

Pediatric electroencephalography. *Parent's knowledge and experience*

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Electroencephalography (EEG) remains the single most important physiologic test of the cerebral cortex. It is a very important tool in investigating and managing children with epilepsy. However, the patient's cooperation is needed to minimize movement and muscle artifacts, which can interfere with EEG interpretation. When the clinical suspicion of epilepsy is high, and the awake recorded EEG is normal, sleep EEG may provide additional diagnostic information. The EEG procedure, like most in-hospital procedures, can be frightening for children and distressing for their parents.¹ The placement of EEG leads and the requirement of being still may result in further distress to an already frightened child. The EEG indication, most commonly seizure or epilepsy, is by itself stressful to these families and may affect the child's adaptation and interactions.² Therefore, it is not unusual for parents and children to be anxious prior to an EEG procedure. This feeling may be exaggerated if they received inadequate information or were misinformed and therefore interferes with their understanding, support, cooperation, and patience, all essential for a successful pediatric EEG procedure. To our knowledge, parent's perceptions and knowledge of the EEG procedure have received limited study. Significant deficits in nature and safety of EEG were found in one study and correlated with mothers' socioeconomic status and educational levels.³ Our objectives were to study parent's perceptions and knowledge of the EEG procedure before the study, and examine their impressions afterward. We hypothesized that many parents are not well informed of the EEG procedure and therefore most will find the experience better than they anticipated.

Consecutive parents of children coming for outpatient EEG were included prospectively at the Clinical Neurophysiology Laboratory, Department of Neurosciences, King Faisal Specialist Hospital & Research Centre (KFSH&RC), Jeddah, Saudi Arabia. Families were recruited for the study between March and June 2010. Inpatient referrals were excluded. A quantitative approach was implemented through a semi-structured interview design using a 21-item questionnaire. The questionnaire was designed to examine their demographics, knowledge, compliance, and experience during the EEG procedure. Likert scale items were used to assess their EEG information level. Response categories were: 1) not informed at all, 2) somewhat informed, 3) moderately informed, and 4) very well informed. An assigned coauthor conducted the interviews in a private room and individually

assisted them to complete the questionnaire. The last section was completed after the EEG procedure and included one Likert scale item examining their overall EEG experience (worse than expected, as expected, better, and much better than expected). Two additional Likert scale items were completed by the attending technologist to evaluate the parents and child's behavior and cooperation during the test. Response categories were: 1) not cooperative at all, 2) somewhat cooperative, 3) moderately cooperative, and 4) very cooperative. The study design and questionnaire were approved by the KFSH&RC ethics committee, and all participating parents signed an informed consent. Data were collected in Excel sheets and statistical analysis was performed using the Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA) version 17. Descriptive analyses were performed, and the variables were examined using chi-square test. Statistical significance was defined as *p*-values of less than 0.05.

One hundred families completed the questionnaires during the study period. Most families (70%) were from the Jeddah area. The child's age ranged from one month to 16 years (mean 6.6 years, SD 4.4), mothers age ranged from 20-53 years (mean 33.4, SD 6.4), and the father's age ranged from 26-70 years (mean 39.9, SD 8.3). Most of the EEGs (90%) were requested by the pediatric neurology service and seizures or epilepsy were the most common indication (87%). Sleep was achieved in 33% of the recordings and most patients (80%) had a previous EEG experience. Only 24% of the families reported receiving prior information on the EEG procedure, mostly (58%) from the referring physician. Their level of information was weak on the Likert scale with only 16% feeling very well informed of the EEG procedure. No correlation was found between parent's information level and their socio-demographic or EEG variables, including having a previous EEG. Some of the parents had apprehensions and misconceptions regarding the EEG procedure, including that it involves needles (3%), electrical shocks (4%), causing pain (6%), or requiring the administration of intravenous medications (11%). After the EEG procedure, 71% of parents found their experience better or much better than they expected. None of them reported a worse than expected experience. The EEG experience correlated with their information levels as shown in the Table 1. Those who were informed regarding the EEG procedure were more likely to have an as expected experience (34% versus 9%, *p*=0.004). Most parents were highly cooperative and helpful during the procedure (98%), while the child was difficult and not as cooperative in 27% of cases. Neither parents nor child's behavior correlated with the level of EEG information.

The study results documented significant deficiency in parent's information regarding the EEG procedure with only a small percentage (16%) feeling very well informed. This is similar to the findings of Arhan et al,³ who looked at mothers' knowledge before and after providing them with an EEG information leaflet.³

Table 1 - Correlation between the parent's information level and their overall EEG experience. Those who were informed were more likely to have an as expected EEG experience.

EEG experience	Level of EEG Information				Total
	Not informed	Somewhat informed	Moderately informed	Very well informed	
As expected	2	13	9	5	29
Better than expected	10	18	9	3	40
Much better than expected	10	2	11	8	31
Total	22	33	29	16	100

Significant deficits were found regarding the use, details, and safety of the EEG procedure and the study emphasized the efficiency of the information leaflet in improving mother's awareness.³ Some parents in our study had significant misconceptions that could have been easily clarified by providing adequate information. These misconceptions may affect their expectations and behavior during testing. This was suggested by the finding that informed parents were more likely to have an as expected experience (Table 1). Therefore, parents who were poorly informed had a better or much better than expected experience as a direct result of their limited knowledge, misconceptions, and possibly high pretest anxiety, which all affected their expectations. It appears that they were relieved after the test and realized that it was better than they anticipated. However, some authors found that providing patients with information prior to other diagnostic procedures does not have a significant impact on their anxiety levels.⁴ In our hospital, we routinely provide written information to the parents at the time of obtaining the EEG appointment. But, it seems that they either do not read it carefully or forget about it. We also provide information and a verbal explanation at the time of the test by the attending EEG technologist. More involvement of the referring physician is needed in order to optimize parent's knowledge prior to testing.

In one study, a relation was found between parent's educational level and their level of information.³ We did not find any correlation with various socio-demographic or EEG variables. In addition, neither the parent's nor the child's behavior correlated with the level of EEG information. Other authors found a positive correlation between the lack of knowledge and parent's anxiety and child's behavior during an in-hospital procedure, such as EEG.⁵ The lack of significant associations in our study could be related to our sample size. Most of the parents in our study were highly cooperative and helpful during the procedure, which made a difference to the quality of the EEG recording. The majority of survey-based research has found that parents strongly favor being present for their child's medical procedures.⁴ It is important for parents to be actively involved in assisting the EEG technologist in the preparation and recording of the EEG. We also use a lot of behavioral support, music, and patience during testing and always try to avoid drug sedation. This may explain the parent's high

satisfaction rate and cooperation. The advantages of this practice have been documented in the literature.

There are some limitations to our study. Our sample was not large; however, it was representative of children coming for EEG with variable ages and socio-demographic backgrounds. Parent's reporting bias may have affected the results since the questions on their knowledge and perceptions, as well as technologists' evaluations are predisposed to subjective judgments. We tried to overcome this problem by assigning one coauthor to personally assist all parents in completing the questionnaire. Finally, the questionnaire is self-structured and hence has not been used or validated in previous studies.

We conclude that many parents are not well informed of the EEG procedure, which affected their expectations and EEG experience. Some parents had significant apprehensions, and misconceptions, however, most found the EEG experience better than they expected. Several areas for quality improvements were identified, and hopefully these will help in delivering effective care and in improving parent's perceptions regarding EEG procedures.

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