JCSM
Journal of Clinical Sleep Medicine

SCIENTIFIC INVESTIGATIONS

Individuals with Autism Spectrum Disorders Have Equal Success Rate But Require Longer Periods of Systematic Desensitization than Control Patients to Complete Ambulatory Polysomnography

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Study Objectives: Polysomnography (PSG) is the gold standard for the assessment of sleep, yet the extensive apparatus required for monitoring with PSG can be difficult to tolerate, particularly in children. Clinical populations, such as those with anxiety or tactile sensitivity, may have even greater difficulty tolerating the PSG equipment. This study evaluated an innovative protocol for obtaining full PSG in individuals diagnosed autism spectrum disorders (ASD) or developmental delay (DD), as well as typically developing controls (TD). The primary aim was to assess whether this protocol was equally successful for obtaining PSG between these groups.

Methods: One hundred sixty-one individuals were recruited for participation; 93 with a diagnosis of ASD, 23 with a diagnosis of DD, and 45 TD. The participants and families were instructed on a procedure of systematic desensitization to the ambulatory PSG equipment; PSG was performed in the home of the participant.

Results: PSG was successfully attained in 144 (89.4%) participants. There was no difference in completion rate by diagnosis ($p = 0.1$), though younger age ($p = 0.018$) and duration of desensitization ($p = 0.024$) did predict PSG failure. Further, it was found that individuals with ASD took longer to desensitize to the equipment (16.08 d), than those with DD (8.04 d) or TD (0.98 d).

Conclusions: Systematic desensitization to PSG equipment, in combination with PSG completed in the home, allows for individuals with ASD to be equally successful in completing PSG, though they do take longer to acclimate to the equipment.

Keywords: autism spectrum disorder, polysomnography, pediatric, methodology

Citation: Primeau M, Gershon A, Talbot L, Cotto I, Lotspeich L, Hardan A, Hallmayer J, O'Hara R. Individuals with autism spectrum disorders have equal success rate but require longer periods of systematic desensitization than control patients to complete ambulatory polysomnography. *J Clin Sleep Med* 2016;12(3):357–362.

INTRODUCTION

Neurodevelopmental conditions represent a broad collection of brain-based disorders that manifest in behavioral, cognitive, and emotional disturbances. Examples include autism spectrum disorders (ASD), anxiety spectrum disorders, attention deficit hyperactivity disorder (ADHD), and developmental delay. Sleep disturbances are frequently noted in these populations, with as many as 80% of children with ASD having a parent-reported sleep disturbance.[1] Similarly, children with cognitive deficits disorders, such as developmental delay (DD), are reported to have sleep disturbances.[2]

Sleep disturbances, particularly short sleep duration, are known to have a significant effect on daytime functioning in adults and in healthy children, negatively affecting mood, cognition, and motor skills.[3,4] The initial evidence in children with neurodevelopmental disorders also suggests that sleep disturbance is associated with worse daytime functioning.[1]

Yet, sleep disturbances in neurodevelopmental populations have been understudied. This dearth of research is significant because such sleep disturbances may represent a treatable sleep disorder; for example, cognitive impairment may be associated with sleep disordered breathing.[5] In addition, greater understanding of alterations in sleep structure could provide

BRIEF SUMMARY

Current Knowledge/Study Rationale: Polysomnography (PSG) is a valuable tool for sleep assessment in both research and clinical populations, yet children, particularly those with neurodevelopmental conditions, such as Autism Spectrum Disorders (ASD) or anxiety, can find it particularly difficult to comply with the standard implementation of PSG, thereby restricting its large scale use. The protocol described was developed specifically to address these limitations, reduce anxiety in participants, and improve the yield of data attained.

