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Behavioral intervention to increase compliance with electroencephalographic procedures in children with developmental disabilities

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Abstract

The EEG, or electroencephalogram, is a neurophysiological technique used to detect and record electrical activity in the brain. It is critical to the diagnosis and management of seizure disorders, such as epilepsy, as well as other neurological conditions. The EEG procedure is often not well tolerated by children with developmental disabilities because of anxiety about unfamiliar equipment, difficulty inhibiting motion, and tactile defensiveness. The inability of children with developmental disabilities to tolerate an EEG procedure is especially problematic because the incidence of epilepsy is considerably higher in children with disabilities. This clinical outcome study sought to determine the efficacy of using behavioral intervention to teach children with developmental disorders to cooperate with an EEG procedure. The behavioral training employed modeling, counterconditioning, escape extinction, and differential reinforcement-based shaping procedures. Results indicated that behavioral training is successful in promoting EEG compliance without restraint, anesthesia, or sedation.

Keywords

Electroencephalogram; Seizure; Pediatric; Developmental disability; Sleep; Behavioral intervention; Compliance; Anxiety; Tactile defensiveness

1. Introduction

Epilepsy is characterized by abnormal electrochemical firings in the brain. The condition is estimated to occur in 5 of every 1000 children and is thought to be the most common neurological disorder of childhood [1]. The incidence of epilepsy is considerably higher for children with disabilities, particularly mental retardation, autism, brain injury, and cerebral palsy [2]. For example, some have estimated that up to 30% of children with autism also experience seizures by adolescence [3].

The electroencephalogram (EEG) procedure is employed by neurologists to record electrical signals from the brain to examine normal and abnormal patterns. The EEG results are used to diagnose and monitor seizure disorders, epilepsy, and changes in response to pharmacological

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intervention. To conduct an EEG, 20 or more electrodes are placed on the child's scalp, forehead, and upper face.

There are various methods for conducting the EEG, but most often a standard EEG or an overnight EEG study is conducted. A standard EEG is typically carried out during the daytime and requires placement of the electrodes on the child's head for approximately 1 hour. To complete the test successfully, the child must tolerate skin preparation and placement of all leads and remain still during the recording. Some children require an overnight EEG study to examine EEG/seizure activity during sleep. Sleep increases the likelihood of epileptiform activity, particularly during the transition from sleep to wakefulness [4]. For this reason, children are often monitored overnight, which requires they tolerate placement of the leads, remaining relatively still, and keeping the leads in place throughout the night. Any EEG requires limited movement for a predetermined period and tolerance of new sensations involved in attaching sensors to the head. The EEG procedure often provokes distress in children with developmental disabilities because of anxiety about unfamiliar equipment, difficulty inhibiting motion (particularly in children with hyperactivity), and tactile defensiveness. Tactile defensiveness which has been identified in children with autistic spectrum disorder [5,6] and other developmental disorders [7], is a pattern of observable behavioral and emotional responses, which are aversive, negative, and out of proportion to certain types of tactile stimuli that most people would find to be nonpainful or nonaversive [8]. Often children who exhibit tactile defensiveness do not tolerate aspects of the EEG procedure that require the patient to be touched, such as placement of EEG leads on the scalp. In summary, children with developmental disabilities may be more likely to undergo an EEG, but also may be more likely to have difficulty tolerating it.

Noncompliance with medical procedures or regimens is a widespread problem, and is particularly common among children with disabilities. In some settings, this is addressed by employing restraint, sedation, or anesthesia; however, these methods often alter the test results and cause unnecessary stress for the child. Sedation in children with neurological and/or developmental disorders often lacks efficacy [9] or has unwanted side effects such as vomiting [10]. In a recent study, administration of clonidine was proposed to be a safer method of sedation for children with autism, but only 85% of the children were actually sedated and the medication took a mean of 58 minutes to achieve sedation. The hour between the time of medication administration and adequate sedation can be stressful for the child and family waiting in an unfamiliar setting [3]. In contrast, behavior therapy techniques have been used to increase children's compliance with a number of stressful medical procedures and regimens including gynecological exams [11], tracheostomy suctioning and care [12–14], self-catheterization [15,16], neuroimaging [17,18], radiation therapy [19–21], and needle sticks [13,22,23].

