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Women with epilepsy have poorer knowledge and skills in child rearing than women without epilepsy

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ABSTRACT

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Keywords: Women Gender Epilepsy Child rearing knowledge Practice Kerala Registry of Epilepsy and Pregnancy (KREP) Outcome Epilepsy can negatively impact the child rearing ability of women because of the risk related to seizures, adverse effects of antiepileptic drugs and psychosocial factors.

Objective: To compare the child rearing knowledge (CRK) and practices (CRP) of women with epilepsy (WWE) with a matched group of women without epilepsy (WWoE).

Methodology: This study was carried out in the Kerala registry of epilepsy and pregnancy (KREP) at Sree Chitra Tirunal Institute for Medical Sciences and Technology in India. We prospectively recruited 100 WWE in first trimester of pregnancy from the KREP and 93 age, education and parity matched pregnant WWoE from the antenatal clinics of the Government medical college Thiruvananthapuram. Their child rearing knowledge (CRK) and practices (CRP) were evaluated with previously validated protocols. The CRK was assessed at the time of enrolment (first trimester of pregnancy) and the CRP was assessed when the baby was three to four months old.

Results: Eighty-eight women each from WWE and WWoE had completed the study, over a period of three years. WWE and WWoE were comparable for age $(25.56 \pm 4.66 \text{ and } 25.69 \pm 4.49 \text{ years})$, pregnancy outcome and type of delivery. WWE had excess fetal loss and postnatal seizures. The CRK was significantly lower for WWE (23.53 ± 6.3) than for WWoE (26.08 ± 5.3) . The CRP was significantly lower for WWE (25.01 ± 9.6) than for WWoE (28.14 ± 7.1) . WWE performed poorer in all domains of child rearing practices namely feeding, growth and development, cleaning and protection and infant stimulation. Poorer CRK was strongly associated with lower CRP while several demographic and economic characteristics were not relevant. WWE fared poorer in feeding and nursing their babies in spite of having the right knowledge in that domain. This may be due to several undisclosed concerns and social dynamics that need to be addressed while preparing any interventions.

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1. Introduction

There are over 2.5 million women with epilepsy (WWE) in India, and 52% of them are in the reproductive age group.¹ The maternal and fetal outcome for WWE, have drawn wide attention.^{2–8} Several pregnancy registries have brought out their observations and recommendations regarding risk of fetal malformations in WWE. Recently detailed guidelines have been brought out by professional groups to help physicians to manage epilepsy and pregnancy.^{4,9} The pregnancy outcome is normal in more than ninety percent of WWE.¹⁰ Nevertheless, maternal epilepsy or prenatal exposure to antiepileptic drugs (AED) can

* Corresponding author at: Department of Neurology, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum 695011, Kerala State, India. Tel.: +91 471 2524468; fax: +91 471 3446433. increase the risk of infertility,¹¹ fetal loss,^{12–14} and major congenital malformations.^{15–17} Recently it was demonstrated that children of WWE are at risk of developmental delay, low IQ.^{18,19} low linguistic achievements,²⁰ and scholastic performance.^{21–23}

Maternal epilepsy can adversely influence infant development through several mechanisms. We had earlier observed that the maternal AED exposure or epilepsy explained 10 per cent of this variation in infants of WWE. Maternal IQ and other unascertained factors probably played more important role in the infants' cognitive development.²⁰ The child rearing skills and practice of the mother probably have important influence on the child's development. Child rearing practices (CRP) are maternal behaviors oriented to meet the developmental needs of the infants. These practices fall under the four broad domains of (a) feeding, (b) protection including prevention of accidents and injuries, (c) monitoring of growth and development and (d) appropriate infant stimulation. Our preliminary survey indicated that several WWE did not have adequate skills or knowledge in these domains and were hesitant to take full responsibility of their babies.²⁴ There are

