ECUADORIAN JOURNAL OF PEDIATRICS
rev-sep.ec

ORIGINAL ARTICLE

Sleep disturbances in children with autism spectrum disorder and their personal and family affectation.A single-center observational studyin Mexico

Karla Denisse González Lara*[1], Nayeli Limón García[2], Martha Alejandra Maldo- nado Burgos[2], Erica Cervantes Aldaz[2], Jessica Yamile Cancino Rios[2], José Jesús Co- lón Pérez[2]

1 Specialty in Family Medicine, Postgraduate Studies Division, National Autonomous University of Mexico, Chihuahua, Mexico.

2 Regional Autism Center "Delicias," Family MedicineUnit No. 33, Mexican Social Security Institute, Chihuahua, Mexico.

Received: October 3; 2022
Accepted: November 27, 2022
Published: December 17, 2022
Editor: Dr. Francisco Xavier Jijón Letort.

Cite:
González K, Limón N, Maldonado M, Cervantes E, Cancino J, Colón J, Sleep disturbances in children with autism spectrum disorder and their personal and family affectation. A single-center observational study in Mexico. Ecuadorian Journal of Pediatrics 2022;23(3):20206.
DOI: https://doi.org/10.52011/77 e-ISSN: 27376494

Copyright González K, et al. This article is distributed under the terms of the Creative Commons CC BY-NC-SA 4.0 Attribution License, which permitsnon-commercial use and redistribution provided by the source and original author.

Abstract

Introduction: Sleep disorders in children impact development, affecting behavior, mood, and cognitive functions and decreasing selective attention and memory. This study aimed to determine sleep disturbances in children with autism spectrum disorder (ASD) and their individual and family involvement at theDelicias Chihuahua Regional Autism Center.

Methods: This cross-sectional studyincludedchildren with ASD in whom some sleep disturbance was determined, and its relationship with individual and family affectation was sought; in addition, age, sex, school grade, functional level of ASD, and family affectations were evaluated. The sleep screening questionnaire for children with ASD, the adapted questionnaire for children withASD -BRUNI, and the satisfaction questionnaire on the activities of parents, primary caregivers, and firs-tline family members were applied. Descriptive statisticswere used, and the prevalence odds ratio(MPR) was used in a second analysis.

Results: A total of 57 patients were analyzed; 43 (75.4%) were men, 28 (49.1%) were at the grade 1 ASD functionalevel, 16 (28.1%) had poor individual performance, 56 (98.2%) their relatives reported poor performance,and 43 (75.4%) had sleep disturbances. Preschool children have a 2.5 timeshigher risk of having individual involvement. Patients in functional level ASD grade 3 have a 2.15 timeshigher risk of having individual involvement. Those who wake up tired have a 5.93 timeshigher risk of having individual involvement.

* Corresponding author.

Email: dra.karlita.glz@gmail.com (Karla Denisse González Lara/)AddressAv. Melchor Ocampo s/n, El Palomar, 31204 Chihuahua, Chih., Mexico.

Telephone: [52] (614) 4164323

Conclusion: The family affectation of performance is muchgreater than the personal affectation of children with ASD, which generates changes in family dynamics.

Keywords: MESH: Night Terrors, Sleep Onset andMaintenance Disorders, Autistic Disorder, Cognitive Dysfunction

Introduction

American statistics mention that 1 in 68 children have an autism spectrum disorder (ASD) 1[]; in Mexico, in a 2016 report, it is mentioned that 1 in 115 children have some ASD [2]; this is estimated to bebecause there are more than 400,000 children with ASD in Mexico. Of these, a variable proportion between 40 and 80% present sleep disturbances, equivalent to 160,000 and 320,000 children. These figures are alarming, and although ASD is not preventable, the sleep disturbances that these children present do have a way ofbeing prevented and improved by intervening early to ensure that they have a better quality of life and, as well as their parents, primary caregivers, and families.

Children on the autism spectrum usually have other conditions in addition to this.Nevertheless, not all are visible or cared for since not all are considered at risk, or even some disorders that were not considered a condition, as was the case with sleep disturbance. Sometimes both parents and health personnel who care for patients with autism spectrum disorder pay more attention to alterations and conditions that affect the quality of life of these patients and prevent their integration into the communityat both the educational and social levels. They ignore that they overlooked the less palpable alterations,such as the case of sleep disturbances, which, although on some occasions the symptoms were frankly evident, on other occasions the parents no longer visualized the problems because they became part of the "normal" routine of the patient with an autism spectrum disorder. Over the years, parents have paid more attention, so much so that sleep disturbances are a frequent reason in the neuropediatric consultation of patients with anautism spectrum disorder. These sleep disturbances may have implications for how the patient behaves during the day, in their daily activities, or their reactions to changes in their routines when something unforeseen happens and may even affect the livesof the rest of the family and the primary caregivers of the patien.t Through timely detection and adequate intervention, we can more easily achieve the primary purpose in children with autism, which is a good quality of life with the greatest possible self-sufficiency.

