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Promoting medication compliance in epileptic children: a cross sectional survey

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Abstract

Background Compliance with medication is crucial for the favorable prognosis of children with epilepsy. The objective of this study was to assess the determinants of medication compliance and to construct a predictive model for the risk of non-compliance among pediatric epilepsy patients.

Methods The study included children diagnosed with epilepsy and treated at our hospital between February 1 and September 30, 2023. We evaluated the demographic characteristics and medication compliance profiles of these patients. The predictive model's performance was assessed using the receiver operating characteristic (ROC) curve to determine its sensitivity and specificity.

Results A total of 168 children with epilepsy were analyzed. The rate of non-compliance with medication was found to be 32.74% (55 out of 168). Logistic regression identified the educational level of parents (OR = 2.844, 95% CI: 2.182–3.214), monthly household income (OR = 1.945, 95% CI: 1.203–2.422), the number of medications taken (OR = 1.883, 95% CI: 1.314–2.201), and the level of epilepsy knowledge received (OR = 2.517, 95% CI: 1.852–3.009) as significant factors influencing non-compliance (all $p < 0.05$). A total score threshold of 6 was set for the predictive model. The area under the ROC curve was 0.713 (95% CI: 0.686–0.751), indicating the model's discriminative ability.

Conclusions The compliance to medication regimens among children with epilepsy is suboptimal and influenced by a multitude of factors. This study has developed a predictive model for medication compliance, which could serve as a valuable tool for clinical assessment and intervention planning regarding medication compliance in pediatric epilepsy patients.

Keywords Compliance, Children, Epilepsy, Treatment, Care, Nursing

Introduction

Epilepsy is a neurological disorder caused by abnormal discharge of neurons in the brain. Globally, it is estimated that approximately 70 million individuals are living with epilepsy, with China alone accounting for a significant proportion of this population, harboring at least 9 million affected individuals. Notably, a substantial majority of these cases, nearly two-thirds, are concentrated among the pediatric population, specifically those under the age of 18 years [1, 2]. The total prevalence rate of epilepsy in children is about 151/ 100,000, which is more than 4 times that of adults [3]. The first-line treatment of

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epilepsy is long-term oral antiepileptic drugs, which can effectively control 70% of the incidence of epilepsy [4]. 30–40% of patients need other treatment measures, such as ketogenic diet, vagal nerve stimulation surgery, etc., but they still need to take antiepileptic drugs for a long time [5, 6]. Therefore, improving the medication compliance of patients with epilepsy is of great significance to the prognosis of patients.

Antiepileptic drug therapy is the most important and commonly used means for the treatment of epilepsy [7]. If the family members of the children can carry out standard treatment for the children, about 80% of the children can be completely controlled by drugs. It is reported that 70 to 80% of children with epilepsy in China can be treated with systematic regular antiepileptic drugs, but about 20% of children's epilepsy cannot be controlled [8, 9]. Epilepsy is a neurological disorder influenced by a multitude of factors, predominantly stemming from a lack of parental awareness regarding the diagnosis and treatment protocols. This condition is further complicated by the unique challenges associated with pediatric epilepsy management. The condition not only significantly impairs the physical and psychological well-being of the affected children and their caregivers but also imposes a substantial economic burden on the family unit. Consequently, this can impede the enhancement of the children's overall quality of life [10, 11]. Consequently, compliance to prescribed antiepileptic medications is pivotal in the chronic management of epilepsy [12]. It has been reported by many studies [13–15] that there are about 29% of patients with poor compliance in the treatment of epilepsy, among which the treatment non-compliance rate of children with epilepsy is between 25% and 50%. At present, the body of research concerning medication compliance among children with epilepsy is notably limited, with the determinants of this compliance still not well elucidated. There is a substantial need to delve into the patterns of medication compliance in this vulnerable demographic, dissect the underlying causes of potential non-adherence, and enhance the strategies for compliance management. Such an investigation holds profound implications for optimizing treatment outcomes and improving the health and well-being of children with epilepsy [16]. Therefore, the objective of this study is to systematically assess the determinants influencing medication compliance in pediatric epilepsy patients, to develop a predictive model that can predicate compliance behaviors in this patient group, to offer valuable insights into the clinical management and nursing practices for children with epilepsy.

