Children's Sleep Habits Prior, During, and After Active OMAS: An Initial Analysis

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Eleventh International Workshop on Opsoclonus Myoclonus Ataxia Syndrome

omslifefoundation.org

Introducing the Team

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Purpose of the study

- Sleep and behavior issues are two well known issues associated with OMAS
- OMAS focus has been primarily on stabilizing the symptoms
- Specific studies on sleep are limited
- Changes in sleep behavior may persist after a patient is in remission

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Method for developing the study

Compared Four Existing Surveys

- CSHQ – Children's Sleep Habits Questionnaire
- PSQI – Pittsburgh Sleep Quality Index
- CSDI – Composite Sleep Disturbance Index
- ESS – Stanford Sleep Study

Decided on abbreviated CSHQ

- Excludes questions not relevant to study population (original CSHQ is for children over age 4, most active OMAS patients are younger).
- Reduces participant fatigue by shortening survey

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The Human Aspect

The importance of this study came to light in a pilot test, in which we asked 15 caregivers to test 3 surveys. In handwritten notes in the margins of the pages, caregivers wanted us to know:

- Specific details about their children not covered by any of the surveys
- The emotional toll on the patients from sleep difficulties
- Remedies/therapies that were helpful
- Above all, the desire to share the information given to help others in similar situations

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Subgroups

1 Bedtime Resistance

Goes to bed at same time

Falls asleep in own bed

Falls asleep in other's bed

Needs parent in room to sleep

~~Struggles at bedtime~~

~~Afraid of sleeping alone~~

2 Sleep Onset Delay

Falls asleep within 20 mins

3 Sleep Duration

~~Sleeps too little~~

~~Sleeps the right amount~~

Sleeps same amount each day

4 Sleep Anxiety

Needs parent in room to sleep

Afraid of sleeping in the dark

~~Afraid of sleeping alone~~

~~Trouble sleeping away~~

5 Night Wakings

Moves to other's bed in night

Awakes once during night

Awakes more than once

6 Parasomnias

~~Wets the bed at night~~

~~Talks during sleep~~

Restless and moves a lot

~~Sleepwalks~~

Grinds teeth during sleep

Awakens screaming, sweating

~~Alarmed by scary dream~~

7 Sleep Disordered Breathing

Snores loudly

~~Stops breathing~~

~~Snorts and gasps~~

8 Daytime Sleepiness

Wakes by himself

~~Wakes up in negative mood~~

~~Others wake child~~

~~Hard time getting out of bed~~

~~Takes long time to be alert~~

~~Seems tired~~

~~Watching TV~~

~~Riding in car~~

*bolded questions appear on both original and abbreviated CSHQ

<u>Scale</u>

0 (Never)

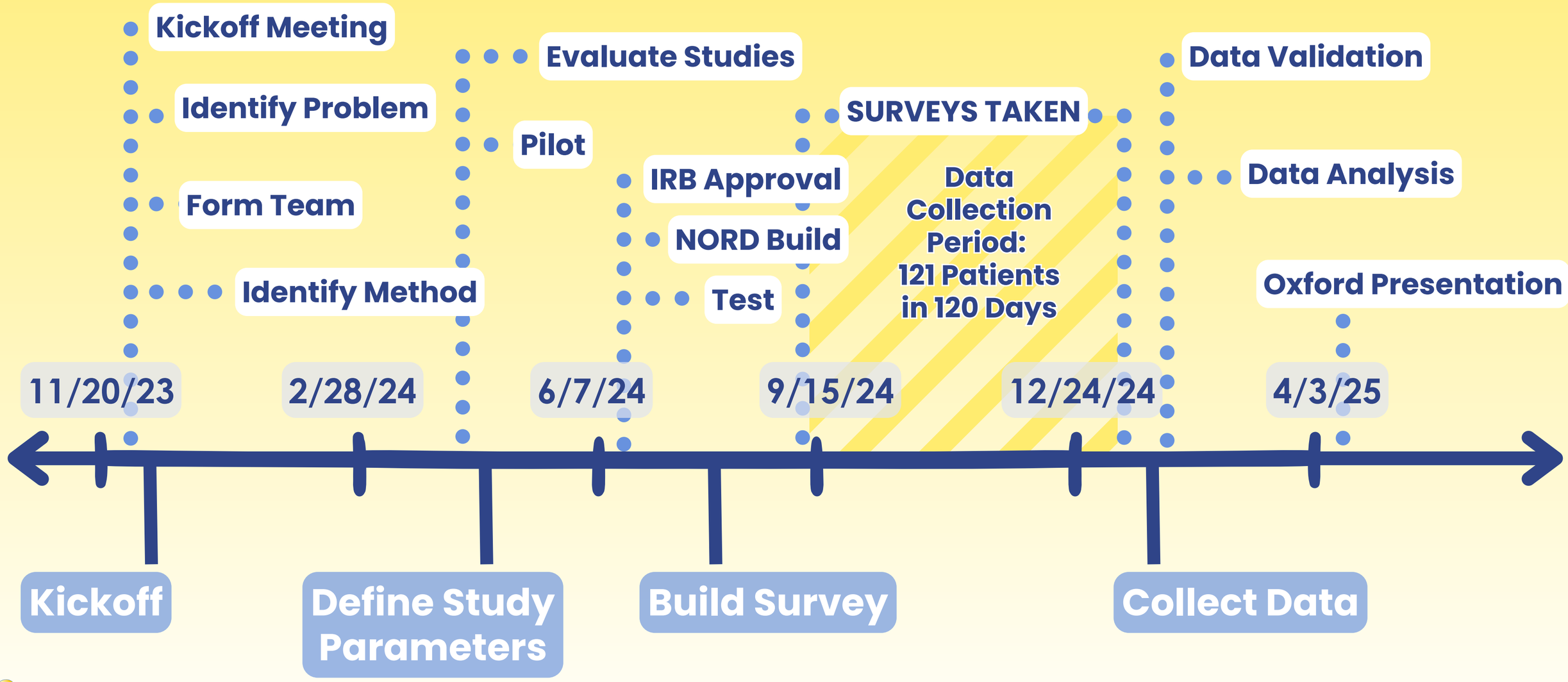
1 (Rarely)

2 (Sometimes)

3 (Often)

4 (Always)

200 Days from Fielding to Data Presentation



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OMAS Sleep Study Timeline

Analyzing the Data

We first asked: Is the patient currently in active OMAS or in remission?

If a patient was currently in **active OMAS**, we asked the participant to answer each question for the average week **twice**, once each for

Before

and

During

active OMAS.

If a patient was currently in **remission**, we asked the participant to answer each question for the average week **three times**, once each for

Before,

During,

and

After

active OMAS.

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Results Summary

Caregivers of 121 children with active (n=28) or in remission (n=93) OMAS

domain	question	Overall[1]	Pre to During[2]	During to Post[2]	Pre to Post[2]	Pre (n)	During (n)	Post (n)
1: bedtime resistance	Child falls asleep in own bed.	0.001	0.001	0.001	**0.161**	116	119	93
1: bedtime resistance	Child goes to bed same time at night.	0.001	0.001	0.001	**0.540**	114	118	92
1: bedtime resistance	Child falls asleep in parent's/sibling's bed.	0.001	0.001	0.001	**0.080**	113	117	90
1: bedtime resistance	Child needs parent in room to fall asleep.	0.001	0.001	0.001	0.001	113	117	91
2: sleep onset delay	Child falls asleep within 20 min.	0.001	0.001	0.001	**0.052**	116	120	93
3: sleep duration	Child sleeps same amount each day.	0.001	0.001	0.001	**0.404**	115	120	93
4: sleep anxiety	Child afraid to sleep in dark.	0.001	0.001	0.004	**0.368**	109	111	91
5: night wakings	Child wakes once each night.	0.001	0.001	0.001	**0.063**	116	118	93
5: night wakings	Child moves to different bed at night.	0.001	0.001	0.001	**0.951**	105	110	89
5: night wakings	Child wakes more than once at night.	0.001	0.001	0.001	0.027	115	119	92
6: Parasomnias	Child has restless sleep.	0.001	0.001	0.001	0.034	112	116	90
6: Parasomnias	Child grinds teeth while sleeping.	0.001	0.001	**0.188**	0.002	95	109	90
6: Parasomnias	Child wakes upset.	0.001	0.001	0.001	**0.902**	115	119	92
7: Disordered breathing	Child snores.	0.005	0.001	**0.351**	0.038	113	117	93
8: daytime sleepiness	Child self-wakes	**0.317**	**0.644**	**0.135**	**0.291**	118	120	93
		Overall[1]	**Pre to During[2]**	**During to Post[2]**	**Pre to Post[2]**			

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Blue-shaded cells indicate p>0.05. [1]Kruskal-Wallis p-value, [2]Dunn's Post-hoc Test p-value

Subgroup 1: Bedtime Resistance

Kruskal-Wallis Test: Goes to bed at the same time.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	69.505	2	<0.001	0.215	0.148	0.331

Dunn's Post Hoc Comparisons: Bedtime same.

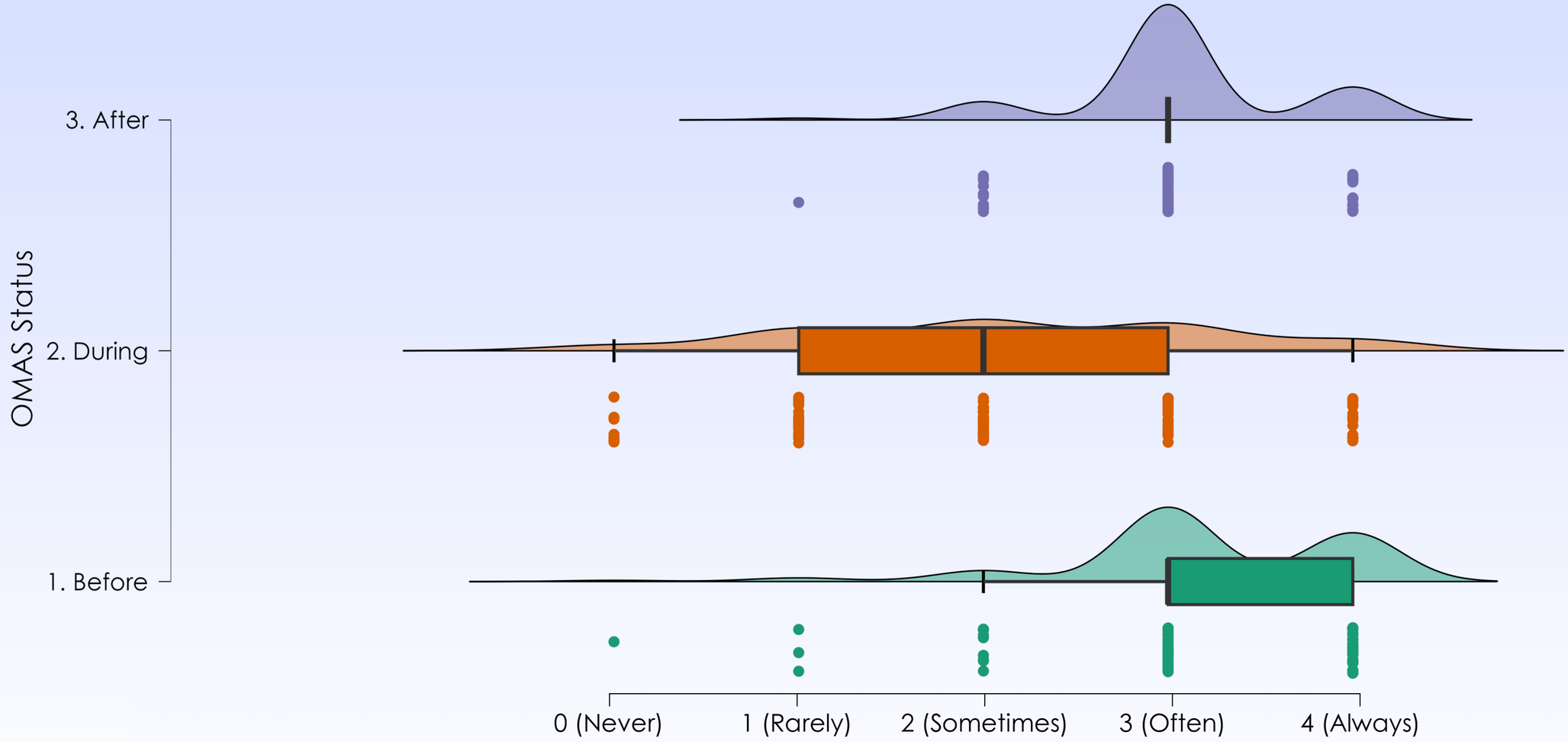
P<.05 P<.01 P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	7.892	200.333	109.814	0.534	<0.001	<0.001	<0.001
1. Before	3. After	1.400	200.333	183.196	0.138	0.161	0.484	0.161
2. During	3. After	-6.041	109.814	183.196	0.484	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child goes to bed at the same time at night.