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possibly several factors, such as lack of confidence, fear of dropping the baby while handling, fear of unexpected seizures and lethargy, attitude of the other family members that may negatively influence the child rearing practices of WWE. It is important to assess the child rearing knowledge and practices of WWE in order to ascertain the relationship between infant development and maternal epilepsy. There have been limited studies in this area. largely because of shortage of well-validated instruments to assess the CRK and CRP with special reference to WWE. In an earlier paper, we had validated a questionnaire-based instrument to assess the CRK and CRP in WWE. (Some details of this instrument that was used in this study is given in the methodology.) The objective of this study was to prospectively assess the CRK and CRP of WWE with appropriate and validated instruments and compare the same with that of a control group of women without epilepsy (WWoE). The results would help plan appropriate interventions for WWE to improve both CRK and CRP.

2. Materials and methods

The study was conducted in the Kerala registry of epilepsy and pregnancy (KREP). The details of this registry are presented elsewhere.^{25,26} To summarize, this registry enrolls WWE prospectively in the preconception phase or in the first trimester of pregnancy and follow them up according to a standard protocol through pregnancy, delivery and later until the child is ten years old. The maternal epilepsy classification, AED usage, seizure frequency and fetal outcome are recorded prospectively. All infants are evaluated for malformations at birth and for developmental outcome at 12 months, IQ and language development at 6 years and detailed neuropsychological evaluation and language assessment at 10 years of age. In this study we evaluated the CRK during antenatal period and CRP at three months after delivery. We used a case control design in which the cases were drawn from the KREP and the controls were drawn from the antenatal clinic of Medical College, Trivandrum. The cases and controls were matched for age, education and parity. The inclusion criteria for cases were presence of active epilepsy meeting ILAE classification requirements, pregnancy not beyond first trimester, and ability to read local language - Malayalam. WWE with major co morbidities (psychiatric illness, mental subnormality, cardiac disorders, etc.) were excluded. Controls were women without epilepsy or other co morbidities and not taking any medications other than those prescribed routinely during pregnancy. This study had the approval of the Ethics committees of both institutions and an informed consent was obtained from each participant.

2.1. Instruments

We used the Child Rearing Knowledge Scale (CRKS) and Child Rearing Practice Scale (CRPS) to measure the knowledge and practice in these domains. We designed these instruments and validated it in an earlier publication.²⁷ The CRKS is a questionnaire type of scale containing 20 multiple response questions on infant care. These questions fall under four domains of child rearing viz. (a) feeding, (b) monitoring of growth and development (c) protection including prevention of accidents and injuries and (d) appropriate infant stimulation. The scale is prepared in the vernacular language (Malayalam) for self-administration in about 20 min time and carries a total score of 40. The CRPS consisted of 25 items divided into 4 subscales, that covered the four major child rearing domains related to early infancy and related practices viz. feeding (items 1-7), growth and development (items 8-9), cleaning and protection (items 10-21), and infant stimulation (items 22-25). The domain-cleaning and protection was further sub-classified into hygiene of the baby (items 10-14), infection prevention (items 15–17), and prevention of accidents and injuries of the baby (items 18–21). The items were scored based on the reported behaviors of mothers on these four domains. Out of the 25 maternal behaviors in the CRPS, 3 were rated on a four-point scale and the remaining 22 were dichotomous Yes/No questions. The total CRP score was calculated as the sum total of the four subscale scores and ranged from 0 to 34. Higher scores indicated better child rearing practices. The CRP Scale could be administered in 20 min time. The content validity ratio of individual items in the scales ranged from 0.6 to 1 and the reliability of CRKS was 0.89.