Study Impact: This protocol allowed individuals with ASD to be as successful at attaining PSG as their developmentally delayed or typically developing peers; however, they required significantly longer to desensitize to the PSG equipment. The tools described in this article may have utility for both clinicians and researchers performing PSG in pediatric populations.

a window into the underlying neural processes related to the neurodevelopmental dysfunction.[6]

Full polysomnography (PSG), the gold standard objective measure of sleep, is required to provide the specificity of information to characterize sleep disorders as well as sleep architecture in children with these neurodevelopmental disorders. Specifically, PSG is required for the diagnosis of sleep disordered breathing, periodic limb movement disorder, and narcolepsy, and is the only way to differentiate sleep macroarchitecture.[7,8] Previous efforts have been made to operationalize a "child-centered" approach to performance of PSG in clinical settings,[9] which has contributed to most typically developing children and their families rating the in-laboratory PSG experience as "satisfactory" and without pain or subsequent adverse psychological outcomes.[10] A few studies with small sample sizes have achieved successful in-laboratory PSG in pediatric ASD populations.[11–15] However, in order to increase the likelihood of success some of these studies have had to reduce the number of recording channels (i.e., below the number recommended to assess sleep disorders and sleep architecture), or excluded the thermistor and cannula for assessment of sleep disordered breathing, in order to increase the likelihood of success.

There are very few reports of PSG studies in pediatric neurodevelopmental samples due in part to the difficulty of conducting these studies. Numerous unique characteristics of children with neurodevelopmental disorders may limit their ability to tolerate PSG and result in higher proportions of failed sleep recordings. Indeed, even for children without psychiatric disorders, the idea of spending the night in a medical facility can be anxiety provoking. Further, specific core symptoms of a neurodevelopmental disorder may interfere with obtaining in-laboratory PSG. For example, in ASD, children may have difficulty tolerating changes in routine such as sleeping in a laboratory. Other symptoms may affect the conduct of PSG in any setting. Children with cognitive impairments (whether due to DD, ASD, or other conditions) may not fully understand the noninvasive nature of PSG, potentially resulting in fear and reluctance to participate. Children with ASD may also exhibit sensory sensitivities (e.g., tactile sensitivity),[16] potentially reducing compliance.

In the current study, we utilized two components to circumvent these unique challenges of using PSG in pediatric patients with neurodevelopmental disorders and healthy, typically developing children. First, we used ambulatory PSG. Ambulatory PSG done in the typical sleep environment allows us to reduce the disruption of routine for the children examined. Second, we developed a systematic desensitization protocol to prepare subjects and their parents for PSG. Our primary aim was to examine whether the rates of successful ambulatory PSG recordings using systematic desensitization differed according to neurodevelopmental diagnosis, in a group consisting of 93 individuals with ASD, 23 with DD, and 45 typically developing matched control patients. We also investigated if the time taken to reach a successful PSG following systematic desensitization differed according to group. Finally, we conducted between- and within- group analyses to examine whether demographic factors affected the rate and time taken to obtain a successful PSG and whether symptoms of the disorders such as IQ and sensory sensitivities, similarly impacted our outcomes.

METHODS

Subjects

Our protocol was originally developed for a study evaluating sleep in children in whom ASD was diagnosed, who frequently have anxiety, rigidity, and sensory sensitivity that can make medical procedures more difficult to perform than in general pediatric populations. The protocol was subsequently extended to children with DD and typically developing control patients. DD was defined as no ASD diagnosis; noneligible for special education services under ASD; IQ below 80; and a score below 51 on the Social Communication Questionnaire. The study has been approved by the local institutional review board. Since 2010, 161 potential participants have been recruited for participating in sleep research utilizing the described protocol. Individuals between the ages of 3 to 25 y were recruited. Research of individuals with ASD commonly focuses on those younger than 21 y; several parents requested their adult child be included in the current study, which was deemed to be appropriate, as the prefrontal cortex does not reach adult dimensions until the early twenties.[17]

All were offered the opportunity to participate in this evaluation of sleep, and the consenting caregiver determined if the subject would be able to tolerate the desensitization procedure. Two hundred four individuals were approached to participate. Of the 161 (78.9%) who consented to participate in the desensitization protocol, 93 (57.8%) received a diagnosis of ASD, 23 (14.3%) received a diagnosis of DD, and 45 (28%) were TD. An additional 43 potential subjects (21.1%) declined to participate; 13 (30.2%; 12 ASD, 1 TD) declined because the primary caregiver determined the subject would be unable to tolerate equipment, but in 30 (69.8%; 23 ASD, 3 DD, 4 TD) the reason for decline was not documented.