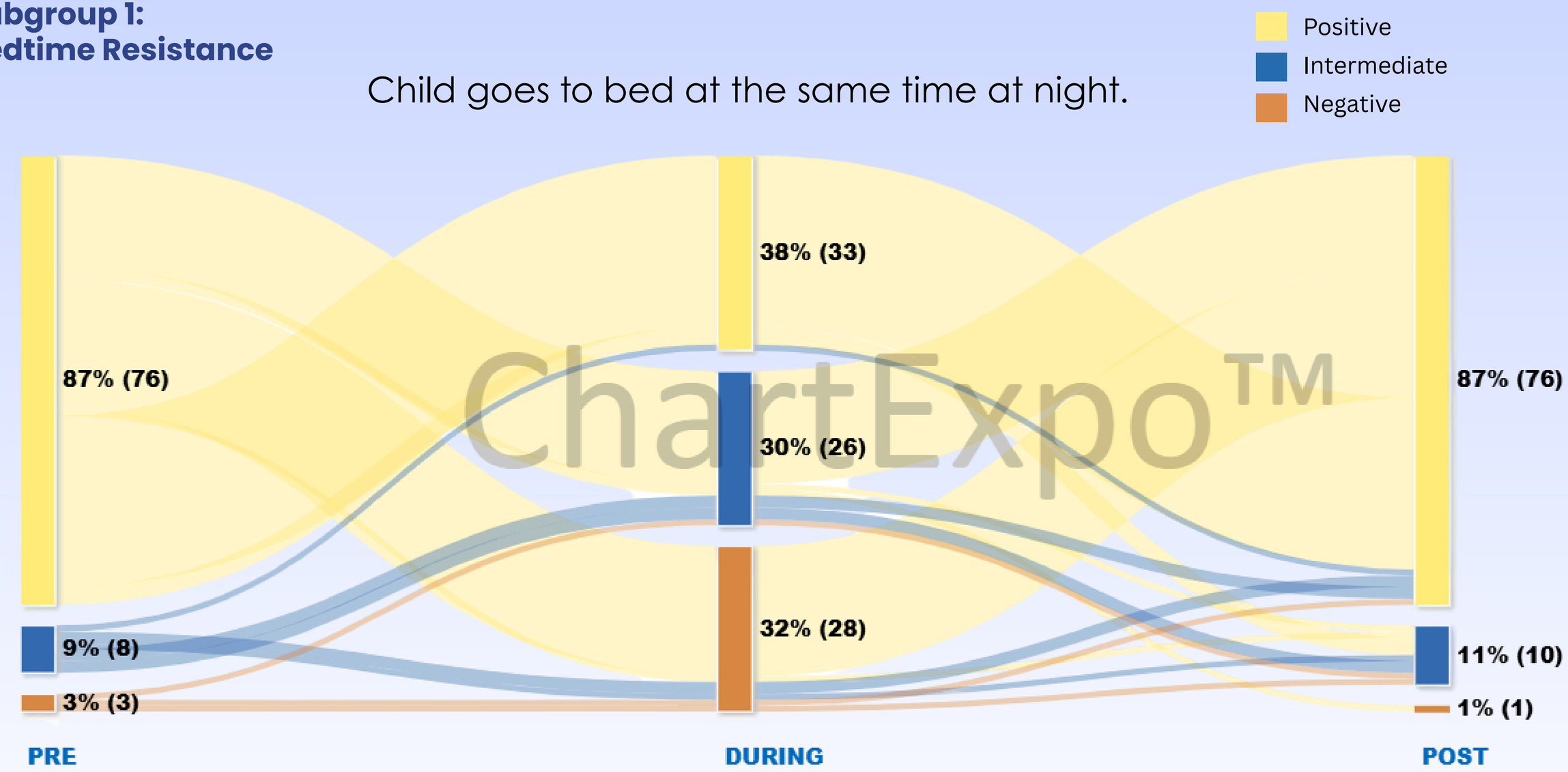
OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	114	3.193	0.763	0.071	0.239
2. During	118	2.169	1.096	0.101	0.505
3. After	92	3.065	0.589	0.061	0.192



Child goes to bed at the same time at night.

Subgroup 1:
Bedtime Resistance

Child goes to bed at the same time at night.



Limited to individuals with pre-during-post responses (n=87)

Most patients experience difficulties with sleep during active OMAS

- The “during” category was most often different enough to be statistically significant from the other two categories.
- This pattern was consistent across all subgroups
- However, as the “during” category had the most varied distribution, it is important to note that not all patients experienced the same degree of issues.

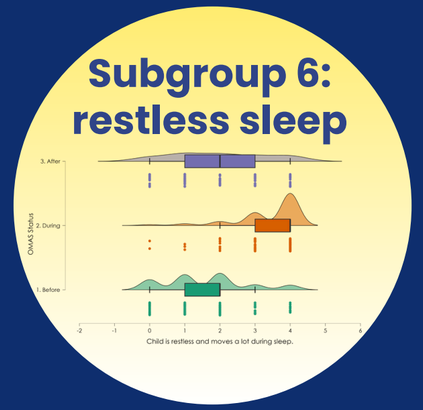
Some patients have suboptimal sleep habits that persist in remission

In some of the subgroups, we see a reduced recovery as patients enter remission.

In these cases, the **“after”** OMAS responses are closer to the **“during”** OMAS responses than the **“before”** responses are to the **“during”** responses.

This is more prevalent in subgroups involving sleep anxiety and parasomnias.

In most cases this is slight and the **“before”** and **“after”** categories are still more similar to each other than either is to the **“during”** category



Next Steps

Publications

Developing publications that will aim to guide the general medical community on effective treatments and therapies for OMAS patients suffering from ongoing sleep and behavior issues

Behavioral Studies

The preliminary results from this study suggest that there is much to learn about behavior and sleep to potentially help those struggling with sleep issues during active OMAS or even during remission.

Expansion of the Study

The sleep survey is part of the OMS Registry with NORD and continues to be live and collecting data for future use. With what we have learned from this first look at the data, we can also branch out into other future surveys

Translation to Other Languages

We are currently in the process of upgrading the registry for translation into multiple languages.

Quality of Life Studies

In addition to this study, we are in the process of conducting a study on quality of life with the Texas Children's Hospital. With the understanding that sleep is connected to quality of life, comparison between the studies will be of interest.

Endless Possibilities

With the demonstrated ability to collect data at this volume in a short time frame, the OMS registry is ready to be utilized to make a difference.

Thank You

OMS life Foundation
Coffee Challenge
OPEN
omslifefoundation.org/coffee-challenge

Subgroup 1: Bedtime Resistance

Kruskal-Wallis Test: Goes to bed at the same time.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	69.505	2	<0.001	0.215	0.148	0.331

Dunn's Post Hoc Comparisons: Bedtime same.

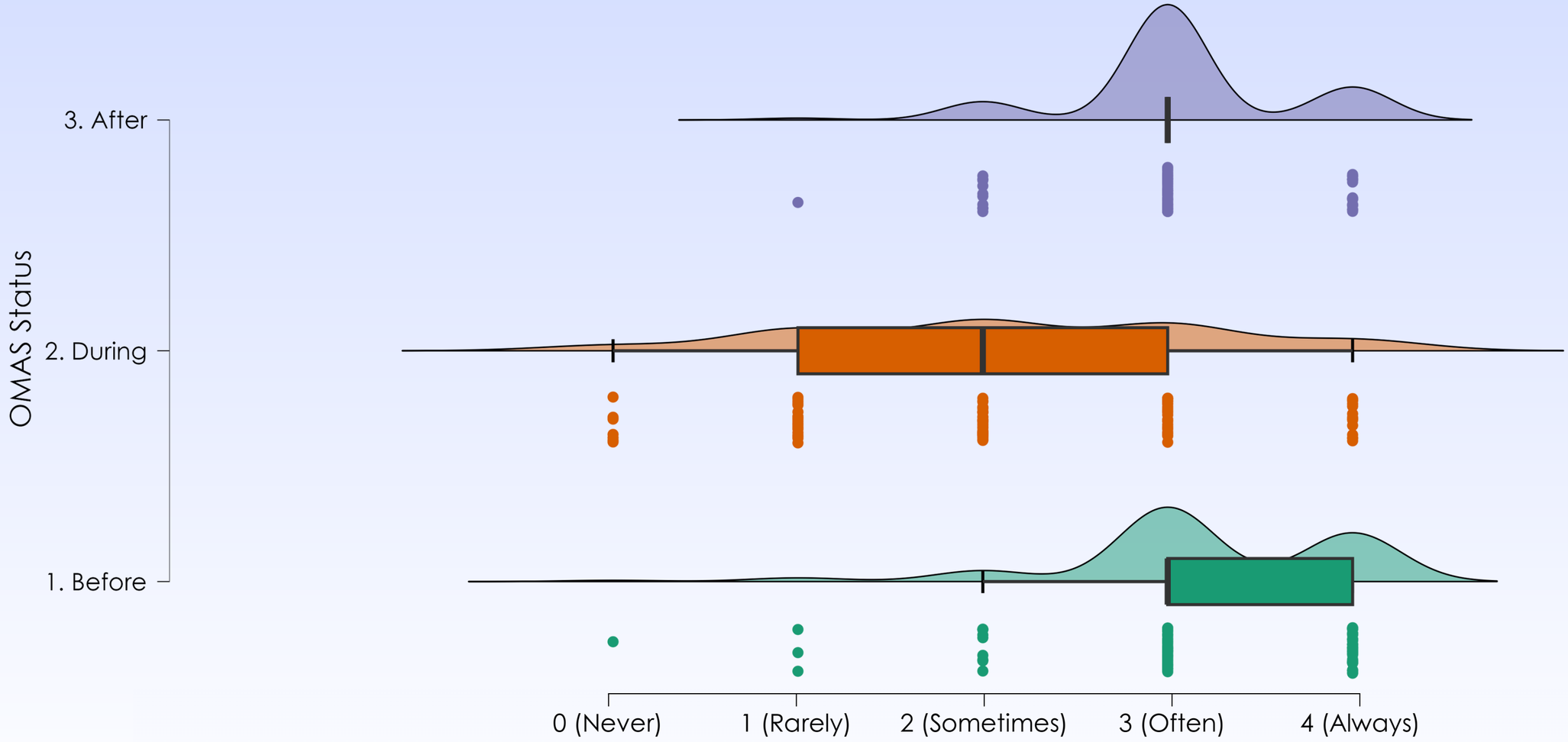
P<.05 P<.01 P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	7.892	200.333	109.814	0.534	<0.001	<0.001	<0.001
1. Before	3. After	1.400	200.333	183.196	0.138	0.161	0.484	0.161
2. During	3. After	-6.041	109.814	183.196	0.484	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child goes to bed at the same time at night.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	114	3.193	0.763	0.071	0.239
2. During	118	2.169	1.096	0.101	0.505
3. After	92	3.065	0.589	0.061	0.192



Child goes to bed at the same time at night.

Subgroup 1: Bedtime Resistance

Kruskal-Wallis Test: Falls asleep alone in own bed.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	71.341	2	<0.001	0.218	0.137	0.318

Dunn's Post Hoc Comparisons: Falls asleep alone.