All women enrolled in the study were evaluated with a standard proforma in the first trimester of pregnancy for sociodemographic details and CRK. On second visit (3 months postpartum) the CRP was evaluated. Face to face interview was conducted to collect data. The socio-demographic details were assessed with the Standard of Living Index (SLI) which is an estimate based on the housing condition and ownership of modern amenities. The SLI composite score ranged from 0 to 33. SLI is classified as low (score is \leq 10), medium (score 11–20) and high (score >20). The quality of the antenatal health care was assessed with the antenatal health index (AHI) that took in to consideration the quality of care from preconception stage to third trimester of pregnancy on a score ranging from 0 to 17. The clinical data regarding epilepsy, AED therapy, seizure recurrence, delivery and postpartum care were abstracted from the medical records.

2.2. Statistics

The data from the proforma were abstracted on to a spreadsheet and were analyzed with SPSS for windows version 17.0. The results are expressed as means \pm standard deviation, and 95% CI for continuous variables or as frequencies for categoric variables. The two study groups were compared with *t*-test (for continuous variables) or with chi square test or by Fisher exact test (for proportions). ANCOVA was done to control the effect of selected covariates on the outcome. Probability value of 0.05 or less was taken as statistical significance. Multiple linear regression was carried out to model the variation in CRK and CRP.

3. Results

During the period April 2003 to March 2006, we recruited one hundred WWE attending the pregnancy registry and 93 healthy women matched for age, education, parity and duration of pregnancy as control group. Seven WWE who had very low educational status and multiparity did not get matched pairs of WWoE. Their demographic characteristics, family structure, SLI and AHI are presented in Table 1. The gravida status of WWE (and WWoE) was as follows: primi gravida 55 (54), 2nd gravida 26 (30), gravida three or more 19(9). There were more multigravidae in the epilepsy group when compared to WWoE. The parity status of WWE (and WWoE) was as follows: nullipara 61 (59), para one 37 (31), para two 2 (3). WWE had history of abortion or stillbirth more often (24%) than WWoE (15.1%). The epilepsy for WWE was classified as generalized epilepsy (37), localization related (57) or others (6). There were 12 patients who were not on any AEDs, 62 on one AED, 21 on two AEDs, and 5 on three AEDs. The AEDS used were Carbamazepine (31%), Valproic acid (23%), Phenytoin sodium (17%), Phenobarbitone (13%), Lamotrigine (3%), and Topiramate (1%).

3.1. Pregnancy outcome

The pregnancy outcome of WWE (and WWoE) was as follows: live birth 92 (91), abortions and intrauterine death 8 (2). There was one neonatal death each in both groups. The mode of delivery for

Table 1

Demographic characteristics of women with epilepsy (WWE) and women without epilepsy (WWoE).

	WWE (<i>n</i> = 100)	WWoE (<i>n</i> =93)	р
Age in years mean (SD)	25.56 (4.66)	25.69 (4.49)	0.846
Age at marriage in years mean (SD)	23.19 (4.10)	23.28 (4.00)	0.878
Age of husband in years mean (SD)	31.52 (5.07)	31.68 (4.72)	0.824
Education of women; <i>n</i> (%)			
<12 years	73 (73.0)	68 (73.0)	0.985
University level	27 (27.0)	25 (27.0)	
Family structure; n (%)			
Nuclear	17 (17.0)	13 (14.0)	0.692
Extended	83 (83.0)	80 (86.0)	
Residence; n (%)			
Urban	28 (28.0)	52 (55.9)	< 0.001
Rural	72 (72.0)	41 (44.1)	
Antenatal health index mean (SD)	10.33 (2.69)	8.77 (1.98)	< 0.001
Standard of living index; n (%)			
Low (SLI <10)	36 (36.0)	15 (16.0)	0.007
Medium (SLI 11–20)	41 (41.0)	51 (55.0)	
High (SLI >20)	23 (23.0)	27 (29.0)	

WWE was comparable with that for WWoE; normal delivery 53 (57), Cesarean section 34 (29), and Vacuum/Forceps delivery 6 (5). WWE had seizures during delivery (3) or postpartum period (17) while none of the WWoE had seizures. WWE did not show either excess intrapartum complications such as severe bleeding and prolonged labor or post partum problems such as post partum hemorrhage and puerperal infections compared to WWoE.

