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ORIGINAL ARTICLE

Sleep quality in Down syndrome

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Abstract

Objective: To analyze the sleep quality of patients with Down Syndrome treated at a specialized outpatient clinic. **Methods:** Data collection was based on the Pittsburgh Sleep Quality Index, a specific tool for quickly and effectively analyzing sleep quality in a random sample of 70 patients between July 2022 and February 2023. As the PSQI is not valid for children under 10 years in Brazil, the common variables of the Childrens Sleep Habits Questionnaire (CSHQ)19 and PSQI-BR were considered in children to allow data analysis. Statistical analysis of the data was carried out using the R Core Team software. **Results** The average age of the 70 participants was 14.4 years old, with 50% male and 57.2% had poor sleep quality. The final scores had a mean of 4.92 (0 + 12). The perceived sleep quality was “good” or “very good” in 77.1%, and 42.9% started sleeping within 30 minutes. All had a sleep duration of at least 6 hours, and 91.4% had a sleep efficiency equal to or greater than 85%. 87.2% had some sleep disorder. The use of sleeping pills occurred in 12.9%, and 77.2% had daytime dysfunction. **Conclusion:** The majority (77.1%) judged their sleep quality to be good, but after a more detailed analysis of their sleep, it was observed that it was poor in 57.2%. It reinforces the longitudinal follow-up of this population in integral health for investigation and treatment.

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INTRODUCTION

Down syndrome (DS) is the most common chromosomal disorder in humans.^{1,2} An estimated 300,000 people with DS live in Brazil.³

DS comprises a set of physical, intellectual, and psychological conditions that vary from person to person. Typical facial signs, delayed global development, cognitive impairment, short stature, and other associated diseases may be present.^{1,2,4}

Sleep is crucial in maintaining homeostasis and physical, cognitive, and social development. Changes in its quality or quantity increase the risk of cardiovascular, metabolic, immune, and neurological disorders.⁴⁻⁸

In several studies, a high prevalence of sleep disorders⁹⁻¹¹ has been observed, with worsening sleep quality impairing the development of language, memory, and motor coordination, in addition to increased morbidity and mortality due to psychiatric, cardiovascular, and neurological disorders.^{9,12-16}

Due to the changes in craniofacial and oral muscles associated with DS, individuals with the condition are particularly prone to obstructive sleep apnea (OSA), which can occur in more than 50% of cases.⁹⁻¹¹ Children with DS have a different sleep architecture compared to children without DS, with differences sustaining throughout adolescence and early adulthood, including alterations in REM sleep, fragmented sleep, staying awake longer before falling asleep, and having lower sleep efficiency.⁹⁻¹¹

Sleep quality plays a significant role in predicting health and quality of life issues. People with DS are at increased risk of several diseases that can be aggravated by poor sleep quality. Therefore, sleep is a required subject in medical consultations.¹⁰

This study analyzes the sleep quality of patients treated at the Down Syndrome Outpatient Clinic of CHC-UFPR based on the Pittsburgh Sleep Quality Index (PSQI-BR) questionnaire.¹⁷

MATERIALS AND METHODS

This cross-sectional, observational, and descriptive study included patients seen at the Down Syndrome Outpatient Clinic of the Hospital Care Complex of the Federal University of Paraná (CHC-UFPR). Patients and their legal guardians were asked to answer the PSQI-BR questionnaire. Statistical analysis was performed on software package R (R Core Team, 2022) version 4.2.1. Sleep has been thoroughly explored in the interviews conducted at CHC-UFPR. The PSQI-BR developed by Buysse¹⁷ assesses sleep quality through a standardized questionnaire that is easy to understand and answer, differentiating between “good sleepers” and “poor sleepers” during one month. The Brazilian Portuguese version of the questionnaire has been validated for adults and adolescents aged 10 years and older.¹⁸ Since it was not validated for children under 10 in Brazil, common variables from the Children’s Sleep Habits Questionnaire (CSHQ)¹⁹ and the PSQI-BR were included in the dataset. Thus, a quantitative assessment was made possible in 70 patients aged five years and older, randomly selected from the patients with scheduled appointments between July 21, 2022, and February 9, 2023.

The variables consisted of the total score, sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disorders, use of sleep medication, and daytime dysfunction due to sleepiness (Table 1).

The study’s inclusion criteria were having DS, being a patient at the Down Syndrome Outpatient Clinic CHC-UFPR, and being 5 years or older.

The variables were expressed as means, standard deviations, and absolute and relative frequencies.

The study followed the standards of Resolution 510/2016 on Research with Human Beings. Special attention was paid to vulnerable individuals. Informed consent was optional since the study used information from patient medical records. The Human Research Ethics Committee of CHC-UFPR approved the study and granted it a Certificate of Presentation for Ethical Assessment (CAAE) nº 13011113.0.0000.0096.

Table 1. Study variables gathered from the responses in the pittsburgh sleep quality index (psqi-br).

Variables	Score 0	Score 1	Score 2	Score 3
Sleep quality	Very good	Fairly good	Fairly bad	Very bad
Sleep latency	< or =15 minutes	16 to 30 minutes	31 to 60 minutes	60+ minutes
Sleep duration	>7h	6-7h	5-6h	Less than 5 hours
Sleep efficiency	More than 85%	75-84%	65-74%	Less than 65%
Sleep disturbance	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
Sleep medication	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
Daytime dysfunction due to sleepiness	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
Total score	Good 0-4	Bad 5-10	Slee disturbances More than 10	

SOURCE: The author (2023).