Measures of cognitive function, language, and autism severity were also evaluated whenever possible. The Stanford-Binet version 5 provided our measure of cognitive function,[18] and the Sensory Profile Questionnaire for measures of sensory functioning,[19] Autism Diagnostic Interview-Revised,[20] and Autism Diagnostic Observation Schedule provided measures of autistic symptoms.[21]

Systematic Desensitization Protocol

Equipment

The PSG (Compumedics Siesta, Abbotsford, Victoria, Australia) consists of a six-channel electroencephalogram (EEG) (F3/F4, C3/C4, O1/O2), electrooculogram (EOG), electromyogram (EMG), electrocardiogram (EKG), nasal flow, oral thermal flow sensors, and abdominal and thoracic effort (inductance plethysmography), with the capability to record sleep in the individuals' homes. The EEG leads are embedded in a cap (Quik-Cap, Compumedics; Abbotsford, Victoria, Australia), which allows for all the EEG leads to be quickly

aligned to the correct location, and uses a special conductive gel (Quik Gel) that also secures the lead in place. All data are recorded on a small portable unit that the participant can move around with.

Desensitization

Introduction to the equipment and the evaluation process starts at the initial consent/assent visit. This visit typically takes place in the home of the family. Research team members describe the equipment in detail to the subject and participating caregiver. A book is used to illustrate, including step-by-step instructions and pictures of children wearing the equipment (**Figure 1**). This story is designed along the lines of social stories, designed by Gray, to address specific difficulties of children with ASD, including need for predictability and preference for visual cues.[22,23] Technicians are trained in the use of developmentally appropriate language to describe the device sensors. The team members are trained to be constantly observing the subject for any discomfort or distress during this discussion, and provide information while maintaining the comfort of the subject and family. Participants who agree to join the research study are provided a kit that contains portions of the PSG equipment (Quik-Cap, nasal cannula, EKG stickers, and EMG leads). The parents are instructed to complete 1 w of "practice" with the PSG equipment, designed on the principles of systematic desensitization[24] and graded exposure similar to techniques used to assist with acclimatizing to treatments for sleep disordered breathing.[25] The equipment provided for "practice" does not include the actual working items that will be used for obtaining data; for example, nonfunctional Quik-Caps are provided to the families. This allows the family the flexibility to take as long as necessary to acclimate to the equipment, without hampering the opportunity for other studies to be collected using functional equipment.

Systematic desensitization is based on the principle of reciprocal inhibition in which the individual is taught to apply a relaxing response when presented with anxiety provoking stimuli,[24] such that the anxiety response becomes deconditioned and no longer triggered by the identified stimulus. The technician works with the caregiver and participating subject to identify which of the items seems the least anxiety-provoking, and together they rank the items from least to most fear inducing. They then create a program, whereby the caregiver gradually introduces the equipment to the bedtime routine. For some subjects, this is quickly accomplished with 1 or 2 nights of "practice" with the QuikCap and nasal cannula on. For others, the process begins with practice occurring during waking hours, due to the high level of arousal caused by the equipment. Parents or siblings who are less anxious about the equipment might wear it to reduce the anxiety in the participating subject, and early practice wearing it while reading or cuddling with parents (i.e. a relaxing activity) can be extremely helpful in reducing anxiety around the equipment.