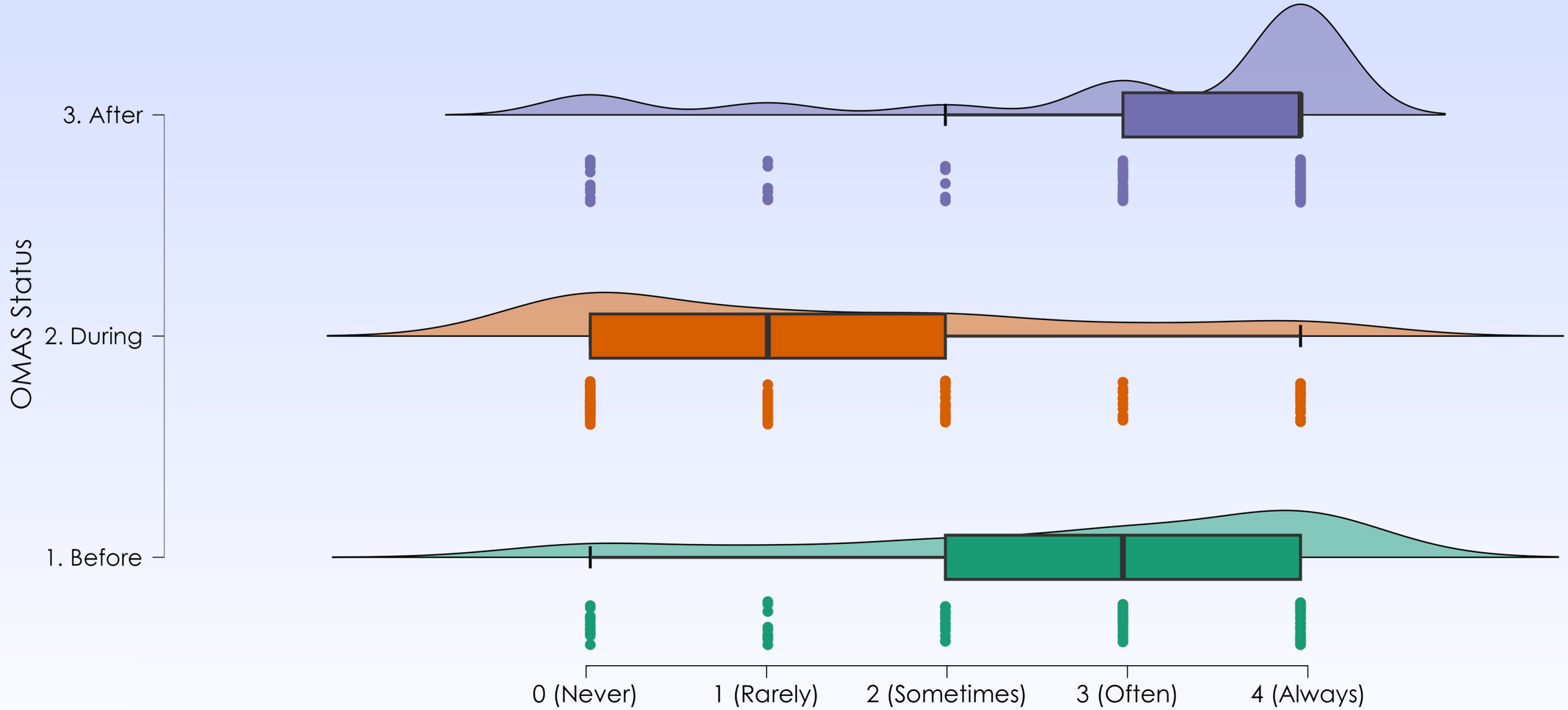
P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	6.357	185.280	109.294	0.485	<0.001	<0.001	<0.001
1. Before	3. After	-1.877	185.280	209.220	0.174	0.060	0.181	0.060
2. During	3. After	-7.881	109.294	209.220	0.582	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child falls asleep alone in own bed.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	116	2.733	1.392	0.129	0.509
2. During	119	1.378	1.426	0.131	1.035
3. After	93	3.086	1.373	0.142	0.445



Child falls asleep alone in own bed.

Subgroup 1: Bedtime Resistance

Kruskal-Wallis Test: Falls asleep in parent/sibling's bed.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	32.177	2	<0.001	0.101	0.048	0.190

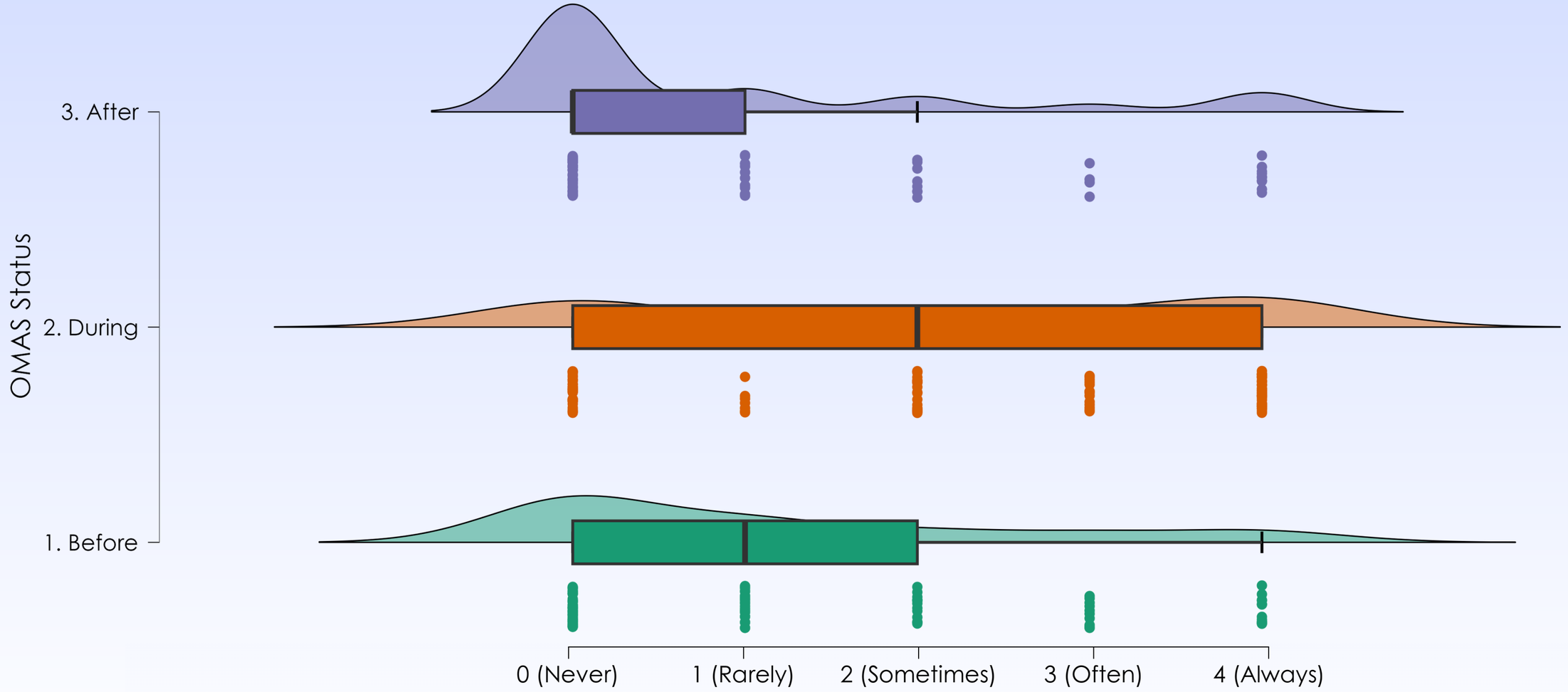
Dunn's Post Hoc Comparisons: Parent/sibling's bed. P<.05 P<.01 P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-3.916	150.049	195.392	0.298	<0.001	<0.001	<0.001
1. Before	3. After	1.752	150.049	128.344	0.156	0.080	0.239	0.080
2. During	3. After	5.449	195.392	128.344	0.399	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child falls asleep in parent's or sibling's bed.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	113	1.204	1.403	0.132	1.165
2. During	117	2.120	1.662	0.154	0.784
3. After	90	0.889	1.378	0.145	1.550



Child falls asleep in parent's or sibling's bed.

Subgroup 1: Bedtime Resistance

Kruskal-Wallis Test: Child needs parent in the room.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	57.882	2	<0.001	0.181	0.108	0.259

Dunn's Post Hoc Comparisons: Needs parent.

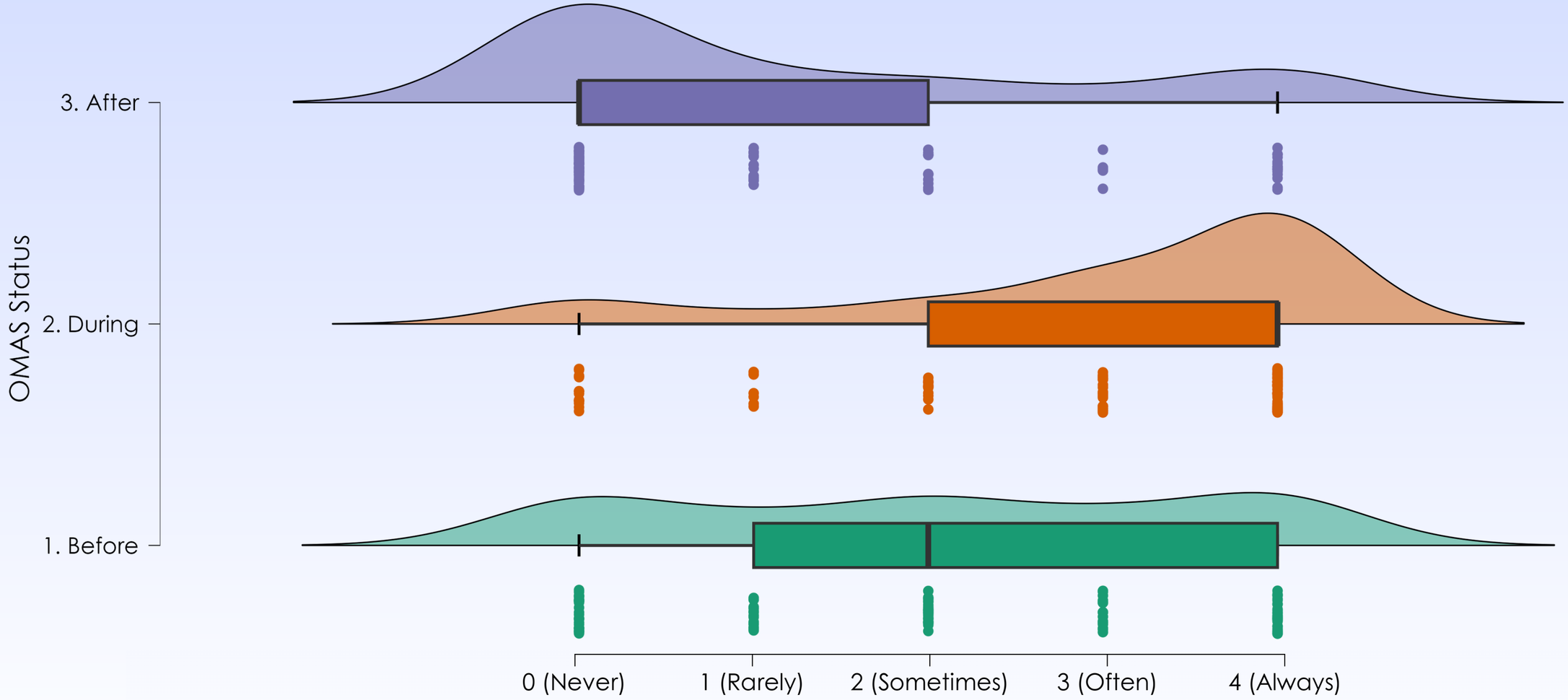
P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-4.328	154.646	205.927	0.348	<0.001	<0.001	<0.001
1. Before	3. After	3.440	154.646	111.126	0.307	<0.001	0.002	<0.001
2. During	3. After	7.550	205.927	111.126	0.556	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child needs parent in the room to fall asleep.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	113	2.053	1.511	0.142	0.736
2. During	117	2.974	1.355	0.125	0.456
3. After	91	1.220	1.555	0.163	1.275



Child needs parent in the room to fall asleep.