Methods

Ethical issue

This study was a cross-sectional survey design. The study had been obtained the ethical approval from the ethical committee of children's hospital of Nanjing medical university (approval number: 202401015-1). The written informed consents had been obtained from all the guardian of included children.

Sample size calculation

Drawing from established methodological report [17], the optimal sample size for a questionnaire-based study was typically recommended to be at least tenfold the number of variables under examination. In the context of this investigation, which utilized a scale encompassing 11 distinct variables, the requisite sample size was meticulously calculated. Accounting for a projected 10% attrition rate during the distribution and collection of the survey instruments, as well as the need to ensure statistical robustness, the calculated sample size necessitated a minimum of (11*10*(1+10%)=121) participants. Consequently, the study design mandated the inclusion of at least 121 children diagnosed with epilepsy to meet the methodological standards and achieve a reliable and valid analysis.

Study population

The study populations of this study were children with epilepsy who were treated in our hospital from February 1 to September 30, 2023. The diagnosis of epilepsy was in accordance with the classification and diagnostic criteria of epilepsy issued by the international league against epilepsy (ILAE) [18, 19]: (1) epilepsy has a tendency to continue to attack again, and electroencephalography (EEG) examination shows typical epileptiform discharge; (2) recurrent seizures, two or more times, EEG examination shows abnormal epileptiform discharge. (3) recurrent attacks in a short time, frequency≥1/day, normal EEG but abnormal imaging examination, and recurrent attacks induced by fixed fever and typical epileptiform discharge. The inclusion criteria of children in this study were follows: the age of children was less than 18 years old; the diagnosis of epilepsy was in accordance with the diagnostic criteria of epilepsy established by the ILAE; the history of diagnosis and treatment of epilepsy was more than 1 year. The children and guardians informed consent and volunteered to participate in this study. The children with mental illness were excluded.

Survey tool

General information questionnaire

In order to understand the possible factors, this study designed a basic information questionnaire, which includes two parts: The general data of the guardians

included gender, age, marital status, religious belief, education level, family monthly income, whether they received education on the knowledge of epilepsy. The general data of the children included gender, age, body mass index (BMI), whether the child was the only child of family, payment of medical expenditure, number of drugs taken, number of convulsions in recent 6 months. Under the guidance of the questionnaire collectors, the information was filled in by the guardians of the children according to the actual situation.

Treatment compliance questionnaire

In this investigation, a rigorously validated questionnaire [20] was employed to assess medication adherence. This instrument was noted for its simplicity and expedience, along with its demonstrated reliability and validity. Upon evaluation, the questionnaire exhibited an impressive overall Cronbach's α coefficient of 0.906, indicative of strong internal consistency. Furthermore, the Cronbach's α coefficients for the individual dimensions ranged from 0.82 to 0.94, reinforcing the scale's reliability and validity [21, 22]. The questionnaire included the following four questions: (1) do you sometimes not pay attention to taking medicine to your child? (2) have you forgotten to give your child medication? (3) have you ever stopped taking medication when your child's symptoms are worse? (4) have you ever stopped taking medication when your child's symptoms have improved? According to the family members' answers to the four questions, the treatment compliance was evaluated, the answers to all the four questions were "no", that is, the family members had good compliance with drug treatment, and as long as the answer to more than one of the four questions was "yes", it was considered that the family members had poor compliance with drug treatment.

Data collection

The investigators all received unified training in advance. First of all, they strictly abided by the principles of voluntariness, equality and confidentiality, before collecting the questionnaire, under the introduction of the doctor in charge of diagnosis and treatment, they explained the importance and significance of the study to the children and guardian in detail, and to obtain the consent and cooperation of the family members. In the course of the survey, unified professional guidance terms were used to give appropriate explanations to the items and questions that guardian did not understand one by one. The completion time of each questionnaire was not less than 10 min. After the questionnaire was completed, the questionnaire would be collected on the spot and the integrity of the questionnaire would be tested. If any omissions or deficiencies were found, the family members were encouraged to make up the missing items on the basis of not violating the voluntary principle. After the questionnaire survey, two different personnel input the data at the same time to ensure the authenticity of the data.

