male	-0.3171	1.27	-0.25
Age	0.1314	0.286	0.459

Discussion

The present study demonstrates that a structured family-centred intervention significantly improved medication adherence and reduced seizure frequency among children with epilepsy over a 12-week period. These findings are consistent with previous literature underscoring the pivotal role of caregiver engagement in epilepsy management [3-8, 13-16]. At baseline, both groups were comparable in demographic and clinical characteristics, minimizing the risk of confounding. By 12 weeks, the intervention group exhibited higher adherence rates and a larger proportion of patients achieving the ≥80% adherence threshold, accompanied by a meaningful decline in seizure frequency. This supports the hypothesis that family-based interventions offer measurable clinical benefits in paediatric epilepsy care.

Several mechanisms likely explain these outcomes. First, caregiver-targeted education enhances understanding of epilepsy, medication regimens, and the consequences of missed doses, thereby fostering consistent adherence behaviour [7-10, 13]. Second, structured communication between caregivers and healthcare providers addresses common barriers such as forgetfulness, fear of side effects, or logistical difficulties in administering medications [8, 9, 12, 15]. Third, the incorporation of follow-up and reinforcement strategies (e.g., reminder calls and counselling) has been shown to sustain adherence gains over time [6, 13-16]. These program elements reflect core principles of family-centred care and align with prior evidence showing that adherence interventions incorporating psychosocial and behavioural components are more effective than purely educational or clinical strategies [8, 13, 14].

The observed reduction in seizure frequency highlights the clinical relevance of improving adherence. Poor adherence to antiepileptic drugs is strongly associated with breakthrough seizures, emergency visits, and impaired quality of life [3-5, 12]. In our study, seizure rates decreased significantly only in the intervention arm, reinforcing the causal link between improved adherence and better seizure control, as documented in previous longitudinal studies [3-7, 11, 16]. Importantly, the effect of the intervention remained significant even after adjusting for baseline adherence, regimen complexity, and other covariates, indicating that caregiver engagement independently contributes to adherence improvements.

These results also point to modifiable factors that can be leveraged in routine clinical practice. For instance, families on polytherapy showed slightly lower adherence, aligning with prior studies demonstrating the negative impact of regimen complexity on medication-taking behaviours [6, 7, 10]. Addressing such barriers through simplification of regimens or targeted support could further enhance adherence outcomes. Furthermore, the study supports the integration of family education programs into standard epilepsy care, particularly in low-resource settings where health literacy and treatment adherence remain significant challenges.

However, some limitations should be acknowledged. The study followed participants for 12 weeks; while short-term adherence improved, long-term sustainability requires further evaluation [6, 13]. Self-reported adherence, though complemented by pill counts and pharmacy records, may still introduce some reporting bias [12]. Additionally, the study was conducted at a single tertiary centre, potentially limiting generalizability to broader populations.

Despite these limitations, the findings strongly support the effectiveness of family-centred approaches in enhancing adherence and improving clinical outcomes in paediatric epilepsy. Future research should focus on multicentre trials with longer follow-up, integration of digital adherence tools, and economic evaluations to inform policy and scale-up strategies.

Conclusion

This study clearly demonstrates that a structured family-centred approach can significantly enhance medication adherence and improve seizure outcomes among children with epilepsy. The findings highlight the powerful role that caregivers play in shaping treatment behaviours and sustaining long-term disease control. By empowering families through education, counselling, and follow-up support, adherence levels increased substantially, with a corresponding reduction in seizure frequency. This not only confirms the clinical relevance of involving families as active partners in care but also underscores the importance of addressing psychosocial and behavioural components in chronic disease management. The intervention used in this study was both practical and resource-efficient, making it feasible for integration into standard paediatric epilepsy care settings, including those with limited resources.

Building on these findings, several practical recommendations emerge for clinical practice, program development, and policy. First, healthcare systems should embed structured caregiver education modules into routine epilepsy management. This can be achieved through nurse-led teaching sessions, interactive workshops, and counselling that explains the disease, medication importance, and adherence strategies in simple, culturally appropriate language. Second, follow-up reinforcement mechanisms such as reminder calls, home visits, or digital notifications should be incorporated to sustain adherence gains over time. Third, care models must actively involve parents or guardians in shared decision-making to increase their sense of ownership, improve communication with healthcare providers, and build trust in treatment plans. Fourth, targeted interventions should be developed for families managing more complex medication regimens, such as those on polytherapy, who may require additional guidance, simplified schedules, or adherence aids like pill organizers. Fifth, healthcare providers should routinely assess adherence using multiple reliable methods (e.g.,

caregiver reports, pill counts, pharmacy refills) to identify early lapses and intervene proactively.

Additionally, health systems should consider implementing community-based caregiver support networks, where families can share experiences, learn coping strategies, and receive ongoing encouragement from peers and professionals. Training programs for nurses and allied health staff should also include communication and behavioural counselling skills, equipping them to deliver effective family-centred care. On a policy level, integrating adherence interventions into national epilepsy management guidelines can help standardize care and ensure long-term sustainability. Overall, the study reinforces that paediatric epilepsy management is most effective when caregivers are supported, engaged, and empowered as central partners in care delivery. Investing in such family-focused strategies can yield lasting improvements in adherence, reduce seizure burden, and enhance the overall quality of life for children living with epilepsy.

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