RESULTS

Seventy patients, half male, and half female were included in the study. Their ages ranged from 5 to 51, with an average of 14.4. Table 2 shows the results of the data collected based on the PSQI-BR.

Study participants using sleeping medication (12.9%) had a medical prescription, and 10% took it daily at night, including risperidone 1 mg, amitriptyline 25 mg, and periciazine five drops.

Table 2. Data extracted from the pittsburgh sleep quality index (psqi-br) questionnaires of 70 patients seen at the chc-ufpr down syndrome outpatient clinic (2022-2023)

		n=70	%
Females		35	50
Males		35	50
Ages 5 to 9 years		25	35,7
10 to 19 years		25	35,7
20 to 51 years		20	28,6
Final score	Mean		4.92 (0 + 12)
	Mode		5 (24.2%)
Sleep quality	Good	30	42.8
	Bad	37	53
	Slee disturbance	3	4.2
Subjective sleep quality	Very good	36	51.4
	Good	15	21.4
	Bad	1	1.4
Sleep latency	< or = 15 minutes	40	57.1
	31 to 60 minutes	21	30
	16 to 30 minutes	5	7.1
Sleep duration	8 to 12 hours	67	95.7
	6 to 7 hours	3	4.3
Sleep efficiency	> 85% of the time	64	91.4
	75 – 84% of the time	6	7.6
Sleep disturbances	Less than once a week	47	67.2
	None	9	12.8
	Once or twice a week	1	1.4
Sleep medication	None	61	87.1
	Daily use	7	10
	Once or twice a week	2	2.9
Daytime dysfunction	More than once a week	25	35.8
	None	16	22.8
	Three or more times a week	15	21.4
	Once or twice a week	14	20

Fonte: O autor (2023).

DISCUSSION

We found a high prevalence (57.2%) of poor sleep quality among people with DS, as reported in other studies.^{10,16,20}

More than half (53%) of the participants reported having poor sleep quality, and 4.2% experienced sleep disturbances, which indicates the urgent need to offer them sleep treatment.²¹

More than three-quarters (77.1%) of the respondents rated the perceived sleep quality, a self-reported qualitative indicator, as good or very good. Patients and guardians tend to overestimate patient sleep quality, making this a less sensitive indicator in investigating sleep disorders. The same phenomenon occurs in children with typical development and children with DS.¹⁵

Polysomnography, a gold-standard diagnostic test, must be used to diagnose sleep disorders. Adequate treatment minimizes adverse impacts on the memory of children with DS.¹⁵

Scores above 1 in sleep latency indicate issues. Increased time to fall asleep was observed in 35.8% of cases, causing lower sleep efficiency. This may be directly related to watching screens before bedtime, a habit mentioned by some participants that has adversely affected sleep latency.²²

Sleep duration is calculated by subtracting sleep latency from the total time spent in bed. Regarding sleep duration, all participants reported that they slept at least six hours per night, with the majority sleeping between eight and 12 hours per night. It is one of the main factors in the perception of sleep quality,²³ which might explain the perceived quality of sleep.

Sleep efficiency is the ratio between sleep time and total time spent in bed. Most (94.1%) participants were rated as having good sleep efficiency. This indicates that longer latencies are related to longer sleep durations as a compensatory mechanism.²⁴ Only 12.8% of participants did not experience any sleep disturbances. These disturbances are related to external factors, such as temperature and noise, and personal factors, including respiratory conditions (difficulty breathing, snoring, and apnea), urinary and bowel habits, pain, and nightmares. The high incidence observed may be related to diseases associated with Down syndrome, such as obstructive sleep apnea, craniofacial disorders, endocrine diseases, and obesity.^{25,26}

Detected in 77.2% of the patients, daytime dysfunction from sleepiness includes drowsiness, mood, and cognitive changes. This serves as an indication of non-restorative sleep of insufficient sleep quality or quantity. These dysfunctions directly affect the quality of life, reducing school and work performance and adversely impacting social relationships.^{27,28}

Sleep is a health determinant directly related to global development and disease risk in various organs and systems. Our results were supported by other publications,

reinforcing the importance of assessing and treating the sleep of individuals with DS proactively.¹⁰

Most (77.1%) participants rated their sleep quality as good, although a more detailed analysis revealed that it was poor in 57.2% of the cases. This reinforces the need to monitor them longitudinally and comprehensively to investigate and treat conditions (overweight, obesity, psychiatric disorders, facial and orthodontic changes, allergic rhinitis, adenotonsillar hypertrophy, sleep disorders, among others)²⁶ with a positive impact on global development, reducing the risk of metabolic, cardiovascular and neurodegenerative diseases commonly seen in DS, and improving quality of life.

Our study's limitations include the subjective views of patients and guardians and the wide age variation of our population. Efforts should be made to make studies based on more objective, reliable data gathered with portable equipment or smartphone applications used at the participants' homes during sleep.

The institution where this study was conducted has operated since 1997 and provides longitudinal monitoring with a comprehensive health approach and family guidance. The team includes two to three pediatricians, three dentists, specialists from the university hospital, and an active otorhinolaryngology service.²⁹ Children are referred for treatment in facilities close to their homes and advised to attend school regularly. The goal is to improve muscle tone, individual autonomy, development, and inclusion, as well as encourage self-determination and the adoption of an active lifestyle to prevent overweight and obesity.³⁰ Differences are apparent between patients from the general population who are not monitored, populations described in older publications, and the subjects included in this study.

In Brazil, more than 100 people with DS have attained higher education degrees and worked in various sectors. The possibilities of individuals with DS are amplified when sleep is cared for seriously to improve quality of life.

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