Subgroup 2: Sleep Onset Delay

Kruskal-Wallis Test: Falls asleep within 20 minutes.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	87.416	2	<0.001	0.267	0.176	0.372

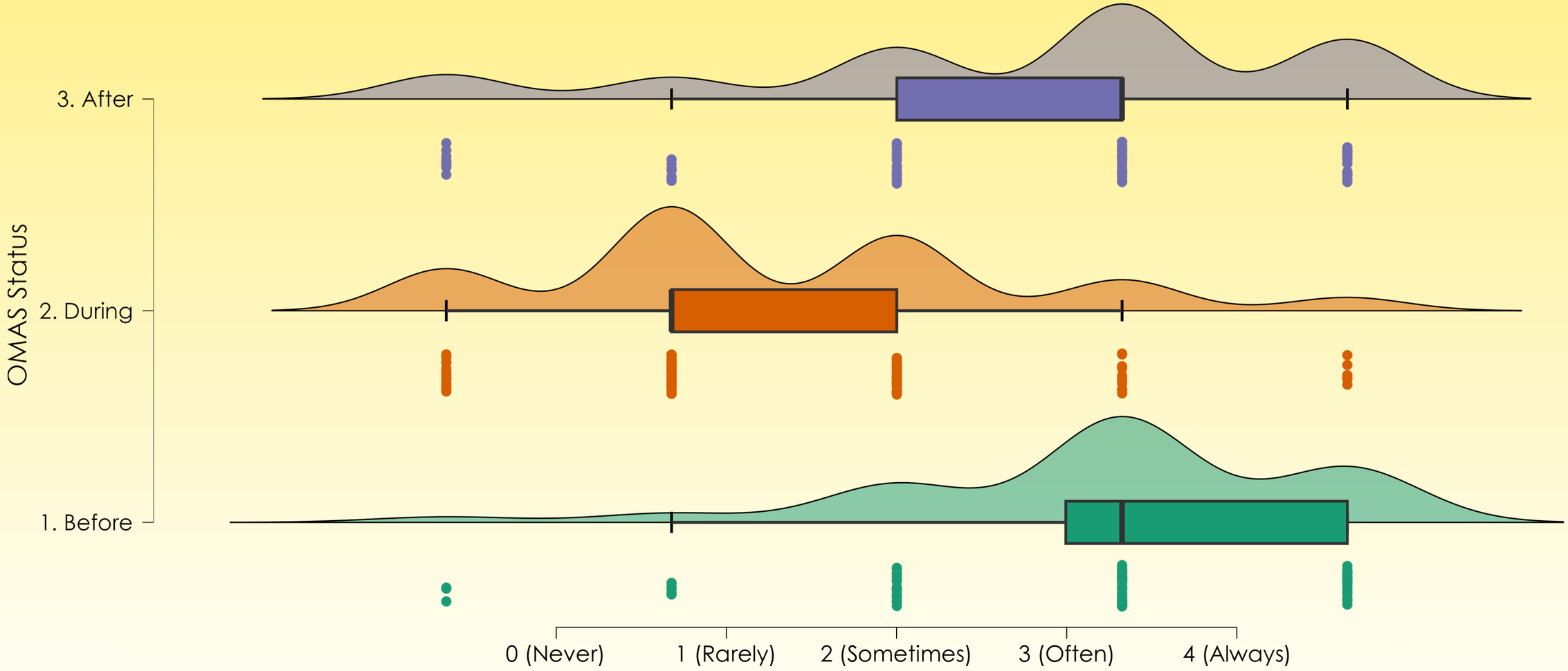
Dunn's Post Hoc Comparisons: Asleep in 20 mins. P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	8.969	211.409	103.546	0.666	<0.001	<0.001	<0.001
1. Before	3. After	1.945	211.409	186.409	0.139	0.052	0.155	0.052
2. During	3. After	-6.494	103.546	186.409	0.491	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child falls asleep within 20 minutes.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	116	2.914	0.919	0.085	0.315
2. During	120	1.508	1.053	0.096	0.698
3. After	93	2.570	1.219	0.126	0.474



Child falls asleep within 20 minutes after going to bed.

Subgroup 3: Sleep Duration

Kruskal-Wallis Test: Sleeps about the same amount.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	94.035	2	<0.001	0.288	0.188	0.382

Dunn's Post Hoc Comparisons: Same amount.

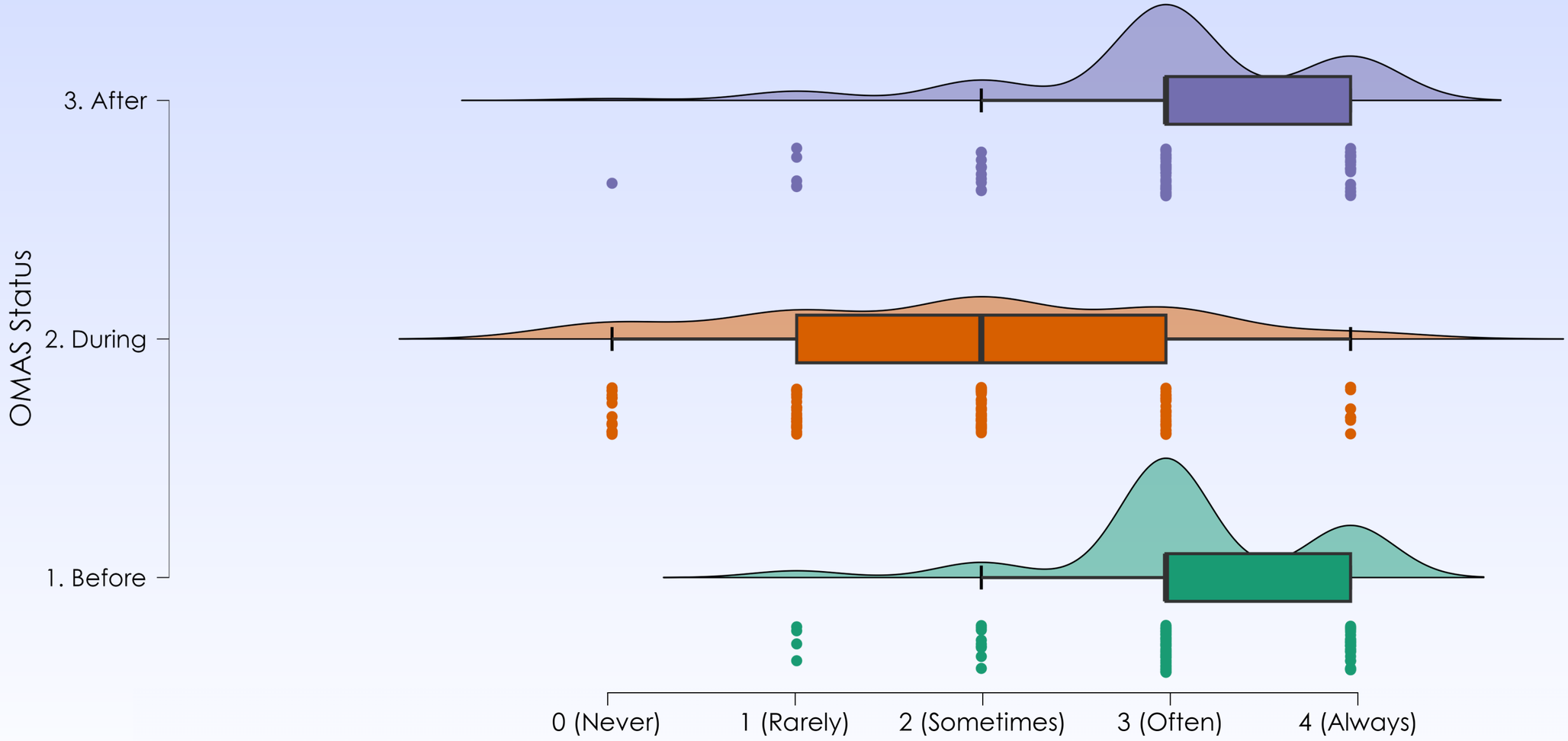
P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	8.886	205.270	101.875	0.631	<0.001	<0.001	<0.001
1. Before	3. After	0.834	205.270	194.892	0.062	0.404	1.000	0.404
2. During	3. After	-7.551	101.875	194.892	0.566	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Sleeps about the same amount each day.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	115	3.122	0.690	0.064	0.221
2. During	120	1.875	1.112	0.102	0.593
3. After	93	3.000	0.834	0.086	0.278



Child sleeps about the same amount each day.

Subgroup 4: Sleep Anxiety

Kruskal-Wallis Test: Child needs parent in the room.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	57.882	2	<0.001	0.181	0.108	0.259

Dunn's Post Hoc Comparisons: Needs parent.

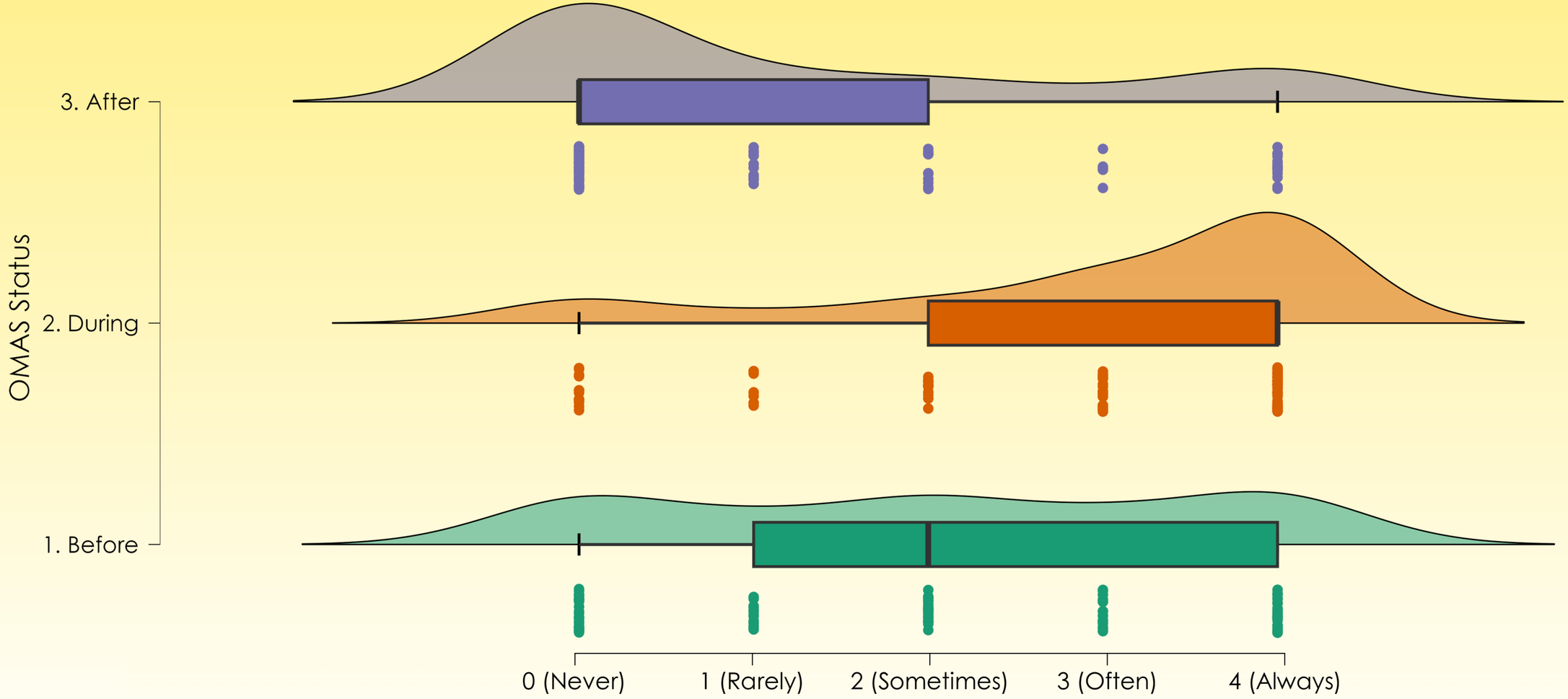
P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-4.328	154.646	205.927	0.348	<0.001	<0.001	<0.001
1. Before	3. After	3.440	154.646	111.126	0.307	<0.001	0.002	<0.001
2. During	3. After	7.550	205.927	111.126	0.556	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child needs parent in the room to fall asleep.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	113	2.053	1.511	0.142	0.736
2. During	117	2.974	1.355	0.125	0.456
3. After	91	1.220	1.555	0.163	1.275



Child needs parent in the room to fall asleep.

