

Program to Support Child Sleep from the Occupational Therapy Perspective during the COVID-19 pandemic

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ABSTRACT

Introduction. Here we describe the interim results of the Program to Support Child Sleep from the Occupational Therapy Perspective (Programa de Acompañamiento al Sueño en la Infancia desde Terapia Ocupacional, PASITO) for children with neurodevelopmental disorders (NDDs) aged 3–10 years with insomnia, conducted between June 2020 and September 2021.

Population and methods. Pre- and post-intervention quasi-experiment in an intervention group and a control group using the Sleep Habits Questionnaire (SHQ) and the Consensus Sleep Diary (CSD).

Results. A total of 22 children with NDDs participated, 8 in the control group. The overall SHQ score for the intervention group improved ($p < 0.001$) from 54.9 (SD: 5.5) to 48.4 (SD: 4.5) and moved closer to the reference range of 42.6 (SD: 4.9). The CSD showed an increased sleep duration, earlier sleep onset, and fewer night wakings.

Conclusion. These interim favorable results demonstrate that the PASITO may be a possible intervention to manage sleep problems in children with NDDs.

Keywords: sleep; neurodevelopmental disorders; autism; occupational therapy; pediatrics.

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INTRODUCTION

Sleep problems have an effect on childhood growth and development.¹ Between 50% and 95% of children with autism spectrum disorder (ASD) report sleep problems, often insomnia.² The COVID-19 pandemic³ has caused a significant increase in these problems.⁴ People with neurodevelopmental disorders (NDDs), and specifically those with ASD, were among those affected the most in terms of mental health and well-being.⁵ A study revealed increased irritability, aggressiveness, wandering, anxiety, and feeding and sleeping difficulties in people with ASD in Latin America.⁶ Another study conducted in Argentina described a 55% prevalence of sleep problems in children with NDDs.⁷

The pandemic caused an extensive occupational disruption⁸ because it affected the activities that give meaning and occupational identity to daily activities, that give a sense of belonging to a context and of transcendence in life.⁹ In the face of such disruption, occupational therapy emphasized the need to care for oneself and others based on individual strengths, favoring pleasant experiences, promoting a sense of belonging in routines and rituals, and fostering daily organization and balance.¹⁰

Under these premises, the Program to Support Child Sleep from the Occupational Therapy Perspective (Programa de Acompañamiento al Sueño en la Infancia desde Terapia Ocupacional, PASITO) was designed for and implemented in children with NDDs and persistent difficulty in the onset, maintenance, or quality of sleep. The program was carried out by Panaacea between June 2020 and September 2021. The intervention is based on the occupational right to sleep¹¹ of children with NDDs and their caregivers, which implies the right to participate, to the development of potential, and to full satisfaction, according to their culture and beliefs, to receive support when perceived as necessary, and the right to equal access to sleep as an occupation.

This article describes the interim program results by assessing the changes in sleep referred by the parents of children with NDDs based on the results of the Sleep Habits Questionnaire (SHQ)¹² and the Consensus Sleep Diary (CSD)¹³ following the PASITO intervention.

POPULATION AND METHODS

A quantitative, quasi-experimental pre- and post-intervention approach was implemented in an intervention group and a control group, made up

of children with NDDs who, having completed the intervention quota, were enrolled on a waiting list.

Participants were children aged 3 to 10 years who had NDDs and insomnia and were admitted to the PASITO program carried out by Panaacea. The sample was selected by convenience including children with NDDs and at least a primary caregiver. Inclusion criteria were confirmed using an online questionnaire. Children had a diagnosis of neurodevelopmental disorder based on the DSM-5 diagnostic classification,¹⁴ had a primary care physician, and had sleep problems consistent with insomnia as assessed by their physician: sleep onset delay, sleep maintenance issues and/or very early waking resulting in non-restorative sleep for at least the past month, and impact on daily functioning. The program exclusion criteria were acute febrile or respiratory symptoms, changes or initiation of medication that affected sleep, neurodegenerative diseases, or underlying evolutionary diseases.

The intervention was disseminated to the general public and health care providers using Panaacea's social media.