The parents alerted the research assistant when they thought their child was able to tolerate the equipment sufficiently to participate. Most become acclimated to the equipment within 1 w, and so at that time, the same technicians are scheduled to return. Some are not yet acclimated, and the PSG is rescheduled to allow more time to achieve comfort. Some have difficulty only with the nasal flow cannula; for these individuals, the PSG continues as scheduled, and the parents instructed on placement of the cannula after the subject falls asleep. Extra time (~2 h) is allowed for the application of electrodes, and the subject is allowed to choose where in their home they would like to have the equipment applied. Frequently, this will be in a room with a television, which can successfully distract the subject so they can sit still during the application of leads, but can also be in the kitchen or on a caregiver's lap. Research assistants tend to start with the less bothersome electrodes (leg, belts), before proceeding to the more difficult sensors (nasal cannula, QuikCap), but the application procedure and timing is guided by the experience of the subject. Certain equipment, such as the syringe used for the conductive gel, is disguised with colorful materials, and plastic tips instead of metal, in order to make it more child-friendly.

Figure 1—An image from the book used to explain the equipment.

In individuals with social or developmental delay, we make particular effort to maintain continuity of research assistants interacting with the family. For example, in a cohort with DD, the same research assistant who performed baseline cognitive testing also completed the instruction in the equipment, and was there on the night of the PSG. We have found this continuity to be of particular help to individuals with special needs.

A known limitation of unattended sleep studies is equipment becoming dislodged during the course of the sleep period, and this is particularly problematic in children, who tend to be very active sleepers. In order to minimize tension on the leads, we have developed a shirt that has a zipper component down the length of the back of the shirt. This conceals the wire "tail" and reduces the likelihood the wires will be pulled and dislodged.

Subjects and caretakers are instructed to keep to their typical schedule and on how to remove the equipment in the morning. The team coordinates pick up at the convenience of the family. The study is then scored, using accepted criteria, by a registered PSG technician who is otherwise not involved in the research study.[26] In line with previous research, we considered the study to be sufficient if they contained at least 4 h of usable data (at least 1 EEG lead, pulse oximeter, EOG, chin EMG intact/without significant artifact obscuring ability to score).[27]

Table 1—Demographics and duration of time to desensitization by success group.

	Successful PSG (n = 144)	Failed Desensitization (n = 17)	p
Gender			0.344
Male	103 (71.5%)	14 (82.4%)	
Female	41 (28.5%)	3 (17.6%)	
Diagnosis			0.100
ASD	80 (55.6%)	13 (76.5%)	
DD	20 (13.9%)	3 (17.6%)	
TD	44 (30.6%)	1 (5.9%)	
Age	11.5 years (4.24; 3.3–25)	8.55 years (4.39; 3.11–17)	0.018
Duration desensitization	9.44 (19.93; 0–189)	21.81 (25.61; 0–104)	0.024
IQ			0.070
< 80	39 (27.1%)	5 (29.4)	
80–120	54 (37.5%)	1 (5.9)	
> 120	14 (9.7%)	–	
Missing	37 (25.7%)	11 (64.7%)	

PSG, polysomnography; ASD, autism spectrum disorder; DD, developmental delay; TD, typically developing.

RESULTS

The sample consisted of 161 individuals who had agreed to participate in PSG. All were presented with the aforementioned desensitization protocol. Of the 161 children attempting PSG, 17 (10.6%) were unable to successfully wear the PSG equipment for > 4 h (**Table 1**).

First, a Chi-square analysis was performed to compare the frequency of success or failure by diagnosis (**Table 1**). There was no difference in the frequency of failed desensitization by diagnosis (χ^2 n = 161) = 4.6, p = 0.1) or sex (χ^2 n = 161) = 0.897, p = 0.344). However, there was an observed difference between success and failure with respect to age and the duration of desensitization. Those in whom desensitization had failed were on average 3 y younger than those who underwent a subsequent successful sleep assessment. As might be expected, those who ultimately failed to undergo the PSG assessment of sleep had significantly longer duration of desensitization.

Second, in order to examine the hypothesis that the duration of time required for desensitization varied by diagnostic category, analysis of variance was performed on all subjects for whom a successful PSG was completed in order to compare if the length of desensitization varied according to diagnostic group. There was a significant difference by diagnostic category (F (2, 157) = 8.995, p < 0.001). *Post hoc* analysis demonstrated that the difference was significant only between ASD and TD (**Table 2**). Specifically, subjects with ASD required an average of 16.08 d to successfully desensitize to PSG equipment, whereas subjects with DD required 8.04 d (mean difference 8.033, ASD versus DD, p = 0.084). However, TD subjects required an average of 0.98 days (mean difference 15.098, ASD versus TD, p < 0.001).