Therefore, we pose the following research question: What sleep disorders in children with autism spectrum disorder and their personal and family affectation at the Delicias Chihuahua Regional Autism Center? To resolve this question, we conducted a cross sectional study in a regional reference center for children with ASD.

Materials and methods

Design of the investigation

This study is an observational, cross-sectional, prospective study.

Scenery

The study was conducted at the "Delicias" Regional Autism Center, Family Medicine Unit No. 33, Mexican Social Security Institute, Chihuahua, Mexico. The study period was from April 1, 2021, to April 30, 2022.

Inclusion criteria

Children diagnosed with autism spectrum disorder receiving treatment at the institution aged two to 17 years and 11 months were entered into the study. Patients whose parents did not want to participate in the research and did not consent to participate were excluded. Patients who could not complete all the questionnaires were removed from the study.

Study size

The population consisted of patients admitted to the institution who met the admission requirements. The sample calculation wasnonprobabilistic, with a census type of all possible cases.

Variables

The variables were sex, age, school grade, functional level of ASD, particular affectation (performance in therapy), family affectation (performance in daily daytime activities), and sleep disturbances.

Data sources/measurement

The data were collected through surveys. The database was coded with serial numbers, thus protecting the confidentiality of the information and identity of the patients. Sleep disturbances were measured with the ICSD-2 scale: Sleep Screening Questionnaire in Children with ASD and Sleep Habits Questionnaire in Children with the 33-item version, with thefollowing indicators: a) Insomnia, b) Parasomnias, c) Hypersomnias, d) Sleep disorder related to breathing (OSAS), e) Disorders of the circadian rhythm, and f) Disorders related to abnormal sleep movements.

Personal affectation was valued as the performance in the therapy with thefollowing indicators: a) good performance and b) poor performance. Family affectation was assessed with the daily activities performance scale, with the indicators a) good performance and b) poor performance.

The three levels of functioning of ASD were classified as the three levels of functioning of the

ASD-Grade 1-Mild

Symptoms that allow him to lead an autonomous life, although he sometimes needs help, have difficulties establishing social relationships, and often shows unusual reactions when interacting with others. Once he achieves social connections, hecan communicate and make himself understood. The child develops standard language and cognitive processes with a great capacity for memory, although they usually manifestaccentuated mental rigidity with ideas that borderobsessiveness. The childrenmanifest a reduced sphere of interests and activities, have difficulties in alternating activities, and present organization and planning problems.

ASD Grade 2

They are children with considerable difficulties in social, verbal, and nonverbal communication; they have problems initiating social interactions. They tend to respond in a "strange" way to interact and develop minimal language. They present repetitive behaviorsthat include motor stereotypes and mannerisms while isolating themselves from the world. They also find it challenging to face changes and have a significantly reduced system of activities and interests that interfere with their development in different contexts. It is usual for them to show some anxiety and resistance when they have to change the focus of their attention. If they receive help, they canperform some daily tasks independently.

ASD Grade 3-severe

These children have severe social, verbal, and nonverbal communication deficits, which interfere with their adjustment and interaction with others. They do not usually initiate social interactions and respond minimally to communicate with other people using unusual strategies. They usually only communicate directly with the closest people. They have a minimal vocabulary and often use unintelligible words, so people can hardly understand what they say. They also have a significant inability to express emotions and be empathetic. They have difficulty coping with minimal changes, and it is common for them to show inflexible behavior in different spheres of their daily life. They show stereotyped movements that interfere with their functioning in other contexts. They cannot live autonomously and independently.

Statistical method

In the initial phase, the data analysis is univariate, descriptive with frequencies and percentages, mean and standard deviation. In the second phase of the analysis, the risk factorswere calculated using the prevalence odds ratio (ORM) and their 95% confidence intervals. The statistical package SPSS v.25 (Armonk, NY: IBM Corp.) was used for the analysis.

Results

The study included 57 patients.

General characteristics

A total of 57 patients were studied, of which 43 (75.4%) were men, 22 (38.6%) were between 6 and 10 years old, with a median of 8 years, and 24 (42.1%) were in primary education.

A total of 28 cases (49.1%)were in grade 1 of the ASD functional level: 16 (28.1%) had poor individual performance, 98.2% of their relatives reported poor performance, 43 (75.4%) had sleep disturbances, 19 (33.3%) reported that they woke up tired, and 43 (75.4%) did not perform adequate sleep hygiene (Table 1).