Statistical analysis

All the data were processed and analyzed with SPSS 24.0 software. Measurement data with normal distribution were expressed by mean±standard deviation, two independent sample t test was used for group analysis. Measurement data without normal distribution was expressed by median and interquartile range, non-parametric test was used for the group comparison. The count data were expressed by frequency and percentage, Chi-square test or Fisher's exact probability test were used for data comparison. First of all, univariate analysis was carried out, and the statistically significant risk factors in the results were included in logistic regression analysis to screen out the independent influencing factors. Pearson correlation analysis was conducted to evaluate the correlation of medication compliance and characteristics of included children with epilepsy. This survey developed a risk prediction model for medication non-compliance in children with epilepsy. The Hosmer-Lemeshow test was performed to evaluate the conformity of the model; the sensitivity and specificity of the developed model were evaluated based on the area under the receiver operating characteristic (ROC) curve. There was significant difference between the two groups when $p<0.05$.

Results

A total of 168 children with epilepsy were included in this survey. The incidence of medication non-compliance in children with epilepsy was 32.74% (55/168). As presented in Table 1, there were statistical differences in the education level of parents, monthly household income, number of drugs taken, number of convulsions in recent 6 months and received education on the knowledge of epilepsy between compliance and non-compliance group (all $p<0.05$). There were no statistical differences in the age, gender, BMI, only child of family, place of residence, payment of medical expenditure between compliance and non-compliance group (all $p>0.05$).

As indicated in Table 2, results of correlation analysis showed that the education level of parents($r=0.556$), monthly household income($r=0.549$), number of drugs taken($r=0.602$), and received education on the knowledge of epilepsy($r=0.610$) were associated with the medication compliance of included children with epilepsy (all $p<0.05$).

As indicated in Table 3, the logistic regression analysis results showed that the education level of parents(OR=2.844, 95%CI: 2.182 ~ 3.214), monthly household income(OR=1.945, 95%CI: 1.203 ~ 2.422), number of drugs taken(OR=1.883, 95%CI: 1.314 ~ 2.201),

Table 1 Characteristics of included children with epilepsy ($n=168$)

Variables	Compliance group($n=113$)	Non-compliance group($n=55$)	t/χ^2	p
Age(y)	6.05 ± 2.18	6.16 ± 2.73	2.045	0.071
Male/female	69/44	34/21	1.988	0.104
BMI (kg/m^2)	20.89 ± 3.42	21.01 ± 3.39	3.066	0.078
Only child of family			1.985	0.112
Yes	83(73.45%)	38(69.09%)		
No	30(26.55%)	17(30.91%)		
Place of residence			1.813	0.202
Rural area	36(31.86%)	20(36.36%)		
City	77(68.14%)	35(63.64%)		
Education level of parents			1.296	0.017
Junior high school	3(2.65%)	23(41.82%)		
Senior high school	56(49.56%)	20(36.36%)		
College	54(47.79%)	12(21.82%)		
Monthly household income			1.118	0.013
< 5000 Yuan	10(8.85%)	23(41.82%)		
5000 ~ 10,000 Yuan	45(39.82%)	21(38.18%)		
> 10,000 Yuan	58(51.33%)	11(20.00%)		
Payment of medical expenditure			1.633	0.052
Medical insurance	101(89.38%)	39(70.91%)		
Self-covered	12(10.62%)	16(29.09%)		
Number of drugs taken			1.851	0.009
1	59(52.21%)	12(21.82%)		
2	35(30.97%)	25(45.45%)		
≥ 3	19(16.81%)	18(32.73%)		
Number of convulsions in recent 6 months			1.986	0.046
≤ 2	77(68.14%)	18(32.73%)		
3 ~ 4	31(27.43%)	32(58.18%)		
≥ 5	5(4.42%)	5(9.09%)		
Received education on the knowledge of epilepsy			1.477	0.039
Yes	89(78.76%)	34(61.82%)		
No	24(21.24%)	21(38.18%)		

Table 2 Correlation analysis of medication compliance and characteristics of included children with epilepsy