The objectives of this article were to use single-subject experimental methods to: (1) prospectively evaluate the effects of a systematic behavior therapy protocol for teaching children with developmental disabilities to cooperate with EEG examinations without sedation, and (2) describe the behavioral training procedures in sufficient detail to allow for them to be used by pediatric staff at other medical institutions.

2. Methods

2.1. Participants

Seven children with developmental disability and/or autism participated in behavioral intervention to increase compliance with the EEG procedure. Six children were treated on an outpatient basis at a pediatric hospital specializing in treatment of children with disabilities; one child was treated on an inpatient basis (while receiving treatment for an unrelated medical

condition) at the same hospital. Age, sex, diagnoses, and type of EEG study required are listed in Table 1.

2.2. Settings and materials

Five therapists with master's degrees trained in behavior analysis and therapy techniques conducted individual treatment of the children. All sessions were 30 to 60 minutes in duration. The number of treatment sessions conducted with each child is given in Table 1.

2.3. Measurement

For each child, a task analysis was developed based on the specific requirements of the individual patient's EEG procedure. The task analysis detailed the sequence of behavioral steps required for successful cooperation with the procedure. The task analysis outlined in Table 2 is a representation. For all children, a task analysis was used to measure the percentage of steps completed/tolerated and the percentage of steps attempted during which escape/avoidance behavior was observed. Percentage of steps completed was calculated by summing the number of steps completed, dividing by the total number of steps in the task analysis, and multiplying by 100. Occurrence of avoidance/escape behavior was calculated by summing the number of steps during which avoidance or escape behavior occurred, dividing by the total number of task analysis steps attempted, and multiplying by 100. Escape/avoidance behavior was selected as an outcome variable based on our clinical observation that escape/avoidance is a useful indicator of a child's level of distress. Additionally, this behavior can directly affect the outcome of the procedure (e.g., child jumping off of the table or removing leads could invalidate the EEG procedure). Escape/avoidance behavior was defined as: any attempt to evade the therapists' physical presence or touch, to push away from the EEG material (skin preparation cream, Q-tip swab, sensor paste, sensor, etc.), to block access to the intended site for placement of a sensor on the body, or to remove a sensor once it was attached.

2.4. Assessment procedures

Each child was referred for behavioral intervention either because of a failed attempt at a standard EEG or an overnight EEG sleep study in the past or because of the referring physician's concern that the child had exhibited anxious and disruptive behavior during other medical procedures and would likely not be able to comply with the EEG study. During the initial assessment with the child and caregiver(s), all children exhibited noncompliance, significant distress, and escape/avoidance behavior during the initial attempt to conduct a mock EEG procedure. For this reason, a formal no-intervention baseline assessment was not conducted, as such an evaluation would likely cause subjects undue emotional distress and would result in poor efficiency (i.e., delay of intervention). The therapist also conducted an informal clinical assessment with the parent or caregiver by interview or survey to gather information about the child's preferred activities or objects.

2.5. Antecedent intervention

The preferred activities or objects (e.g., favorite cartoon/videos, playing with trains) were used to distract the child and countercondition anticipatory (conditioned) anxiety, to motivate cooperative behavior (stickers, small toy cars), and to make the environment more comfortable (favorite stuffed animal or pillow nearby) during the procedure.

2.6. Behavioral training and intervention procedures

Differential reinforcement, escape extinction, counterconditioning, and shaping procedures were employed to teach the children to cooperate with the EEG regimens. Behavioral training was provided to establish the child's cooperation with the EEG sensors and routines involved in acquiring the EEG or overnight EEG/sleep study data. The child was introduced gradually

to the EEG technologist, the monitoring environment, scalp/skin preparation, and EEG lead attachment using mock or actual EEG leads. All children but Ivy began sessions using actual EEG leads; however, Ivy began the first session working with mock EEG leads consisting of barrettes placed next to her scalp. Each child was given instructions one step at a time to enter the therapy room, to sit on a gurney or reclining chair, to lie back in a fully reclining or supine position, to sit still while the therapist touched the child's head with a fingertip, rubbed the attachment site with abrasive paste and a cotton swab, and then attached the EEG sensors one-by-one.