Table 2—Duration of desensitization by diagnostic group category.

	Total Group, age 3–25 years Mean (SD)	Group, age 3–21 years Mean (SD)
ASD	16.08 (24.932)	16.49 (25.530)
DD	8.04 (14.825)	5.65 (12.407)
TD	0.98 (2.874)	1.00 (2.812)

ASD, autism spectrum disorder; DD, developmental delay; TD, typically developing.

Our population did include individuals with ASD older than what is traditionally considered pediatric or transitional age youth range (age ≥ 22 y). When analysis of variance was performed excluding these individuals (n = 10), *post hoc* calculations demonstrated a difference between subjects with ASD and those with DD, as well as subjects with ASD and TD subjects (F (2, 148) = 9.44, p < 0.001), though it had no effect on the overall failure frequency (χ^2 n = 152) = 3.161, p = 0.206, data not shown). When those age ≥ 22 y were excluded, the average time for subjects with ASD to desensitize differed significantly from both subjects with DD (mean difference 10.844; p = 0.031) and TD subjects (mean difference 15.494; p < 0.001). Subjects with DD and TD were not different when individuals age 22 y or older were omitted (mean difference 4.650; p = 0.390; **Table 2**).

Third, we conducted exploratory analysis of the effect of individual characteristics on the duration of time required for desensitization. We selected characteristics that would be readily accessible to clinicians, including diagnosis, age, sex, and IQ (below average, average, above average). In addition, we included a measure of tactile sensitivity, which we thought might be predictive of duration of time to desensitization. Within each diagnostic group, no other variable significantly predicted the duration of desensitization for PSG.

DISCUSSION

The aforementioned methods describe the use of full ambulatory PSG in the observation of sleep in clinical pediatric populations with a neurodevelopmental disorder. Utilizing the novel desensitization protocol, we have successfully obtained 144 of 161 attempted PSGs on predominantly pediatric samples with ASD, DD, and typically developing control patients. As per our primary hypothesis, there was no difference in the ability to successfully obtain PSG by neurodevelopmental diagnosis.

As might be expected, the subjects with ASD took the longest to acclimate to the equipment, and had the highest rates of dropout due to inability to tolerate equipment. However, it is important to note that more than 86% of subjects with ASD were still able to undergo a successful desensitization process, i.e., the sensitization process resulted in a successful PSG. Similarly, in subjects with DD, 87% successfully obtained PSG. Our findings indicate that PSGs can indeed be successfully obtained from populations with neurodevelopmental

disorders, given sufficient time and appropriate procedures for the individual to become acclimated to the equipment. When older subjects (age > 22 y), were excluded, individuals with ASD took significantly longer than those with DD, as well as typically developing to become acclimated. Thus, type of disorder appears to be very important for predicting how long it will take for the sensitization process to lead to successful acquisition of PSG, and can assist others utilizing similar measures to anticipate how long a given individual may require to acclimate to the equipment.

It is important to understand that children are not just "little adults." Though the same criteria are used for adults and children for identifying sleep stages,[28] the American Academy of Sleep Medicine has guidelines that recognize the unique needs of pediatric subjects; they underscore that the application of sleep monitoring equipment must take into consideration the effect on the participant, as is developmentally appropriate for their age. Indeed, older age was associated with an increased success of obtaining a successful PSG following desensitization across all diagnostic groups. However, neither age, sex, nor IQ significantly predicted the duration of sensitization required for a successful PSG. Further, tactile symptoms so common in children with ASD also did not predict duration of sensitization.