Subgroup 4: Sleep Anxiety

Kruskal-Wallis Test: Child is afraid of the dark.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	17.365	2	<0.001	0.056	0.019	0.117

Dunn's Post Hoc Comparisons: Afraid of the dark.

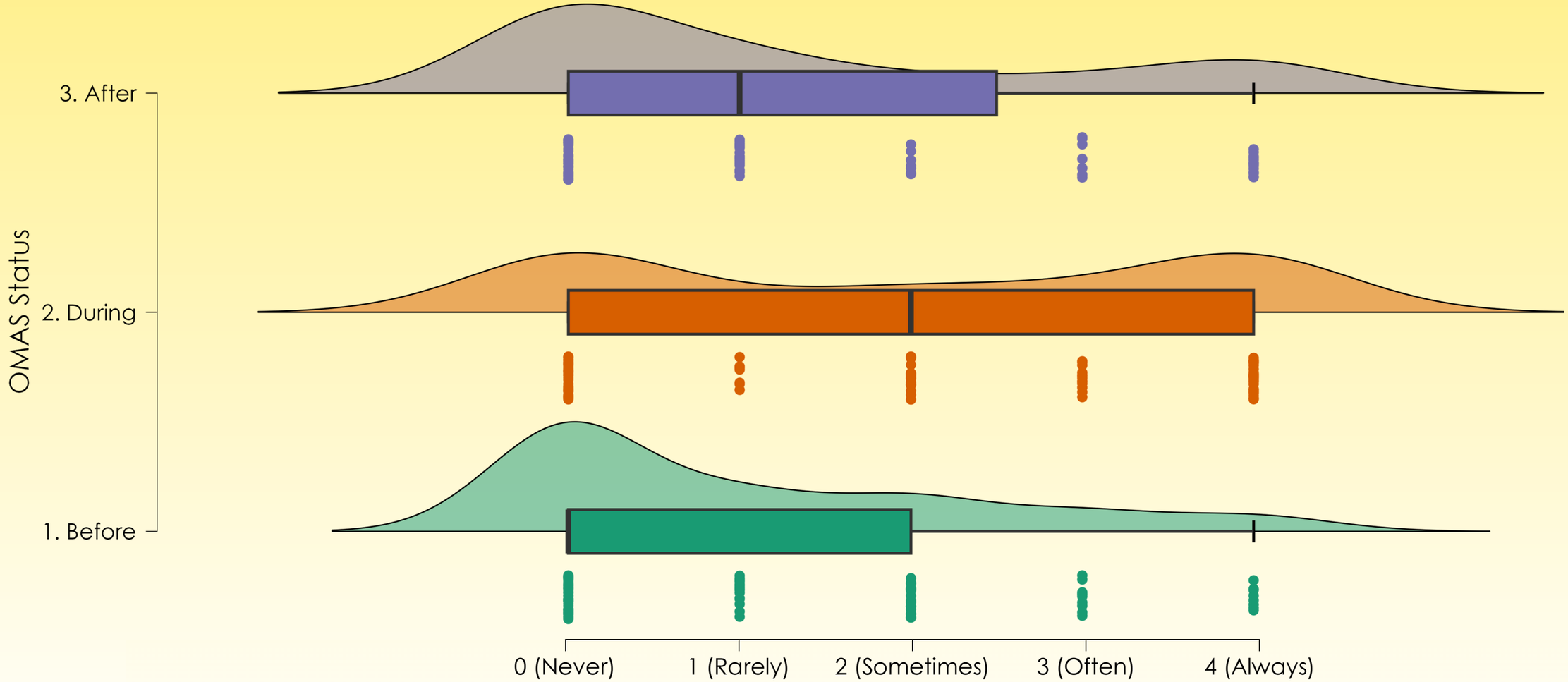
P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-4.003	136.362	182.437	0.302	<0.001	<0.001	<0.001
1. Before	3. After	-0.900	136.362	147.275	0.063	0.368	1.000	0.368
2. During	3. After	2.913	182.437	147.275	0.219	0.004	0.011	0.007

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child is afraid of sleeping in the dark.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	109	1.055	1.304	0.125	1.236
2. During	111	2.009	1.719	0.163	0.856
3. After	91	1.286	1.544	0.162	1.201



Child is afraid of sleeping in the dark.

Subgroup 5: Night Wakings

Kruskal-Wallis Test: Child moves beds.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	40.881	2	<0.001	0.135	0.073	0.210

Dunn's Post Hoc Comparisons: Moves beds.

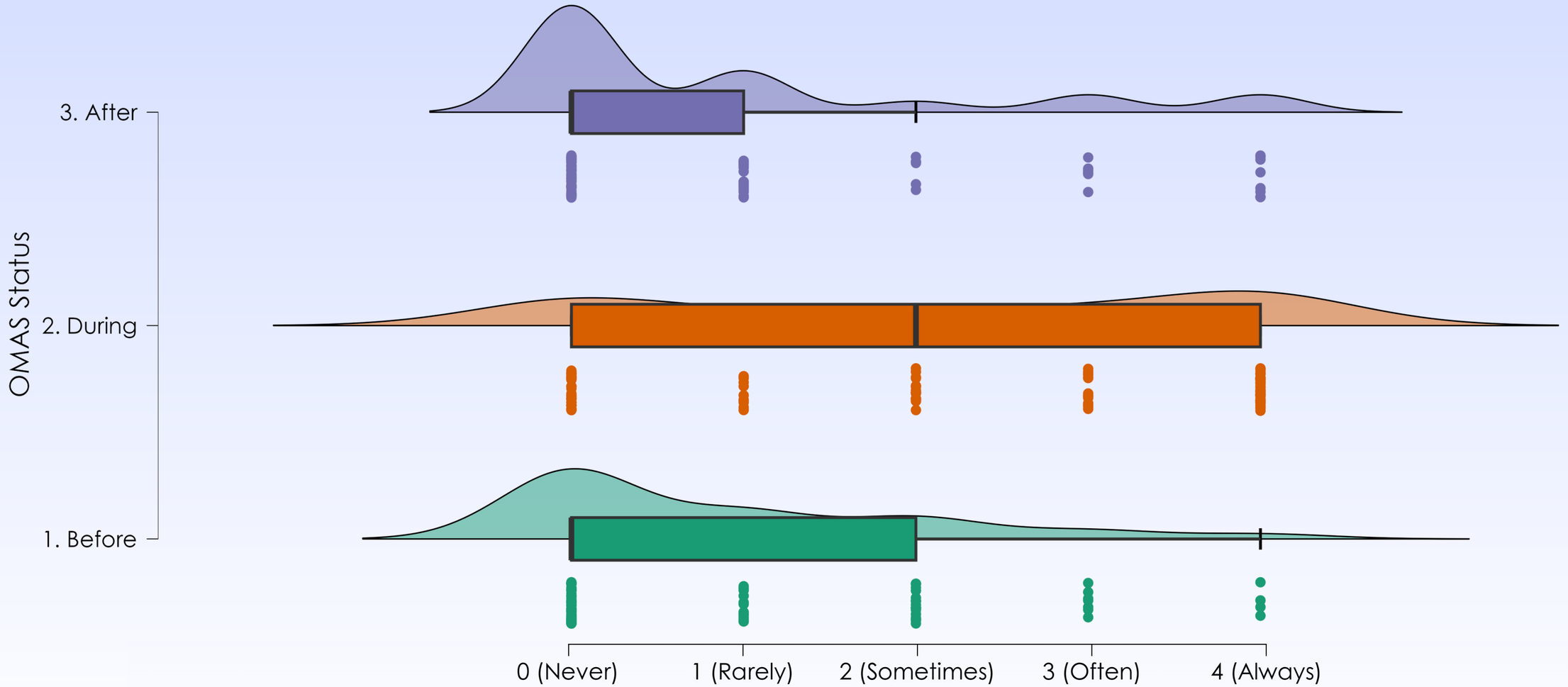
P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-5.623	129.110	193.155	0.432	<0.001	<0.001	<0.001
1. Before	3. After	-0.061	129.110	129.848	0.008	0.951	1.000	0.951
2. During	3. After	5.319	193.155	129.848	0.404	<0.001	<0.001	<0.001

Note. Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child moves to someone else's bed.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	105	0.886	1.138	0.111	1.285
2. During	110	2.164	1.640	0.156	0.758
3. After	89	0.955	1.339	0.142	1.402



Subgroup 5: Night Wakings

Kruskal-Wallis Test: Wakes up once during the night.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε² Lower	Upper
OMAS Status	79.868	2	<0.001	0.245	0.161	0.339

Dunn's Post Hoc Comparisons: Wakes once.

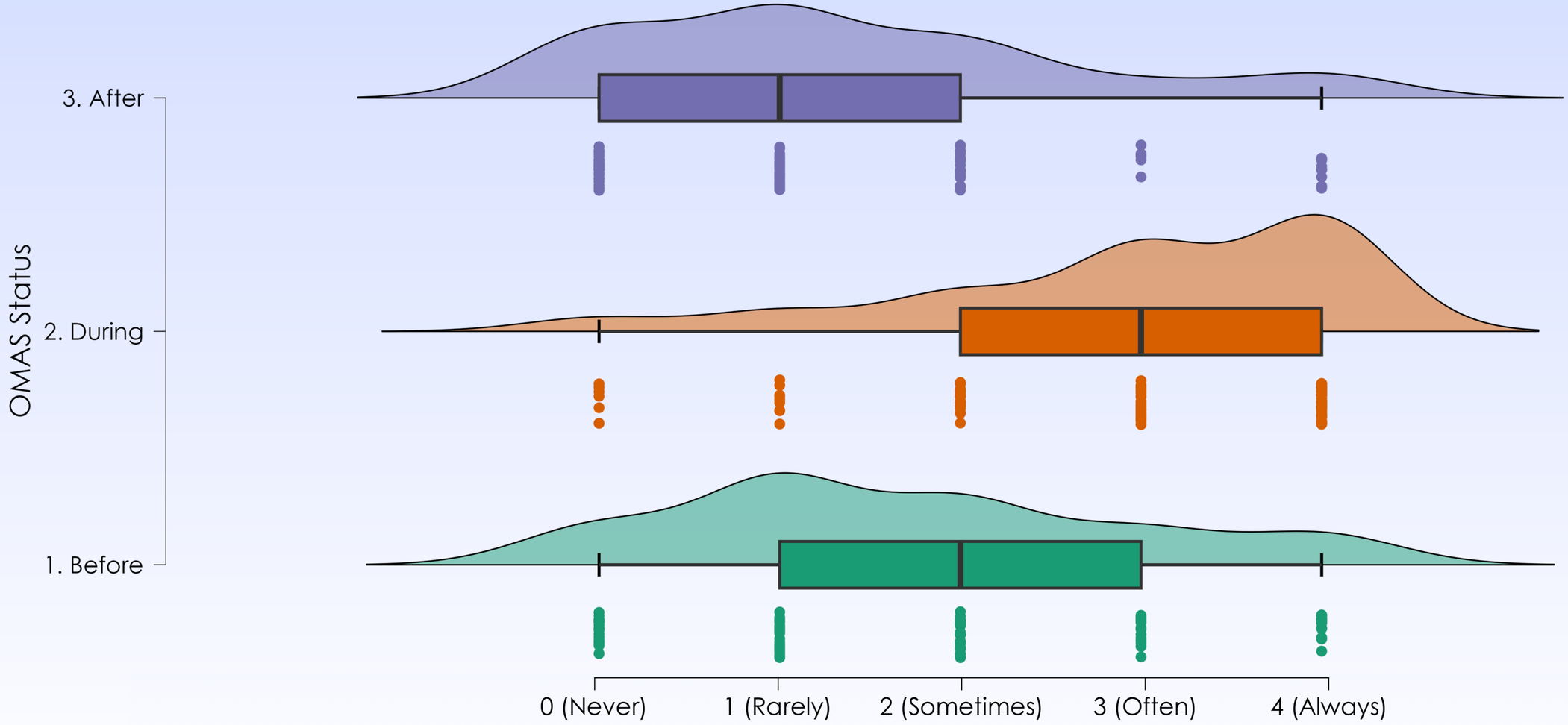
P<.05 P<.01 P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-6.816	141.073	223.492	0.523	<0.001	<0.001	<0.001
1. Before	3. After	1.861	141.073	117.113	0.171	0.063	0.188	0.063
2. During	3. After	8.296	223.492	117.113	0.527	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child wakes up once during the night.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	116	1.733	1.233	0.114	0.711
2. During	118	2.966	1.154	0.106	0.389
3. After	93	1.376	1.224	0.127	0.889



Child wakes up once during the night.