All children were treated using the same approach, regardless of their level of cognitive functioning. However, one child, Van, was blind and hard of hearing, and had severe tactile defensiveness. During the first EEG training session, he evidenced a slow desensitization response and was not able to tolerate initial steps in the task analysis, including having his head touched with a Q-tip and an EEG lead, at any point during the initial session. Therefore, these steps in the task analysis were broken down into smaller components. Van required 14 supplemental sessions (mean duration = 30 minutes) in which shaping, counterconditioning, and differential reinforcement were used to desensitize him to simply having his head touched, first with the therapist's hand, then with a Q-tip, and finally with a lead (without paste). Once he was able to tolerate having his head touched for 10 seconds (longer than necessary for EEG lead placement), training was resumed with the original task analysis.

2.6.1. Reinforcement procedures—Positive reinforcement refers to providing a preferred item or activity contingent on a target behavior one wishes to strengthen (increase in frequency). Differential reinforcement involves providing a reinforcer in response to behaviors one wishes to increase, but not in response to those one intends to decrease. Therapists provided differential reinforcement for cooperation, instruction following, and tolerance of the application of the EEG leads. Music, stories, videotaped cartoons, or other favorite activities were provided as continuous positive reinforcement as long as the child was cooperating with the EEG routine. These activities were briefly withdrawn to provide contingent feedback and brief timeout from positive reinforcement aimed at decreasing behavior that would disrupt the acquisition of EEG data. For example, the child's favorite video would be turned off briefly after each attempt the child made to remove an EEG lead. The therapist ignored negative vocalizations during the session and praised the child for remaining quiet or calm and for observed appropriate behaviors. A routine was developed and maintained at the beginning of each session in which the child would enter the room and pick a favorite type of sticker for use as conditioned reinforcers (tokens) to be exchanged at the end of the session for a preselected tangible reinforcer (preferred object or activity). Then, the therapist began the initial steps of the task analysis. If the child did not wish to earn stickers or a tangible reinforcer, she or he was provided with a continuous reinforcing activity, which was interrupted or removed contingent on disruptive or uncooperative behavior and re-presented when the child was again cooperative (Ivy's case).

2.6.2. Escape extinction—Negative reinforcement involves removing an aversive or non-preferred item or activity contingent on a target behavior, thereby strengthening it (increasing its frequency). Escape extinction refers to blocking the patient's escape from a feared or non-preferred stimulus, thereby weakening the escape behavior that has been maintained by negative reinforcement. In this study escape extinction was used to teach the child that attempts to remove the EEG equipment would not be successful (would not produce negative reinforcement). If the child attempted to avoid or disrupt the placement of the leads, the therapist gently physically interrupted the behavior and redirected the child to engage in alternative behavior that was incompatible with escape, but compatible with the EEG monitoring (i.e., telling the child "hold your toy car" while handing the object to the child, or "clap your hands" during a favorite song).

2.7. Counterconditioning

Counterconditioning involves modifying conditioned anxiety by carefully planned, graduated exposure to the feared or non-preferred stimulus while engaging the patient in a distracting, relaxing, or otherwise pleasurable activity. Each child was systematically and gradually exposed to the procedure to ensure the experience of success and reinforcement, thereby helping the child form a more positive association with the EEG routine and counteract conditioned anxiety stemming from negative experiences during prior attempts at EEG or similar medical procedures.

2.7.1. Shaping—Shaping refers to using differential reinforcement to teach successive approximations of a target behavior. Through carefully planned, gradual exposure of the child to the situation, equipment, and routines required for an EEG along with differential reinforcement of progressively more acceptable behavior (and withholding reinforcement when unacceptable behavior occurs), the child is taught the behavior required for cooperation with the EEG procedures.

The training was provided during a sequence of behavior therapy sessions, which progressed at a pace that was matched to the child's availability for training, ability to follow verbal instructions, and the observed level of procedural anxiety and escape/avoidance behavior. The pace was one that challenged and taught the child, but did not overly distress the child. The specific number of training sessions was individualized according to the child's progress. This information is outlined in Table 1 and the figures discussed later. It is important to note that the occurrence of escape/avoidance behavior did not necessarily preclude the completion of steps in the task analysis. In many cases, although children exhibited these behaviors, they were able to be redirected and tolerated completion of additional steps in the task analysis. Similarly, while a child may not have exhibited high levels of escape/avoidance behavior, the therapist may have determined that the observed level of distress was too high for additional steps in the task analysis to be attempted without increasing the child's anxiety.