Table 1.Characteristicsofpatients with Disorderof SpectrumAutistic of Center Regionalof AutismDelicias AC

Characteristic	Frequency no, (%)
Sex	
Female	14,(24.6)
Male	43,(75.4)
Age	
2to5 years	20,(35.1)
6 to10years	22,(38.6)
>10years	15,(26.3)
Degree School	
Nopeschooled	12(21.1%)
Preschool	12 (21.1%)
Primary	24,(42.1)
Secondary	3,(5.3)
Preparatory	6,(10.5
Level Functional of ASD	
Degree 1	28,(49.1)
Degree 2	16,(28.1)
Degree 3	13,(22.8)
Affectation Individual	
Good performance	41,(71.9)
Wrong performance	16,(28.1)
Affectation Familiar	
Good performance 1,(1.8)	
Wrong performance	56,(98.2)
Alterationsof sleep	
Yes	43,(75.4)
No	14,(24.6)
Wake	
Rested	38,(66.7)
Tired	19,(33.3)
Hygiene of the dream	
Adequate(= or> PC25)	14,(24.6)
Nope adequate (<PCs25)	43,(75.4)

Bivariate analysis

In the bivariate analysis (see Table 2), we found that men have 3% protection for not having individual involvement with intervals that go up to 3.69 times the risk of having individual involvement, and this association is not statistically significant.

Those over ten years of age have a 47% excess risk of having individual involvement with intervals that go up to 4.20 times the risk, and this association is not statistically significant. Preschool children have 2.5 times the risk of having individual involvement with intervals that go up to 16.89 times the risk, and this association is not statisticallysignificant. Patients in functional level ASD grade 3 have a 2.15 times risk of having individual involvement with intervals that go up to 50.41 times risk, this association not being statistically significant. Those who present sleep disturbances have a59% excess risk of having individual involvement with intervals that go up to 6.66 times the risk, and this association is not statistically significant.

Those who wake up tired have 5.93 times the risk of having individual involvement, with intervals that go up to 20.76 timesthe risk; this association is statistically significant. Children with inadequate sleep hygiene have a 60% protection to have individual involvement with intervals that go up to 44% of excess risk, this association not being statistically significant.

Discussion

In the present study, the number of children with autism who presented with sleep disorders was 75.4%, and the same percentage of children had inadequa te sleep hygiene. This percentage agrees with what was mentioned by Cortesi F et al., who mentioned that sleep disturbances in children with autism occur between 40% and 80% [3]. Even when there is sleep impairment in more than 75% of the children, only 28% report poor performance during their therapy, which tells us that most children with ASD manage to overcome the imbalance caused by their sleep disturbance. This difference in percentage makes us reflect on the importance of maintaining a stable routine such as the one carried out during therapies, which helps to carry out all of their activities despite not having had good rest during the previous night.

Despite having sleep disorders, only 33.3% of children perceived waking up tired; the rest perceived having rested well and being satisfied with their sleep. The percentage of children who reported poor performance during their therapies (28.1%) is very similar to the reported rate of those who mentioned having woken up tired (33.3%).

On the other hand, in the family member who is the primary caregiver, 98% of affectation was found in their performance during the day after the child with ASD had a stormy night. This difference of perceptio n shows that the affectation that sleep disturbances in children with ASD have on the family is much greater than on the child himself, or at least that is how the family member appreciates it.

Table 2. Analysis factors of risk associate a n affectation individualin patients with disorder ofSpectrum Autistic.

Characteristic	Affectationindividual Yes N°, (%)	No N°, (%)	PR	CI 95%	*P*
Sex					
Feminine	4,(25)	10,(24.4)	1		
Male	12,(75)	31,(75.6)	0.97	0.25 3.69	0.606
Age					
2 to 5 years	6,(37.5)	14,(34.1)	1.32	0.48 3.66	0.762
6 to 10years	5,(31.3)	17,(41.5)	1		
>10years	5,(31.3)	10,(24.4)	1.47	0.51 4.20	
Degree School					
Nopeschooled	3,(18.8)	9,(22.0)	1.5	0.20 11.54	0.797
Preschool	5,(31.3)	7,(17.1)	2.5	0.37 16.89	
Primary	6,(37.5)	18,(43.9)	1.5	0.22 10.22	
Secondary	1,(6.3)	2,(4.9)	2.0	0.18 22.06	
Preparatory	1,(6.3)	5,(12.2)	1		
Level Functionalof ASD					
Degree 1	6,(37.5)	22,(53.7)	1		
Degree 2	4,(25.0)	12,(29.3)	1.17	0.39 3.53	0.127
Degree 3	6,(37.5)	7,(17.1)	2.15	0.86 50.41	
Alterationsof sleep					
Yes	13,(81.3)	30,(73.2)	1.59	0.38 6.66	0.394
No	3,(18.8)	11,(26.8)	1		
Wake					
Rested	6,(37.5)	32,(78.0)	1		
Tired	10,(62.5)	9,(22.0)	5.93	1.69 20.76	0.004
Hygieneof the dream					
Adequate(= or> PC25)	6,(37.5)	8,(19.5)	1		
Nope adequate (<PCs25)	10,(62.5)	33,(80.5)	0.40	0.11 1.44	0.156

The significant affectation of parents can have several explanations, including that the adult caregiver has many more responsibilities to fulfill during the day and is aware of it. Therefore, physical and mental fatigue is generated, leading to poor performance during daytime activities.