The intervention principles and objectives were based on the essential characteristics of sleep as an occupation¹¹ and those proposed by Hammel,⁸ promoting the implementation of adaptive and maladaptive strategies⁹ and sleep hygiene strategies,¹⁵ adapted to the strengths, difficulties, and interests of each child with NDDs and their primary caregivers. This was a remote, intensive, and individualized intervention coordinated by 2 occupational therapists and mediated by parents. The objectives and strategies are described in *Table 1* and were, in order of priority, caregiver care, pleasant experiences, daily organization, routines and rituals, and rest.

For study inclusion, once the inclusion criteria were verified, intervention groups of up to 4 children with NDDs and their caregivers were established for each intervention cycle. For these groups, an initial video call communication was made, during which the inclusion criteria were confirmed and the informed consent was obtained.

The initial assessment consisted in completing a sociodemographic questionnaire (SQ), the Sleep Habits Questionnaire (SHQ),¹³ and the children CSD¹⁴ on the first 3 days.

On day 4 or 5, an open assessment interview was conducted with each family at an agreed upon time (60 minutes), during which the difficulties and strengths of children with NDDs

TABLE 1. Program objectives and priority order

Priority	Topic	Program objective	Main strategies	Examples
1	Caregiver care	Introduce sleep care strategies for caregivers.	Adaptive: -Encourage commitment to self-care in daytime rest and sleep. -Promote the development or reactivation of support networks. Maladaptive: Promote the change of caregivers' harmful beliefs and/or habits, which result in difficulties in their own sleep.	Ask for specific help to family and friends to generate rest and sleep opportunities for caregivers. Provide scientific information about the effects of poor sleep on empathy and socialization among adults.
2	Everyday pleasant experiences	Favor everyday pleasant experiences during the day imprinting them with meaning and purpose.	Adaptive: Adopt new pleasant and meaningful occupations, based on the assessment of the specific strengths, challenges, sensory profile, and interests of children with NDDs and their primary caregivers. Maladaptive: Promote the classification of difficulties in the performance of daily activities of children with NDDs and their parents, in order to reduce stress.	Create games adapted for children with NDDs and family members that are pleasant and allow for increased exposure to natural light during the day. Adjust and/or adapt activities, for example, tooth brushing, which, given the individual characteristics of children with NDDs and their caregivers, may cause discomfort.
3	Everyday organization in terms of time and space	Promote, among adults, strategies to take care of their children's sleep, based on the synchronization and planning of daily family occupations.	Adaptive: Maintain and/or structure the organization of daily occupations. Maladaptive: Avoid the sustained irregularity or disorganization in the time assigned to daily occupations.	Establish a certain consistency in schedules, delimiting the space, time, and order of daily activities, especially those related to sleep. Provide strategies for time-space restructuring of activities on days when children with NDDs show a greater behavioral difficulty.
4	Sleep routines and rituals	Encourage sleep routines and rituals based on the specific strengths, challenges, sensory profile, and interests of children with NDDs, that provide a sense of belonging to the family culture.	Adaptive: Promote the development or readjustment of family sleep routines and rituals that convey a message of care and belonging to the family structure. Maladaptive: Avoid tasks and adaptation of sleeping areas that are not conducive to sleep and that are not related to the family culture.	Recreate the sleeping area, based on the rituals practiced in each family's culture. Redesign sleeping areas that have elements harmful to this occupation (e.g., colored lights) and that are inconsistent with the family culture (e.g., giving a massage in a family that prioritizes oral tradition).
5	Daily breaks	Encourage scheduled breaks during the day (differentiated from sleep) and significant moments as part of the family dynamics.	Adaptive: Promote the time-space structuring of breaks during the day, with activities based on each child and their family culture. Maladaptive: Avoid a burden of activities that cause stress during the day and do not allow for a break.	Provide strategies for pleasant time-space scheduled breaks during the day, both for children with NDDs and their caregivers. Regulate screen use, especially for school tasks in children with NDDs and for work tasks in adults.

and their caregivers in relation to sleep and daily functioning were inquired.

On day 6, and to initiate the intervention, a 3.5-hour problem-based learning workshop was carried out,¹⁶ in which all caregivers participated. The workshop described adaptive and maladaptive strategies⁹ of daily life in relation to sleep, according to the program objectives (*Table 1*), and facilitated the identification and analysis of these strategies: when and why they occur, relationship with daily functioning, risk of maladaptive behaviors, and impact on family dynamics. After a break, a problem-based learning dynamic process¹⁶ was explained, including examples of hypothetical sleep situations, for brainstorming and developing possible solutions. This strategy involves education focused on the caregivers' learning process, based on the joint experience of solving everyday problems, integrating information from their own knowledge. At the end, caregivers were asked to design a strategy for the next day to start the intervention. The strategies for each session were developed together with the caregivers, prioritizing the proposed objectives. These strategies were followed-up on the following days.