2.7.2. Caregiver and medical staff training—Caregivers and medical staff involved in the EEG/sleep study procedure were provided behavioral training to increase the consistency with which individuals interacted with the child during the procedure. Therapists modeled appropriate verbal interactions, differential reinforcement, and escape extinction procedures during each session for the caregivers and during a brief preparatory meeting with the medical staff conducting the EEG study. The same preferred activities or objects used during behavioral training sessions were used during the actual EEG procedures. Medical staff members were also asked to have all equipment ready and available rather than having the child wait for the application of leads to begin, which often causes distress and frustration if the procedure is too lengthy or unstructured.

2.8. Experimental design

Single-subject experimental methods were used to evaluate the results of the behavior therapy intervention. Specifically, a case series with an AB (initial session–final session) comparison replicated across subjects was used (see Figs. 1 and 2).

3. Results

A paired sample *t* test was used to compare the percentage of EEG task analysis steps completed during the initial treatment session ($M = 21.91$, $SD = 23.09$) with the percentage of steps completed during the last treatment session (the actual EEG procedure in all but one case) ($M = 100.00$, $SD = 0.00$). With an α level of 0.05, the effect of treatment was statistically significant, $t(6) = -8.947$, $P = 0.000$. Likewise, a paired sample *t* test was used to compare the

occurrence of escape/avoidance behavior during the initial session ($M = 56.57$, $SD = 34.49$) with the occurrence of escape/avoidance behavior during the last treatment session (the actual EEG procedure) ($M = 6.30$, $SD = 6.34$). With an α level of 0.05, the effect of treatment was statistically significant, $t(6) = 4.074$, $P = 0.007$. Figs. 1 and 2 illustrate the percentage of steps in the EEG task analysis completed per session for each child, as well as the percentage of steps attempted during which escape/avoidance behavior occurred.

For all children, the percentage of steps successfully completed in each session gradually increased, whereas the percentage of steps with occurrences of escape/avoidance behavior decreased over the same time course. All children began treatment with observed behaviors of crying, attempting to leave the room, attempting to block the therapist's hands from approaching the child's head with the electrode or from picking up the necessary materials, as well as attempting to remove electrodes once placed. Throughout treatment, these escape/avoidance behaviors greatly decreased and all children were able to complete 100% of the steps of the EEG task analysis. One child, Van, had a brief decrease in the number of steps completed on a day when he underwent an unrelated medical procedure and was not feeling well.

4. Discussion

Results indicate that the behavior therapy protocol was successful in improving compliance in these children with autism/developmental delay. The behavioral protocol was founded on the behavioral strategies of task analysis, positive reinforcement, differential reinforcement (reinforcing cooperative behavior while ignoring uncooperative behavior), escape extinction (by blocking or redirecting noncompliant behaviors), counterconditioning (by providing preferred activities to pair a pleasurable experience with a normally stressful situation), and shaping (differentially reinforcing greater cooperation over time). Prior to behavioral training, all children had failed prior attempts at an EEG study or were assumed to be unable to cooperate with the procedure based on experiences with other similar medical regimens according to parent report. During initial therapy sessions, all children exhibited distress and uncooperative behaviors such as aggression, blocking placement of or removing EEG equipment, crying, and screaming. After behavioral training, six of seven children were able to complete their scheduled EEG/overnight study without sedation, restraint, or anesthesia and with minimal distress. The one remaining child, Zeke, would likely have been successful with his actual EEG procedure, but after successful training, his parents declined to follow through with the recommended EEG examination. The results demonstrate the benefits of using behavioral training with children with autism and/or developmental delay to increase compliance with EEG procedures and to decrease uncooperative (escape/avoidance) behaviors that often interfere with or prevent successful EEG assessment.