Variables	r	p
Age(y)	0.212	0.097
Gender	0.115	0.103
BMI (kg/m^2)	0.101	0.064
Only child of family	0.212	0.085
Education level of parents	0.556	0.028
Monthly household income	0.549	0.015
Payment of medical expenditure	0.133	0.092
Number of drugs taken	0.602	0.004
Number of convulsions in recent 6 months	0.158	0.067
Received education on the knowledge of epilepsy	0.610	0.012

Table 4 The scoring criteria of the predicating model for the risk of medication non-compliance in children with epilepsy

Variables	scores
Low education level of parents	3
Monthly household income < 5000 Yuan	2
Number of drugs taken ≥ 3	2
Did not receive education on the knowledge of epilepsy	3

and received education on the knowledge of epilepsy(OR = 2.517, 95%CI: 1.852 ~ 3.009) were the influencing factors of medication non-compliance in children with epilepsy(all $p<0.05$).

As shown in Table 4, this study developed the scoring criteria for the predictive model of medication

Table 3 Logistic regression analysis on the influencing factors of medication non-compliance in children with epilepsy

Variables	β	Wald	OR	95%CI	p
Education level of parents	0.103	0.115	2.844	2.182 ~ 3.214	0.019
Monthly household income	0.126	0.192	1.945	1.203 ~ 2.422	0.034
Number of drugs taken	0.143	0.125	1.883	1.314 ~ 2.201	0.027
Received education on the knowledge of epilepsy	0.117	0.205	2.517	1.852 ~ 3.009	0.040

non-compliance in children with epilepsy. Based on the ROC curve (Fig. 1) and scoring critieria of the prediction model, the sensitivity and specificity of the developed model under different scores were analyzed, and the corresponding Youden index (sensitivity + specificity − 1) was calculated. As presented in Table 5, the Youden index of this model was higher between the total score of 5.5 ~ 6.5. Thus the total score = 6 was adopted as the cuff value of the developed model. At this time, the sensitivity and specificity of the prediction model were both high. The area under the ROC curve (AUC) was 0.713 with and 95% CI: 0.686 ~ 0.751, indicating that the developed model had good discriminative level to predict the medication non-compliance in children with epilepsy.

Discussion

Epilepsy has an important impact on the physical and mental health of individuals and families, it can bring heavy economic burden and reduce the quality of life [23]. Moreover, the characteristics of its chronic diseases also determine that its treatment cannot be achieved overnight, but need to adhere to long-term medication, and need to maintain a stable drug blood concentration, which requires patients must have good compliance [24, 25]. The results of previous investigations [26, 27] show that the main reason for the failure in the treatment of epilepsy is that the patients do not take the medicine according to the doctor's advice, that is, the patients do not comply with the treatment. The patient with epilepsy may stop the drug, change the drug or secretly increase or decrease the drug dose due to various factors during the medication period [28, 29]. These behaviors will to a large extent lead to the increase or decrease of the concentration of antiepileptic drugs in the blood of patients, resulting in a series of side effects and adverse reactions [30]. The patient's low compliance with clinical treatment will lead to the deterioration of the disease [31]. Related studies [32, 33] have proven that patients with poor treatment compliance often have recurrent seizures, which brings a greater economic burden to the health care system. It can be seen that more in-depth researches are needed to take positive measures to improve the clinical medication compliance of patients with epilepsy [34]. The results of this survey have found that the incidence of medication non-compliance in children with epilepsy is 32.74%, and the education level of parents, monthly household income, number of drugs taken, and received education on the knowledge of epilepsy are the influencing factors of medication compliance in children with epilepsy. Besides, this research has crafted a predictive model specifically designed to assess the potential risks associated with non-compliance to medication regimens among pediatric epilepsy patients. This model stands as a valuable tool in the clinical sphere, offering healthcare professionals a more nuanced understanding of the factors that may influence medication compliance in this vulnerable population. By identifying and addressing these risks proactively, health care providers can enhance their ability to support children with epilepsy in maintaining a consistent and effective treatment plan, ultimately improving their quality of life and long-term health outcomes. The predictive capabilities of this model not only aid in the initial assessment of medication compliance but also provide ongoing insights that can guide