Day 7 corresponded to a rest day. From day 8 to 12, daily 45-minute sessions were held with each family at an agreed upon time.

Days 13 and 14 corresponded to rest days. On days 15, 16, and 17, a re-assessment was performed, where each family completed the SHQ and the CSD again for 3 consecutive days. On days 18 or 19, a final re-assessment interview was conducted with each family to identify the strengths and difficulties perceived throughout the intervention and its results. The following week, a final report was delivered.

During the inclusion in each intervention cycle, when the maximum quota of 4 families was completed, a waiting list group was established that served as a control group. The latter completed the assessment and re-assessment questionnaires at the same time as the intervention group (SQ, SHQ, and CSD). Between the assessment and the re-assessment, the control group did not receive any intervention, but started it immediately after the intervention group completed the cycle in that period. Families who did not meet the inclusion criteria were offered a private interview.

All data were analyzed using *ad-hoc* Python software programs.

The study was approved by the Research

and Bioethics Committee of Hospital Interzonal de Agudos Eva Perón. Families were invited to participate in a therapeutic intervention and then to participate in a study on the proposed intervention. Prior to the assessment, an informed consent was provided to be signed online, although the signature did not condition participation and/or continuation in the intervention. All children with NDDs admitted received the intervention and were free to withdraw from the study at any time without this affecting the intervention. The program was fee-based. Grants were offered to those who wanted to participate in the intervention and gave their consent to participate in the study, regardless of whether or not they could pay the fee.

RESULTS

A total of 10 intervention cycles were conducted between June 2020 and September 2021. The intervention group was made up of 22 children with NDDs, whereas the control group included 8 children, of whom 7 received treatment and 1, for family reasons, had to be assisted individually by one of the therapists, outside the program. The sociodemographic characteristics of children and their caregivers are described in *Table 2*.

Table 3 details the SHQ results, for the overall score and the sub-scales pre- and post-intervention in both groups. It also shows the results of the one-sample Wilcoxon signed rank test, obtained using the Python SciPy package.

The overall SHQ score for the intervention group improved ($p < 0.001$) from 54.9 (SD: 5.5) to 48.4 (SD: 4.5) and close to the reference range of 42.6 (SD: 4.9).¹² All sub-scales, except daytime sleepiness, improved with the intervention. Although the control group appeared to have not experienced any improvement, its limited size ($n = 8$) does not allow to establish a statistically significant result regarding this group in this interim study.

Bedtime and sleep onset observed in the SQ were moved earlier in the intervention group ($p < 0.002$), reducing sleep latency (period between bedtime and sleep onset) and making it less variable. Dispersion at wake-up time was reduced. Total sleep duration in the intervention group increased ($p < 0.001$); in average, it changed from 8:50 to 9:40 hours. Among these, children with NDDs aged 3 to 5 years showed an average improvement from 9:00 to 9:50 hours, whereas older children, from 8:20 to 9:20 hours, close to and reaching

TABLE 2. Sociodemographic characteristics of children and their caregivers based on the sociodemographic questionnaire

Parameters	Intervention (n = 22)	Control (n = 8)
Age of children		
3 to 5 years	14	6
Diagnosis		
Autism spectrum disorder	19	7
Autism spectrum disorder/epilepsy	2	0
Overall developmental delay	1	1
Prior medical assessment in relation to sleep		
Yes	22	8
Therapies at the time of intervention		
Online	7	3
In person	6	2
Hybrid	4	1
None	5	2
Medication for sleep problems		
Yes	8	2
Age of caregivers (n = 38*)		
30–34 years	4	3
35–39 years	14	4
40–44 years	9	2
45–50 years	1	0
50–55 years	1	0
Level of education of caregivers (n = 38*)		
Complete secondary education	3	1
Incomplete tertiary education	2	0
Complete tertiary education	3	3
Incomplete university education	2	2
Complete university education	13	2
Complete post-graduate education	6	1

*29 from the intervention group and 9 from the control group. n: number.

the recommended duration,¹⁷ respectively. The frequency of night wakings in the children with NDDs in the intervention group reduced by 45% ($p = 0.025$). No improvements were observed in the control group; its small size did not allow us to establish whether the absence of changes was statistically significant.