3.2. Childrearing knowledge (CRK) and child rearing practices (CRP)

WWE had significantly lower scores for CRK when compared to WWoE even after adjusting for SLI and place of residence. With regard to the individual domains of CRK, the difference between the WWE and WWoE was not statistically significant (Table 2). WWE performed poorer than WWoE with regard to CRP even after adjusting for SLI and place of residence (Table 3).

There was no association between low CRK (<30) and age, education, family structure, place of residence or SLI. CRK was the only factor (among the several factors considered) that had significant association with CRP (see Table 4). The multiple linear regression for CRP (dependent variable) against the predictors antenatal health index, CRK total score, place of residence, standard of living index and maternal epilepsy showed that the model had an r^2 value of 0.106. Among the above predictors, CRK was a significant predictor (p = 0.031).

4. Discussion

The setting of the pregnancy registry in this Institute provided us a unique opportunity to study the CRK and CRP in a cohort of WWE. The WWoE were matched for most of the important extraneous variables that may affect the CRK and CRP. The prospective follow up enabled us to compare the child rearing knowledge and practices of WWE with that of WWoE. We used newly developed and validated scales that measured the diverse aspects of childrearing knowledge and practice in this study. In this study we observed that WWE had lower CRK and CRP when compared to WWoE a feature that remained statistically significant even after adjusting for the variation in SLI and place of residence. This difference was reflected in the domains of growth and development, infant stimulation and protection of CRP. WWE were more vulnerable as they had lower SLI and rural place of residence yet they had better AHI when compared to WWoE. This paradox may be because the WWE might have been more motivated to seek care compared to the WWoE drawn from a general maternity hospital. It is important to note that in spite of higher AHI, WWE had lower CRK and CRP. The impairment in CRP was more pervasive and involved several domains and sub domains. There was significant association between CRK and CRP while other factors such as SLI, AHI or place of residence did not have significant influence on the CRP when examined by chi

Table 2

Comparison of child rearing knowledge of women with epilepsy (WWE) and women without epilepsy (WWoE) sample size WWE *n* = 100, WWoE *n* = 93.

Child rearing knowledge	WWE	WWoE	Unadjusted <i>t</i> -test <i>p</i> value	ANCOVA p value
Total CRK				
Mean (SD)	23.53 (6.29)	26.08 (5.25)	0.003	0.041
95% CI	22.28-24.78	25.00-27.16		
Feeding				
Mean (SD)	6.94 (2.64)	7.52 (2.53)	0.123	0.385
95% CI	6.42-7.47	7.00-8.04		
Growth and development				
Mean (SD)	2.62 (1.96)	3.17 (2.23)	0.071	0.176
95% CI	2.23-3.01	2.71-3.63		
Protection				
Mean (SD)	9.41 (2.96)	10.42 (2.37)	0.010	0.066
95% CI	8.82-10.00	9.94-10.91		
Infant stimulation				
Mean (SD)	4.56 (1.67)	4.97 (1.23)	0.053	0.201
95% CI	4.22-4.89	4.72-5.22		

CI = confidence interval.

ANCOVA with epilepsy status, place of living and standard of living as factors and antenatal health index as covariate.

Table 3

Child rearing practice score of women with epilepsy (WWE) and women without epilepsy (WWoE).