As our results indicate, our research team has been successful at obtaining PSG in 144 children. Developmental disorders such as ASD and DD can present specific difficulties in the performance of any medical procedures. Even typically developing pediatric control patients can have elevated anxiety with the medical appearance of sleep equipment, which may be alleviated by recording in the home environment. Aware of this possibility, other researchers have similarly attempted to allow for some sort of adaptation to sleep equipment. For example, Stores et al.[29] described the results of home PSG in 60 children aged 5–16 y. Though this study utilized far less equipment than we used in the protocol described above (one EEG lead, EOG, chin EMG), the researchers applied the equipment in the afternoon with the intention of allowing the child time to acclimate.[29] However, other groups using ambulatory monitoring have not built in adaptation processes.[27,30–32] Although prior work has demonstrated the feasibility of the use of ambulatory PSG in children, only one other group has utilized full PSG, capturing all the data that would be available were the child to sleep in a sleep laboratory.[27] Further, although the previously mentioned studies demonstrate the acceptability of home PSG in typically developing children, here we demonstrate feasibility in children classically considered to have greater difficulty due to their neurodevelopmental disorder. Our work particularly underscores the importance of implementing sensitization processes, for sufficiently long durations that the child acclimates and a successful ambulatory PSG can be obtained. As such, the aforementioned suggestions may be useful not only in a research setting, but also in the attainment of clinically indicated sleep studies for a child with ASD or developmental delay.

Finally, as noted, there is a dearth of research on sleep in numerous pediatric neurodevelopmental disorders. Importantly, in contrast to seeking treatment for a clinical concern in which the children and parents are motivated to participate due to the direct benefit to them, there is typically reduced motivation to complete PSG studies for research purposes. As such, the methods used to collect data need to be the most tolerable that is possible. Systematic desensitization can help to achieve this goal.

Limitations of the current work include that due to our sample size we are underpowered to ensure there is no significant difference between individuals with ASD compared to the other groups in terms of success rate of the PSGs. Replication of this finding in future larger studies is required. Also, we note that not included in this analysis were 30 children whose parent(s) declined their participation without explanation, and 13 children whose parent(s) declined because they anticipated their child would not be able to tolerate the equipment. Because these families did not consent to participate, we have little information about the clinical context for each child, to compare to those who did participate. Unfortunately, we also did not have the opportunity to see if, with desensitization, these children could in fact acclimate to the equipment. Similarly, we do not know if the parents who chose to go through with the protocol perhaps had children who were somehow less sensitive to tactile stimuli.

We also note that the desensitization protocol does rely on the parents to encourage the child to practice the equipment, and some parents reported significant difficulty from the child with the equipment, but in this investigation we did not document the extent to which a parent encouraged their child or not. Thus, this too may have been a factor that mitigated against a successful PSG. We aim to address this issue in our future investigations. Further, a more gradual exposure with more prolonged adaptation time may have been helpful in these cases.

Overall, our procedures of using systematic desensitization to help acclimate the child to the equipment resulted in a highly successful completion of at-home PSG in a pediatric sample of 100 children with neurodevelopmental disorders, and 44 typical developing. PSG in pediatric research can provide valuable information to sleep researchers, as well as other researchers in the neurosciences, aiming to better characterize certain diseases. The described procedures may be of particular use to research assistants and technicians working with children or sensitive populations to improve the collection of data. Pediatric sleep researchers should consider greater use of ambulatory PSG in combination with a desensitization protocol to improve the experience of completing research protocols. In addition, sleep clinicians, evaluating and treating pediatric patients, may consider the application of such tools in the sleep laboratory.

ABBREVIATIONS

ADHD, attention deficit hyperactivity disorder
ASD, autism spectrum disorders
DD, developmental delay
EEG, electroencephalogram
EKG, electrocardiogram
EMG, electromyogram
EOG, electrooculogram

IQ, intelligence quotient
PSG, polysomnography
TD, typically developing

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Submitted for publication November, 2014
Submitted in final revised form October, 2015
Accepted for publication October, 2015
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DISCLOSURE STATEMENT

This was not an industry supported study. Dr. Hardan has recieved research support from Roche and has consulted for Integragen. The other authors have indicated no financial conflicts of interest.