DISCUSSION

The COVID-19 pandemic increased the prevalence of sleep disorders in the world population, with a limited intervention offer.¹⁸ Children with NDDs and their parents were significantly affected.¹⁹

This preliminary study describes how the PASITO program achieved an improvement in the sleep of a group of children with NDDs aged 3 to 10 years. The improvement in the SHQ overall score is comparable to a similar study in children with NDDs.⁷

After the intervention, the sleep of children with NDDs became more regular, with a slight increase in duration and an earlier onset; the latter improved the chronotype mismatch. Such mismatch, observed in our population before the intervention, was similar to that observed in the entire Argentine population during the pandemic.²⁰ The intervention was more effective in relation to sleep duration in children aged 6 to 10 years, compared to the recommended duration parameter for each age group.¹⁷ A significant decrease in night wakings was also achieved in most of the sample.

The program responds to the growing demand for care to meet specific needs, based on an approach focused on neurodiversity,²¹ quality of life, participation, and occupational rights.²² We consider sleep an essential occupation that, when affected in children, puts at risk the caregiving capacity of primary caregivers, who

TABLE 3. Mean and standard deviation values for the overall score and the sub-scales of the Sleep Habits Questionnaire administered to children pre- and post-intervention

Variable		Group	Pre-intervention		Post-intervention		Wilcoxon test Wilcoxon (hypothesis test: improved score):	Possible range*
			Average	SD	Average	SD	p	
Overall score*		Intervention (n = 22)	54.95	5.57	48.41	4.50	< 0.001	33-99
		Control (n = 8)	52.62	4.14	54.38	4.37	0.09	
Sub-scale	Bedtime resistance	Intervention	14.32	2.40	12.27	1.93	< 0.001	8-24
		Control	14.12	1.96	14.50	2.00	0.22	
	Sleep onset	Intervention	2.41	0.73	1.64	0.66	< 0.001	1-3
		Control	2.62	0.52	2.88	0.35	0.08	
	Sleep duration	Intervention	6.09	1.74	4.27	1.45	< 0.001	3-9
		Control	4.75	1.28	4.75	1.04	0.50	
	Sleep anxiety	Intervention	8.09	1.80	7.59	1.92	0.044	4-12
		Control	7.62	1.85	7.88	1.13	0.24	
	Night wakings	Intervention	5.91	1.90	4.77	1.45	< 0.001	3-9
		Control	5.25	2.49	5.50	2.39	0.30	
	Daytime sleepiness	Intervention	13.27	2.45	13.45	1.57	0.74	8-24
		Control	14.25	2.49	14.38	2.88	0.35	

n: number.

SD: standard deviation.

The reference value for the overall score is 42.6 (SD: 4.9).¹²

* A lower value means a lower sleep difficulty.

often report fatigue and the need for support during interventions.²³ In this regard, the approach should contemplate not only modifying the daily tasks, as proposed by the sleep hygiene model,¹⁵ but should prioritize a caregiver care perspective,²⁴ daily pleasant activities,²⁵ and changes in sleep routines and rituals considering the family's strengths and difficulties.

The strengths of this study are its customized intervention, which provided caregivers with problem-solving strategies, and the design of a remote intervention that may be replicated in a larger population without the need for relocation.

The limitations of this study include the fact that no objective measures were used, such as an actigraphy. However, the results obtained from the instruments used provide information on similar parameters, showing a favorable course after the intervention. Another limitation was that the Sleep Habits Questionnaire has not been validated in the Argentine population. The limited number of participants, recruited through dissemination via Panaacea's social media, does not warrant that the sample is representative of the general population. Moreover, the requirement

of hourly availability by caregivers and Internet connection may imply a bias in terms of families having a high income level compatible with parents' level of education, as observed in the SQ. The small size of the control group made it impossible to compare its course with that of the intervention group with a high level of confidence.

However, since this is an interim study, the results obtained in the intervention group, although provisional, are encouraging to continue the program to the next phase by increasing the number of patients. The contribution of occupational therapy points to a possible approach for children with NDDs and their families, in whom sleep problems jeopardize their quality of life, participation, and occupational rights. ■

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