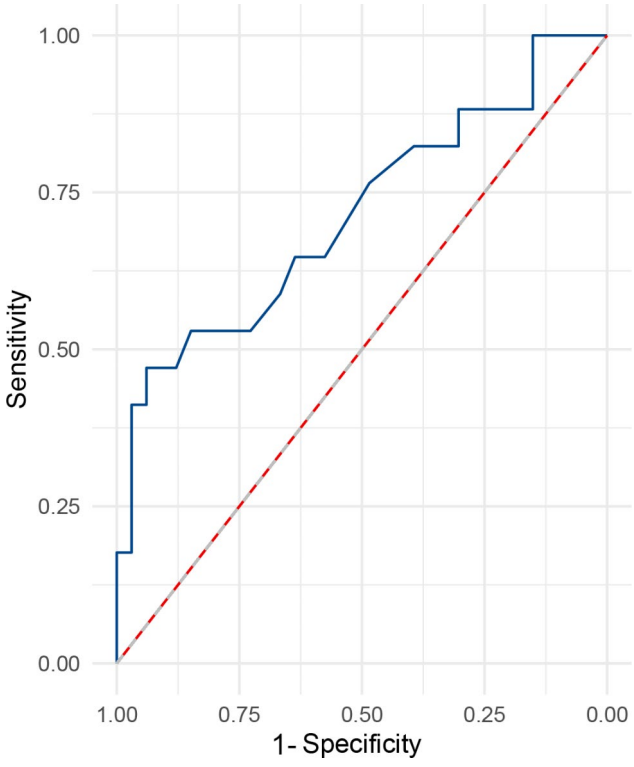

Fig. 1 The ROC curve on the sensitivity and specificity of developed prediction model

Table 5 Sensitivity and specificity of the prediction model under different cuff values

Total score	Sensitivity	Specificity	Yorden Index
-1.0	1.000	0.000	0.000
1.0	1.000	0.125	0.125
1.5	0.974	0.213	0.187
2.5	0.920	0.395	0.315
3.5	0.839	0.551	0.390
4.5	0.804	0.761	0.565
5.5	0.788	0.805	0.593
6.5	0.765	0.846	0.611
7.5	0.577	0.931	0.508
8.5	0.426	0.946	0.372
9.5	0.102	0.960	0.062
10.5	0.027	1.000	0.027
11	0.000	1.000	0.000

adjustments to treatment strategies as needed, ensuring that each child's unique needs are met with precision and care.

The previous survey [35] has shown that the incidence of poor medication compliance in children with epilepsy is 23.08% for caregivers with college education level, while 78.26% for caregivers with high school education level. Therefore, it can be explained that the higher the education level of the caregiver, the more thorough the understanding of the basic knowledge of epilepsy, the deeper the understanding of the treatment of antiepileptic drugs, and the better the compliance of children with medication. Parents with a high level of education can timely make a correct and scientific understanding of the disease of epilepsy in children, fully grasp the best time to see a doctor, and send them to hospital in time when the children have relevant clinical symptoms [36, 37]. And they be able to receive systematic treatment more rationally. However, those parents with low level of education cannot correctly understand children's epilepsy, which not only delays the best time for children to see a doctor, but also cannot correctly treat and accept systematic treatment, which eventually leads to recurrent seizures [38, 39]. Therefore, it is of great significance to improve the educational level of parents of children with epilepsy to ensure timely medical treatment and improve their compliance.

Epilepsy is a disease with a long period treatment. Long-term cure will cause a certain financial burden to poor families, and may stop treatment because they may not afford the high cost of treatment [40, 41]. It has been reported that some patients with poor compliance after taking drugs suddenly stop taking drugs because they cannot afford the cost of treatment [42]. Among them, the prevalence rate of poor treatment compliance is 16.67% for patients with a monthly income of more than 5000 Yuan, and 53.85% for those with a monthly income of less than 3000 Yuan. When some children feel that seizures are not frequent, they stop taking drugs on their own in order to reduce the financial burden, while some children have attacks too frequently to afford such high medical expenses [43]. Some people even change cheap drugs without consultation of health care providers to reduce the medical burden [44]. In view of this problem, attention has been paid to this problem from the social to the national level in China. The Chinese government has increased its investment in medical and health care year by year, and there are also various special funds for epilepsy, which provide families with poor economic conditions and in urgent need of treatment with the ability to maintain treatment the reduce the economic burden of patients with low incomes [45].