Subgroup 5: Night Wakings

Kruskal-Wallis Test: Wakes up more than once.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	82.924	2	<0.001	0.255	0.162	0.340

Dunn's Post Hoc Comparisons: Wakes more.

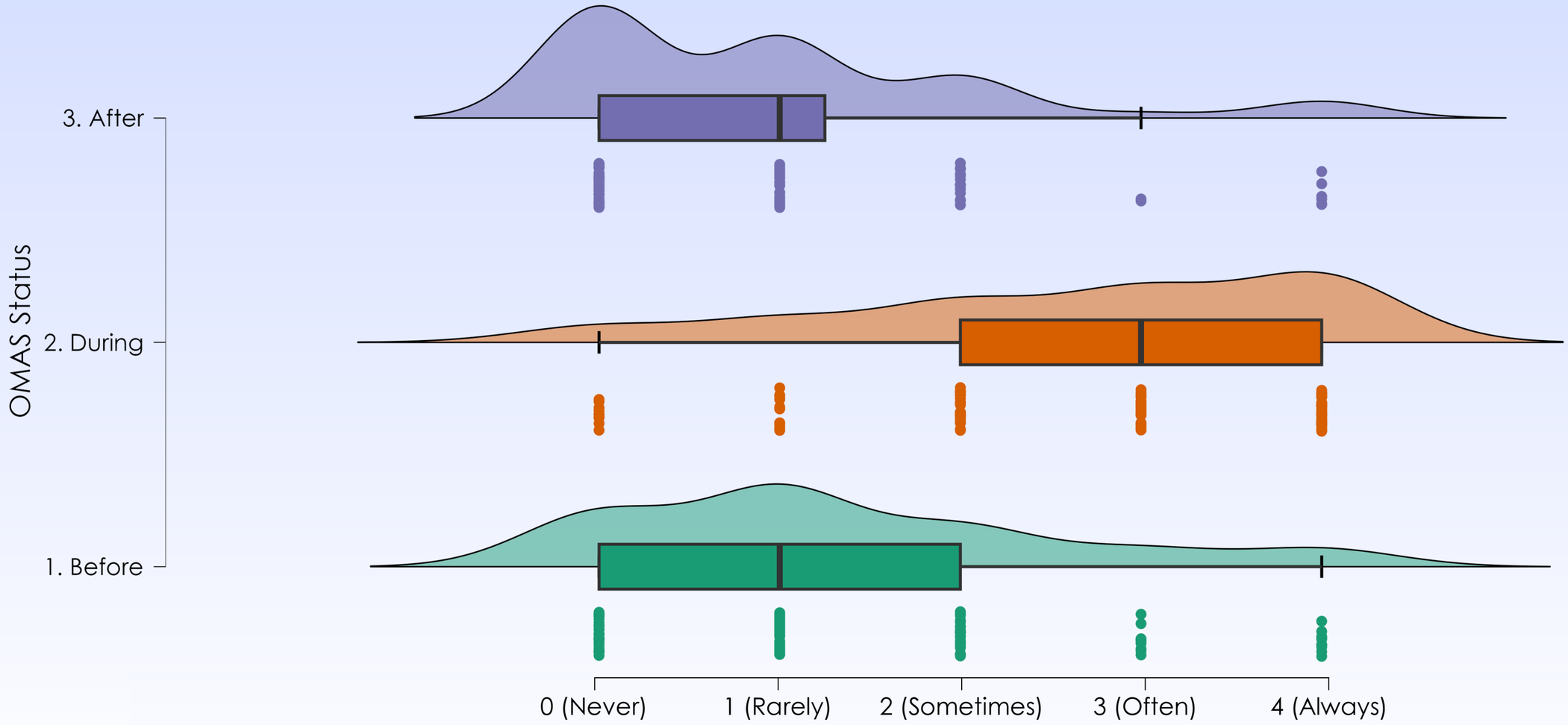
P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-6.718	142.039	222.866	0.745	<0.001	<0.001	<0.001
1. Before	3. After	2.215	142.039	113.538	0.175	0.027	0.080	0.027
2. During	3. After	8.559	222.866	113.538	0.587	<0.001	<0.001	<0.001

Note. Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child wakes up more than once.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	115	1.365	1.209	0.113	0.886
2. During	119	2.647	1.286	0.118	0.486
3. After	92	0.967	1.133	0.118	1.172



Child wakes up more than once during the night.

Subgroup 6: Parasomnias

Kruskal-Wallis Test: Child is restless during sleep.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	110.350	2	<0.001	0.348	0.273	0.470

Dunn's Post Hoc Comparisons: Restless.

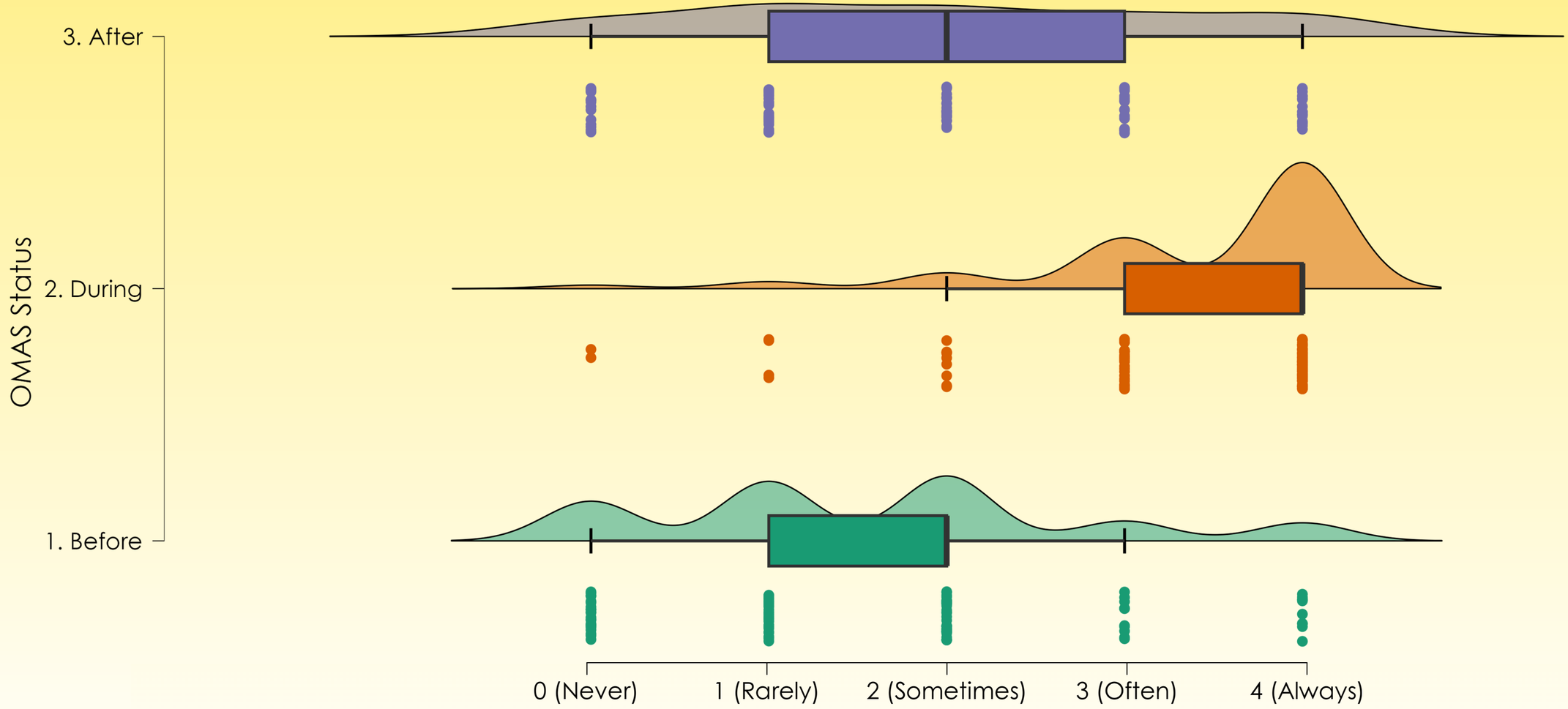
P<.05 P<.01 P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-10.058	108.393	227.621	0.745	<0.001	<0.001	<0.001
1. Before	3. After	-2.124	108.393	135.300	0.175	0.034	0.101	0.034
2. During	3. After	7.345	227.621	135.300	0.587	<0.001	<0.001	<0.001

Note. Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child is restless and moves a lot during sleep.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	112	1.589	1.174	0.111	0.739
2. During	116	3.422	0.906	0.084	0.265
3. After	90	2.011	1.337	0.141	0.665



Child is restless and moves a lot during sleep.

Subgroup 6: Parasomnias

Kruskal-Wallis Test: Child awakens inconsolable.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε² Lower	Upper
OMAS Status	122.669	2	<0.001	0.377	0.284	0.480

Dunn's Post Hoc Comparisons: Inconsolable.

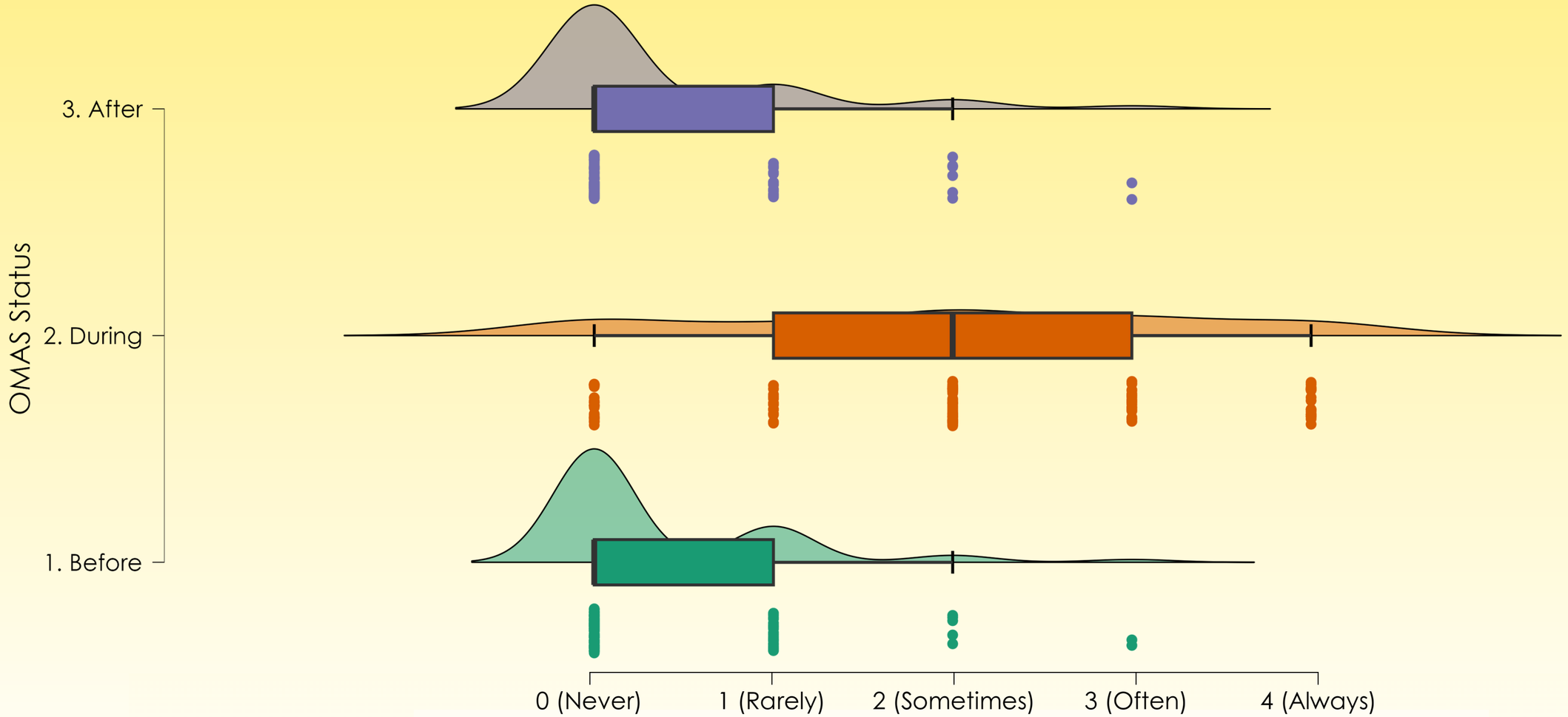
P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-9.685	123.961	233.433	0.302	<0.001	<0.001	<0.001
1. Before	3. After	0.124	123.961	122.467	0.063	0.902	1.000	0.902
2. During	3. After	9.246	233.433	122.467	0.219	<0.001	<0.001	<0.001

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child awakens inconsolable.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	115	0.365	0.653	0.061	1.789
2. During	119	2.025	1.343	0.123	0.663
3. After	92	0.370	0.707	0.074	1.912



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Subgroup 6: Parasomnias

Kruskal-Wallis Test: Child grinds teeth during sleep.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	22.599	2	<0.001	0.077	0.042	0.147

Dunn's Post Hoc Comparisons: Grinds teeth.