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Child rearing practice	WWE	WWoE	Unadjusted <i>t</i> -test <i>p</i> value	ANCOVA p value
n	88	88		
Total CRP score				
Mean (SD)	28.35 (3.23)	29.74 (2.13)	0.001	0.005
95% CI	27.67-29.04	29.29-30.19		
Feeding				
Mean (SD)	11.55 (2.19)	12.15 (1.62)	0.039	0.12
95% CI	11.08-12.01	11.81-12.49		
Growth and development				
Mean (SD)	0.74 (0.44)	0.81 (0.40)	0.283	0.049
95% CI	0.65-0.83	0.72-0.89		
Protection				
a. Cleaning and hygiene				
Mean (SD)	6.27 (0.69)	6.49 (0.63)	0.031	0.024
95% CI	6.13-6.42	6.36-6.62		
b. Infection prevention				
Mean (SD)	3.49 (0.71)	3.58 (0.62)	0.367	0.509
95% CI	3.34-3.64	3.45-3.71		
c. Protection				
Mean (SD)	2.86 (0.35)	2.94 (0.23)	0.075	0.065
95% CI	2.79-2.94	2.89-2.99		
Infant stimulation				
Mean (SD)	3.44 (0.77)	3.77 (0.58)	0.002	0.041
95% CI	3.28-3.61	3.65-3.9		

CI = confidence interval.

ANCOVA with epilepsy status, place of living and standard of living as factors and antenatal health index as covariate.

square test or multiple regression modeling. The analysis of r^2 value in multiple linear regression indicates that only about 11% of the variation in CRP could be explained by epilepsy, place or residence, SLI and antenatal Health put together. Probably several other unknown factors with cultural and social ethos are influencing these practices.

Child rearing is an important maternal commitment of WWE. Yet there have been little scientific evaluation of this area. WWE and their family members often feel insecure and uneasy about attending to the newborn. They are concerned that sleep deprivation due to repeated awakening to nurse the baby may predispose them to seizures. Some WWE refrain from breast feeding while on AEDs believing that it is harmful to the baby. Nevertheless our data did not show any significant difference in the feeding domain, when the data were adjusted for socio-

Table 4

Association between selected variables and child rearing practices (CRP) of women with epilepsy (n = 88).

Variables	CRP score \geq 30	CRP score <30	р
n	40	48	
Child rearing knowledge			
Poor (score <30)	28 (70)	45 (93.8)	0.003
Good (score \geq 30)	12 (30)	3 (6.3)	
Age in years			
<25	19 (47.5)	24 (50)	0.815
25 and above	21 (52.5)	24 (50)	
Education (years of schoo	ling)		
Low (<10 years)	20 (50)	28 (58.3)	0.434
High (11 and above)	20 (50)	20 (41.7)	
Parity			
Primipara	22 (55)	33 (66.8)	0.185
Multipara	18 (45)	15 (31.3)	
Family structure			
Nuclear	7 (17.5)	6 (12.5)	0.51
Extended	33 (82.5)	42 (87.5)	
Place of residence			
Urban	10 (25)	13 (27.1)	0.825
Rural	30 (75)	35 (72.9)	
SLI			
Low	14 (35)	19 (39.6)	0.658
High	26 (65)	29 (60.4)	

demographic characteristics. WWE fall behind others in several domains and sub domains of child rearing such as monitoring growth and development, prevention of accidents and injuries. hygiene and infant stimulation. The specific impairment in infant stimulation in WWE may be related to adverse effects of AEDs or seizures. The hesitation to actively involve in cleaning and bathing babies might be due to fear that the mother may drop the baby or cause injuries to it if she gets a seizure while handling it. Possibly the other members in the family were also restraining them from such activities. In this study, maternal education, place of residence or the standard of living did not influence the child rearing knowledge or practice. Nevertheless, there was significant association between CRK and CRP. Maternal education has a significant and enduring influence on the post-neonatal infant and child survival.²⁸ Osman and el-Sabban,²⁹ reported that mother's educational status had significant influence on her decision to exclusively breast-feed the infants, decide its duration and start supplementary food. Similar results were reported elsewhere.³⁰

5. Conclusions

This is a pioneering study in to the childrearing characteristics of WWE. We observed that WWE had lower childrearing knowledge and practices than WWOE. The most important factor associated with poor CRP was poor knowledge. Further studies from diverse cultural and social backgrounds are necessary to evaluate the trans-cultural variations in CRP and its impact on WWE and their infants.

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