Oral antiepileptic drugs in the treatment of epilepsy is a long process of medication, regular medication is closely related to the prognosis of the disease. Control and medication time after seizures, and relapse after withdrawal are the most concerned issues for patients and their families [46]. Regular medication has a significant effect on the prognosis of children. Related studies have also confirmed that the prognosis of children who can take medicine regularly is significantly better than that of children who cannot take medicine regularly [47]. In the process of long-term treatment, coupled with the lack of self-control at a young age, it is basically difficult to take medicine on time without the strict supervision of parents. For children with poor self-control ability, it is necessary to give positive guidance and support to educate the harm of epilepsy and matters needing attention to the corresponding parents, and help them understand the important role of treatment compliance in controlling epilepsy from all aspects [48].

Many previous studies [49, 50] have found that parents of children are generally lack of knowledge about epilepsy, so it is particularly important to strengthen publicity and education. Regular distribution of epilepsy publicity handbooks, small lectures or webcast classes are necessary to explain the basic knowledge of epilepsy, the significance and benefits of good drug compliance, the harm of poor drug compliance and risk management measures. Wechat communication group can also be established to follow up the medication compliance of children. It can also be scheduled to organize families with good drug compliance to share their experiences. Besides, as a new way to teach epileptic patients and caregivers, video animation will help to enhance children's understanding and medication compliance [51]. At the same time, it also calls on all sectors of society to attach importance to children with epilepsy and do a good job in the education of knowledge about epilepsy, so as to make more people correctly understand the epilepsy [52].

The present investigation is not without its limitations, which merit careful consideration. Initially, the study is confined to a single center, which inherently restricts the generalizability of the findings due to the modest sample size. Additionally, the scope of the influencing factors examined in this research is somewhat narrow, potentially overlooking other significant determinants that could have been integrated into the analysis. Furthermore, the study's cross-sectional design precludes the examination of temporal trends in the treatment compliance among pediatric patients with varying epilepsy trajectories. Future endeavors in this domain would benefit from an expanded temporal frame and an enhanced sample size, ideally encompassing diverse geographic regions, to yield more robust and precise outcomes. Finaly, given the dynamic nature of epilepsy and its treatment, compliance to prescribed medical regimens can fluctuate

significantly over time. This variability is influenced by the progression of the disease, changes in the patients' condition, and the evolving understanding of the disorder among both the children and their caregivers. As the condition evolves, so too do the challenges and responses to treatment, necessitating a continuous reassessment of compliance strategies. This temporal aspect of compliance underscores the importance of longitudinal studies in understanding the full spectrum of treatment compliance in epilepsy, from initial diagnosis through various stages of the disease.

Conclusions

In summary, this survey has found that the incidence of medication non-compliance in children with epilepsy is 32.74%, and the education level of parents, monthly household income, number of drugs taken, and received education on the knowledge of epilepsy are the influencing factors of medication compliance in children with epilepsy. Furthermore, this research has developed a predictive model that predict the likelihood of medication non-compliance among children suffering from epilepsy. This model serves as an instrumental aid in the clinical assessment process, specifically tailored to evaluate the compliance to prescribed medication regimens in this demographic. By providing a more precise and comprehensive evaluation of the factors influencing medication compliance, the model equips healthcare providers with the necessary insights to better support and guide children with epilepsy in adhering to their treatment plans. In the future research, it is necessary to pay more attention to the epileptic children with poor compliance and construct healthy intervention measures to improve medication compliance and improve the therapeutic effect.

Abbreviations

ROC	Receiver operating characteristic
ILAE	International league against epilepsy
EEG	Electroencephalography
BMI	Body mass index

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None.

Author contributions

P L, Y L designed research; P L, L Z, J H, J Q, Y L conducted research; P L, L Z, J H, J Q, Y L analyzed data; P L wrote the first draft of manuscript; Y L had primary responsibility for final content. All authors read and approved the final manuscript.

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Data availability

The data associated with the paper are not publicly available but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

In this study, all methods were performed in accordance with the relevant guidelines and regulations. The study has been reviewed and approved by the ethics committee of Children's Hospital of Nanjing Medical University (approval number: 202401015-1). And written informed consents had been obtained from all the guardians of included children.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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