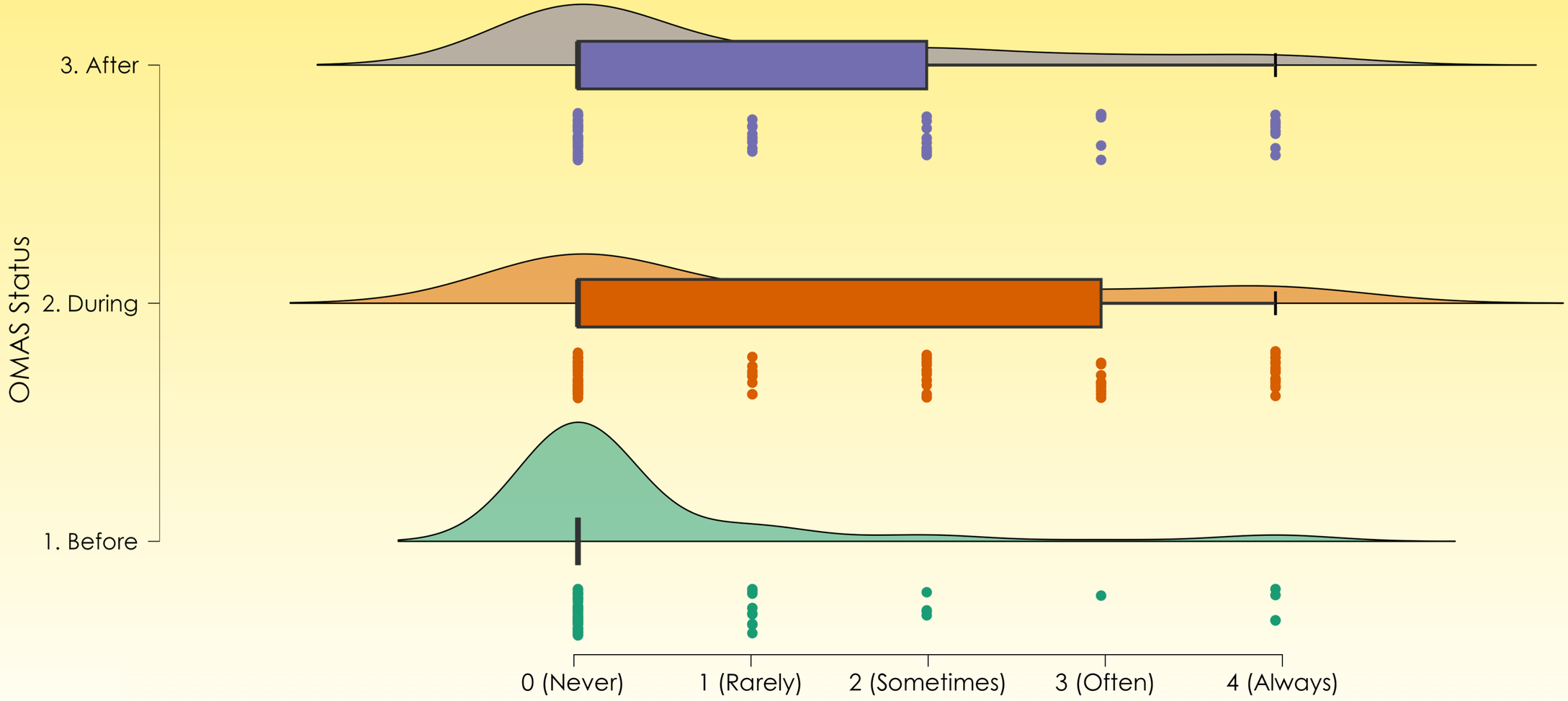
P<.05 | P<.01 | P<.001

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-4.663	119.089	167.312	0.322	<0.001	<0.001	<0.001
1. Before	3. After	-3.174	119.089	153.494	0.242	0.002	0.005	0.003
2. During	3. After	1.317	167.312	153.494	0.101	0.188	0.564	0.188

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child grinds teeth during sleep.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	95	0.389	0.949	0.097	2.436
2. During	109	1.312	1.562	0.150	1.190
3. After	90	0.989	1.362	0.144	1.377



Child grinds teeth during sleep (your dentist may have told you this).

Subgroup 7:
Sleep Disordered Breathing

Kruskal-Wallis Test: Child snores loudly.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	10.545	2	0.005	0.033	0.008	0.076

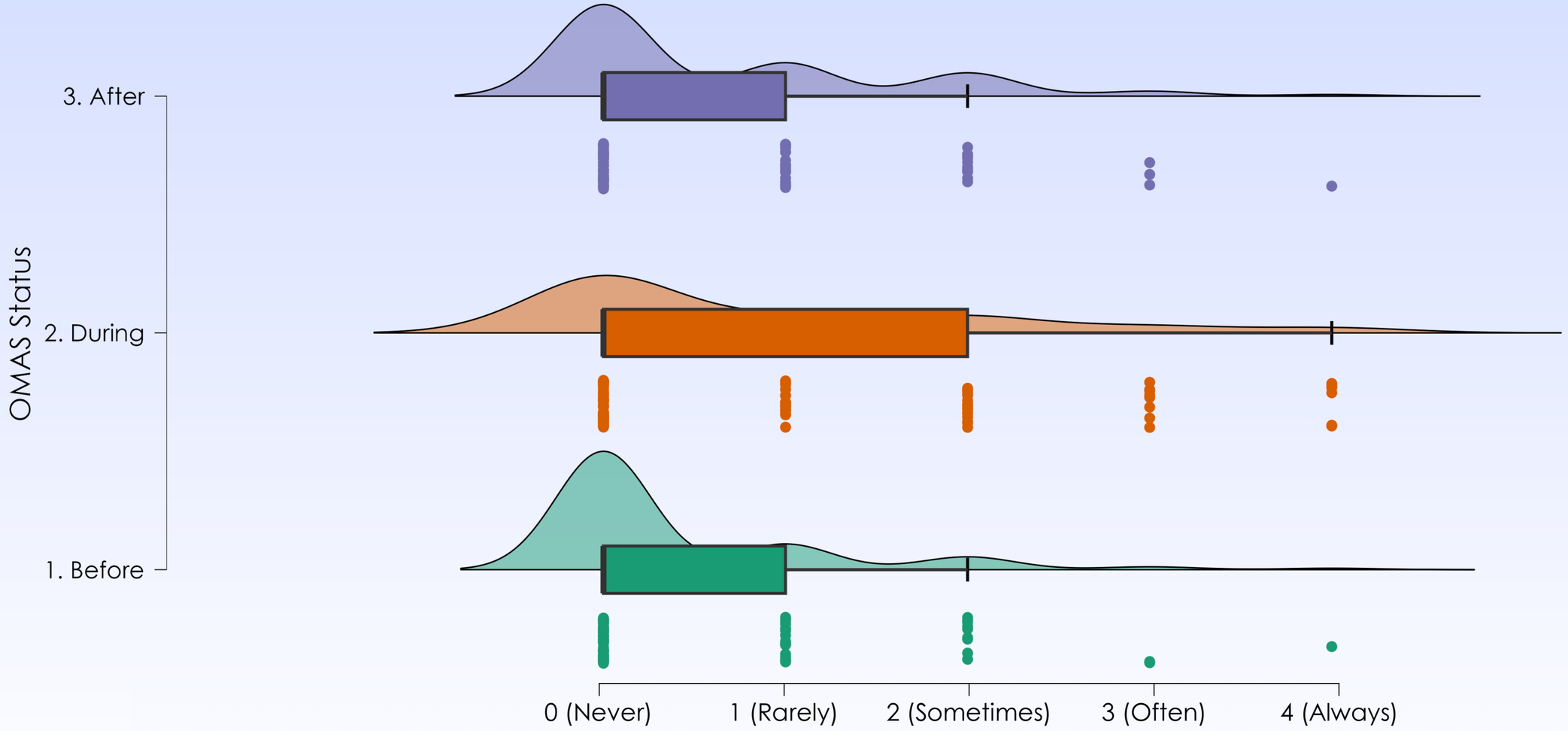
Dunn's Post Hoc Comparisons: Child snores loudly. P<.05 P<.01

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-3.186	143.040	176.816	0.205	0.001	0.004	0.004
1. Before	3. After	-2.076	143.040	166.398	0.150	0.038	0.114	0.076
2. During	3. After	0.933	176.816	166.398	0.070	0.351	1.000	0.351

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child snores loudly.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	113	0.407	0.786	0.074	1.932
2. During	117	0.889	1.209	0.112	1.360
3. After	93	0.656	0.927	0.096	1.413



Child snores loudly.

Subgroup 8: Daytime Sleepiness

Kruskal-Wallis Test: Child wakes up by him/herself.