The ability to complete the EEG procedure allows these children to receive neurological care so that their symptoms may be diagnosed, clarified, or monitored without the discomfort and risks of using sedation or the stress of implementing restraint procedures. Children with autism or developmental disorders are often described as uncooperative for a procedure; however, given sufficient availability for training by a skilled behavior therapist, most children, even those with a wide range of cognitive deficits, emotional disturbances, and disruptive behaviors, can be trained to cooperate with the EEG procedure. Children with severe cognitive deficits or severe disruptive behavior may not respond to behavioral treatment quickly enough for it to be a realistic solution (e.g., if test results are needed urgently or if caregivers cannot continue to bring the child to training sessions).

An EEG technologist or other professional who is willing to undergo training provided by a behavior therapist on these specific behavioral techniques would likely be able to perform this intervention effectively. Given the availability and economics of behavior therapy,

consideration should be given to having EEG technologists trained to carry out this intervention with patients who have only mild cognitive deficits and no history of severe behavior problems. On average, patients in this study required six sessions of individual therapy before they were able to successfully cooperate with the EEG procedure. Therefore, mechanisms of reimbursement for EEG technologists would likely need to be established for this to be a viable option. Currently, specific billing codes exist that allow psychologists to be reimbursed for training patients for medical procedures.

In addition, children with epilepsy often must undergo repeated EEG studies throughout their lifetime to monitor treatment efficacy and severity of the disease. By taking the time to provide behavioral intervention, the child is not only successful with the procedure, but also acquires a life skill that will continue to serve him or her well for future EEG examinations. Children may require some behavioral retraining prior to each repeated EEG procedure, but the level of anticipatory anxiety experienced by the child and his or her parents will likely be less given prior success. It is also worth mentioning that parents are trained on this protocol during treatment and thus may be able to implement these procedures in preparation for other medical procedures that require child cooperation and motion control, procedures that these children will likely encounter throughout their lifetime.

Likewise, the results add further empirical support for the general utility of behavioral interventions in the medical setting to increase compliance with various medical regimens as discussed earlier in this article. However, this intervention is a multicomponent intervention, and we do not yet know if all components are necessary to achieve the same successful results. Additional research is needed to conduct a component analysis of the protocol described here.

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Fig. 1. Percentage of steps in the EEG task analysis completed per session for subjects 1–4 and percentage of steps attempted with escape/avoidance behavior.

Fig. 2. Percentage of steps in the EEG task analysis completed per session for subjects 5–7 and percentage of steps attempted with escape/avoidance behavior.

Table 1

Demographic characteristics of participants

Child	Age/sex	Diagnosis	Cognitive/communication level	Type of EEG study required	Therapy sessions conducted
Jerry	3/M	Epilepsy, encephalopathy, apraxia, neuromotor dysfunction	Developmental delay/verbal communication	Standard	10
Susan	9/F	Seizure disorder, unspecified genetic syndrome, tactile defensiveness	Mild mental retardation/verbal communication	Standard	3
Ivy	2/F	Seizure disorder, autism	Developmental delay/nonverbal communication	Standard, overnight	5
Meg	10/F	Epilepsy, aphasia, apraxia, aggression	Moderate to severe mental retardation/speech and language delay	Standard, overnight	5
Van	9/M	Seizure disorder, schizencephaly, shunted hydrocephalus, cortical blindness, tactile defensiveness	Severe mental retardation/limited nonverbal communication	Standard	8 ^a
Daniel	2/M	Seizure disorder, pervasive developmental disorder, arteriovenous malformation	Developmental delay, verbal communication	Standard	6
Zeke	4/M	Autism, hyperactivity, tactile defensiveness, aggression	Developmental delay, severe receptive expressive language disorder/nonverbal communication	Standard	4

^aThis patient received 14 supplemental sessions of head-desensitization training.

Table 2

Task analysis of EEG procedures for behavioral training

Step	Compliance? Yes/No	Escape/avoidance behavior? Yes/No
Enter room		
Get onto bed/chair		
Touch head		
Q-tip on head		
Q-tip with skin prepping gel on head		
Place 1st lead		
Touch head		
Q-tip with skin prepping gel on head		
Place 2nd lead		
Touch head		
Q-tip with skin prepping gel on head		
Place 3rd lead		
Touch head		
Q-tip with skin prepping gel on head		
Place 4th lead		
If all leads were placed, record total time leads were left on_____		

Note. This is a representation. Typical EEG task analyses include placement of 16 to 25 leads.