Familiar affectation sets a guideline for assessing the extension of comprehensive care for the child with ASD to the family. Treatingpatients with ASD together with their family, who are in charge of most of the patient's time, should be a priority in the health system as a focus of family medicineto improve the quality of life of both the patient and his family and, therefore, the community in general. Ideally, every patient with autism should have the right and facility to have a comprehensive assessment of their primary caregiver, especially by psychology, and have a support group where the caregiver is trained, can listen to testimonials, and receive support both from material didactic as strategies to follow in the attention and care of their family member. Support networks made up of peers are just as important, that is, other primary caregivers with whom each member feels identified and committed, such as a club to socialize and interact that is available and reliable, whether organized by the health insttiution or making agreements with civil associations that are willing to offer this service.

This study was carried out only with questionnaire instruments and had the drawback of being subjective in the responses since they were given both by the children under study and their family caregivers and therapists.Nevertheless, it sets a pattern to be followed by future researchers to complement objective studies such as polysomnography, videosomnography, and others to compare the results and know how reliable it is only to use questionnaire instruments since they are the cheapest and easiest method to obtain. Future studies should consider using video and polysomnography to analyze the degrees of ASD.

Conclusions

The family affectation of performance is much greater than the personal affectation of children with ASD, which generates alterations in family dynamics.

Abbreviations

ASD: Autism spectrum disorder.

Supplementary information

No supplementary materials are declared.

Acknowledgments

We acknowledge and thank the patients, family members, and team members of the "Delicias" Regional Autism Center, Family Medicine Unit No. 33, Mexican Institute of Social Security, Chihuahua, Mexico, for their collaboration in this study.

Author contributions

Karla Denisse González Lara: Conceptualization, Data conservation, Acquisition of funds, Research, Resources, Software, Writing- original draft.
Nayeli Limón García: Conceptualization, Data conservation, Supervision, Acquisition of funds, Investigation, Resources, Writing: review and editing.
Martha Alejandra Maldonado Burgos: Conceptualization, Data conservation, Supervision, Acquisition of funds, Research, Resources.
Erica Cervantes Aldaz: Data curation, research, fundraising, supervision, methodology.
Jessica Yamile Cancino Rios: Conceptualization,data retention, supervision, methodology.
José Jesús Colón Pérez: Conceptualization, Data conservation, Supervision, Supervision, Methodology.
All authors read and approved the final version of the manuscript.

Financing

The authors financed the expenses incurred in the production of this research
The surveys did not constitute an additional cost to the patient or relatives.

Availability of data and materials

The data sets generated and analyzed during the current study are not publicly available due to participant confidentiality but are available through the corresponding author upon reasonable scholarly request.

Statements

Ethics committee approval and consent to participate

It was not required for an observational study.

Publication Consent

This does not apply to studies that do not publish MRI/CT/Rx images or physical examination photographs.

Conflicts of interest

The authors declare they have no conflicts of interest.

References

1. Christensen DL, Baio J, Van Naarden Braun K, Bilder D, Charles J, Constantino JN, et al.; Centers for Disease Control and Prevention (CDC). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years--Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. MMWR Surveil Summ. 2016 Apr 1;65(3):1-23. DOI: 10.15585/mmwr.ss6503a1. Erratum in: MMWR Morb Mortal Wkly Rep. 2016;65(15):404. Erratum in: MMWR Morb Mortal Wkly Rep. 2018 November 16;67(45):12.79 PMID: 27031587; PMCID: PMC7909709.
2. Fombonne E, Marcin C, Manero AC, Bruno R, Diaz C, Villalobos M, Ramsay K, Nealy B. Prevalence of Autism Spectrum Disorders in Guanajuato, Mexico: The Leon survey. J Autism Dev Disord. 2016 May;46(5):1669-85. DOI: 10.1007/s10803-016-2696-6. PMID: 26797939.
3. Cortesi F, Giannotti F, Ivanenko A, Johnson K. Sleep in children with autistic spectrum disorder. Sleep Med. 2010 Aug;11(7):659-64. DOI: 10.1016/j.sleep.2010.01.010. Epub 2010 July 4.PMID: 20605110

DOI: Digital Object Identifier PMID: PubMed Identifier SU: Short URL

Editor's Note

The Revista Ecuatoriana de Pediatría remains neutral regarding jurisdictional claims on published maps andinstitutional affiliations.