Factor	Statistic	df	p	Rank ε²	95% CI for Rank ε²	
					Lower	Upper
OMAS Status	2.299	2	0.317	0.007	4.119×10^{-4}	0.041

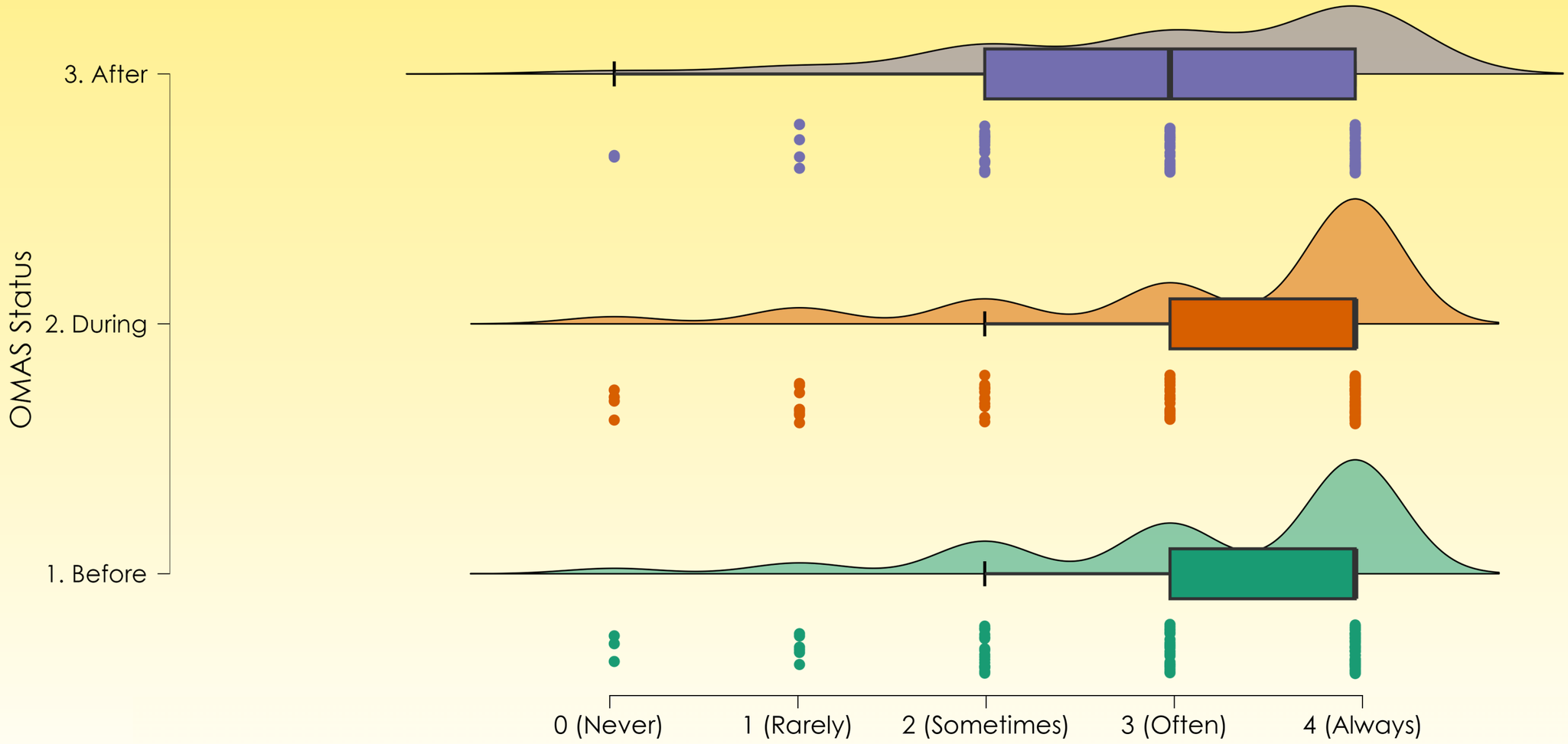
Dunn's Post Hoc Comparisons: Child wakes up by him/herself.

Comparison		z	W_i	W_j	r_{rb}	p	p_{bonf}	p_{holm}
1. Before	2. During	-0.461	167.703	172.938	0.032	0.644	1.000	0.644
1. Before	3. After	1.056	167.703	154.887	0.079	0.291	0.872	0.582
2. During	3. After	1.493	172.938	154.887	0.108	0.135	0.406	0.406

Note: Rank-biserial correlation based on individual Mann-Whitney tests.

Descriptives: Child wakes up by him/herself.

OMAS Status	N	Mean	SD	SE	Coefficient of variation
1. Before	118	3.203	1.042	0.096	0.325
2. During	120	3.217	1.124	0.103	0.349
3. After	93	3.086	1.028	0.107	0.333



Child wakes up by him/herself.

Additional Resources

In the following slides, additional resources are provided for more information not presented during the live presentation.

Original CSHQ

The PDF of the original CSHQ is provided for comparison purposes. Differences have been highlighted to signify where changes were made to the abbreviated version. These changes largely consist of removed questions though the scale has also been broadened to differentiate between “often” and “always”, as well as “rarely” and “never.”

Abbreviated CSHQ

The PDF of the abbreviated CSHQ is also included for review. Please note that this differs from the one used in the OMS registry in two significant ways. The OMS registry version first asks if the patient is in active OMAS or in remission, currently, and then, depending on the answer, will prompt the caregiver or patient to answer each question two or three times, for each time period of before, during, and after active OMAS (with “after” excluded for those currently in the active stage).

A listing of the subgroups

The original CSHQ is often evaluated by grouping the questions into 8 subgroups. We have provided a list of the 8 subgroups with those that are available on the abbreviated version highlighted, as those are the questions we chose to focus on for this initial look into the data.

For more information, please visit:

omslifefoundation.org

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Original CSHQ

Child's Sleep Habits
(Preschool and School-Aged)

_____
Coding

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your child's life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well or the TV set was broken), choose the most recent typical week. Answer USUALLY if something occurs **5 or more times** in a week; answer SOMETIMES if it occurs **2-4 times** in a week; answer RARELY if something occurs **never or 1 time** during a week. Also, please indicate whether or not the sleep habit is a problem by circling "Yes," "No," or "Not applicable (N/A).

Bedtime

Write in child's bedtime: _____

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child goes to bed at the same time at night	☐	☐	☐	Yes	No	N/A
Child falls asleep within 20 minutes after going to bed	☐	☐	☐	Yes	No	N/A
Child falls asleep alone in own bed	☐	☐	☐	Yes	No	N/A
Child falls asleep in parent's or sibling's bed	☐	☐	☐	Yes	No	N/A
Child falls asleep with rocking or rhythmic movements	☐	☐	☐	Yes	No	N/A
Child needs special object to fall asleep (doll, special blanket, etc.)	☐	☐	☐	Yes	No	N/A
Child needs parent in the room to fall asleep	☐	☐	☐	Yes	No	N/A
Child is ready to go to bed at bedtime	☐	☐	☐	Yes	No	N/A
Child resists going to bed at bedtime	☐	☐	☐	Yes	No	N/A
Child struggles at bedtime (cries, refuses to stay in bed, etc.)	☐	☐	☐	Yes	No	N/A
Child is afraid of sleeping in the dark	☐	☐	☐	Yes	No	N/A
Child is afraid of sleep alone	☐	☐	☐	Yes	No	N/A

Sleep Behavior

Child's usual amount of sleep each day: _____hours and _____minutes
(combining nighttime sleep and naps)

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child sleeps too little	☐	☐	☐	Yes	No	N/A
Child sleeps too much	☐	☐	☐	Yes	No	N/A
Child sleeps the right amount	☐	☐	☐	Yes	No	N/A
Child sleeps about the same amount each day	☐	☐	☐	Yes	No	N/A
Child wets the bed at night	☐	☐	☐	Yes	No	N/A
Child talks during sleep	☐	☐	☐	Yes	No	N/A
Child is restless and moves a lot during sleep	☐	☐	☐	Yes	No	N/A
Child sleepwalks during the night	☐	☐	☐	Yes	No	N/A
Child moves to someone else's bed during the night (parent, brother, sister, etc.)	☐	☐	☐	Yes	No	N/A

_____
Coding

Sleep Behavior (continued)

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child reports body pains during sleep. If so, where? _____	☐	☐	☐	Yes	No	N/A
Child grinds teeth during sleep (your dentist may have told you this)	☐	☐	☐	Yes	No	N/A
Child snores loudly	☐	☐	☐	Yes	No	N/A
Child seems to stop breathing during sleep	☐	☐	☐	Yes	No	N/A
Child snorts and/or gasps during sleep	☐	☐	☐	Yes	No	N/A
Child has trouble sleeping away from home (visiting relatives, vacation)	☐	☐	☐	Yes	No	N/A
Child complains about problems sleeping	☐	☐	☐	Yes	No	N/A
Child awakens during night screaming, sweating, and inconsolable	☐	☐	☐	Yes	No	N/A
Child awakens alarmed by a frightening dream	☐	☐	☐	Yes	No	N/A

Waking During the Night

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child awakes once during the night	☐	☐	☐	Yes	No	N/A
Child awakes more than once during the night	☐	☐	☐	Yes	No	N/A
Child returns to sleep without help after waking	☐	☐	☐	Yes	No	N/A

Write the number of minutes a night waking usually lasts: _____

Morning Waking

Write in the time of day child usually wakes in the morning: _____

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child wakes up by him/herself	☐	☐	☐	Yes	No	N/A
Child wakes up with alarm clock	☐	☐	☐	Yes	No	N/A
Child wakes up in negative mood	☐	☐	☐	Yes	No	N/A
Adults or siblings wake up child	☐	☐	☐	Yes	No	N/A
Child has difficulty getting out of bed in the morning	☐	☐	☐	Yes	No	N/A
Child takes a long time to become alert in the morning	☐	☐	☐	Yes	No	N/A
Child wakes up very early in the morning	☐	☐	☐	Yes	No	N/A
Child has a good appetite in the morning	☐	☐	☐	Yes	No	N/A

_____
Coding

Daytime Sleepiness

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
Child naps during the day	☐	☐	☐	Yes	No	N/A
Child suddenly falls asleep in the middle of active behavior	☐	☐	☐	Yes	No	N/A
Child seems tired	☐	☐	☐	Yes	No	N/A

During the past week, your child has appeared very sleepy or fallen asleep during the following (check all that apply):

	1 Not Sleepy	2 Very Sleepy	3 Falls Asleep
Play alone	☐	☐	☐
Watching TV	☐	☐	☐
Riding in car	☐	☐	☐
Eating meals	☐	☐	☐

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Differences from abbreviated CSHQ have been highlighted.

Abbreviated CSHQ

NICHD SECCYD—Wisconsin

CHILDREN'S SLEEP HABITS QUESTIONNAIRE (ABBREVIATED)

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your life when you answer the questions. If last week was unusual for a specific reason, choose the most recent typical week. Unless noted, check Always if something occurs every night, Usually if it occurs 5 or 6 times a week, Sometimes if it occurs 2 to 4 times a week, Rarely if it occurs once a week, and Never if it occurs less than once a week.

BEDTIME

Write in your child's usual bedtime: Weeknights _____:_____ am/pm

Weekends _____:_____ am/pm

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
1. Child goes to bed at the same time at night.					
2. Child falls asleep within 20 minutes after going to bed.					
3. Child falls asleep alone in own bed.					
4. Child falls asleep in parent's or sibling's bed.					
5. Child falls asleep with rocking or rhythmic movements.					
6. Child needs special object to fall asleep (doll, special blanket, stuffed animal, etc.).					
7. Child needs parent in the room to fall asleep.					
8. Child resists going to bed at bedtime.					
9. Child is afraid of sleeping in the dark.					

SLEEP BEHAVIOR

Write in your child's usual amount of sleep each day (combining nighttime sleep and naps): _____ hours and _____ minutes

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
10. Child sleeps about the same amount each day.					
11. Child is restless and moves a lot during sleep.					

NICHD SECCYD—Wisconsin

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
12. Child moves to someone else's bed during the night (parent, sibling, etc.).					
13. Child grinds teeth during sleep (your dentist may have told you this).					
14. Child snores loudly.					
15. Child awakens during the night and is sweating, screaming, and inconsolable.					
16. Child naps during the day.					
(Write in the number of minutes the nap usually lasts: _____ minutes					

WAKING DURING THE NIGHT

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
17. Child wakes up once during the night. 18.					
Child wakes up more than once during the night.					

MORNING WAKE UP

Write in the time child usually wakes up in the morning: Weekdays _____:_____ am/pm

Weekends _____:_____ am/pm

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
19. Child wakes up by him/herself.					
20. Child wakes up very early in the morning (or, earlier than necessary or desired).					
21. Child seems tired during the daytime.					
22. Child falls asleep while involved in activities.					

subgroups

1 Bedtime Resistance

Goes to bed at same time

Falls asleep in own bed

Falls asleep in other's bed

Needs parent in room to sleep

Struggles at bedtime

Afraid of sleeping alone

2 Sleep Onset Delay

Falls asleep within 20 mins

3 Sleep Duration

Sleeps too little

Sleeps the right amount

Sleeps same amount each day

4 Sleep Anxiety

Needs parent in room to sleep

Afraid of sleeping in the dark

Afraid of sleeping alone

Trouble sleeping away

5 Night Wakings

Moves to other's bed in night

Awakes once during night

Awakes more than once

6 Parasomnias

Wets the bed at night

Talks during sleep

Restless and moves a lot

Sleepwalks

Grinds teeth during sleep

Awakens screaming, sweating

Alarmed by scary dream

7 Sleep Disordered Breathing

Snores loudly

Stops breathing

Snorts and gasps

8 Daytime Sleepiness

Wakes by himself

Wakes up in negative mood

Others wake child

Hard time getting out of bed

Takes long time to be alert

Seems tired

Watching TV

Riding in car

***bolded questions appear on both original and abbreviated CSHQ**