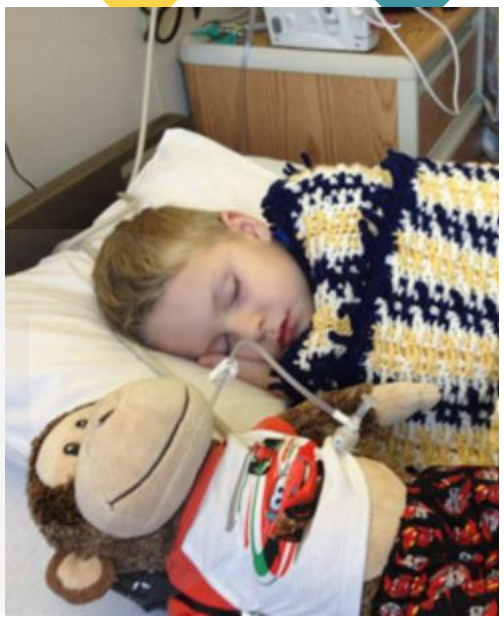
Goodnight Soon? Insomnia in a Medically Complex Toddler: A Multidisciplinary Approach

Elizabeth Super, MD; Associate Professor, Division of Pediatric Pulmonary & Sleep Medicine

David Wagner, PhD, Associate Professor, Psychology



https://tubiefriends.com/main/who-we-help/

OBJECTIVES

1. Obtain full sleep history in medically complex patient.
2. Appreciate medical comorbidities that contribute to sleep disruption.
3. Review off label medications that may be helpful for insomnia
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5. Identify potential behavioral interventions to address sleep challenges.

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Sleep History: General Fx

Medical, developmental, mental health

Current services

Home situation

School/daycare situation

General behavior

Physical activity

Mood + Anxiety/fears

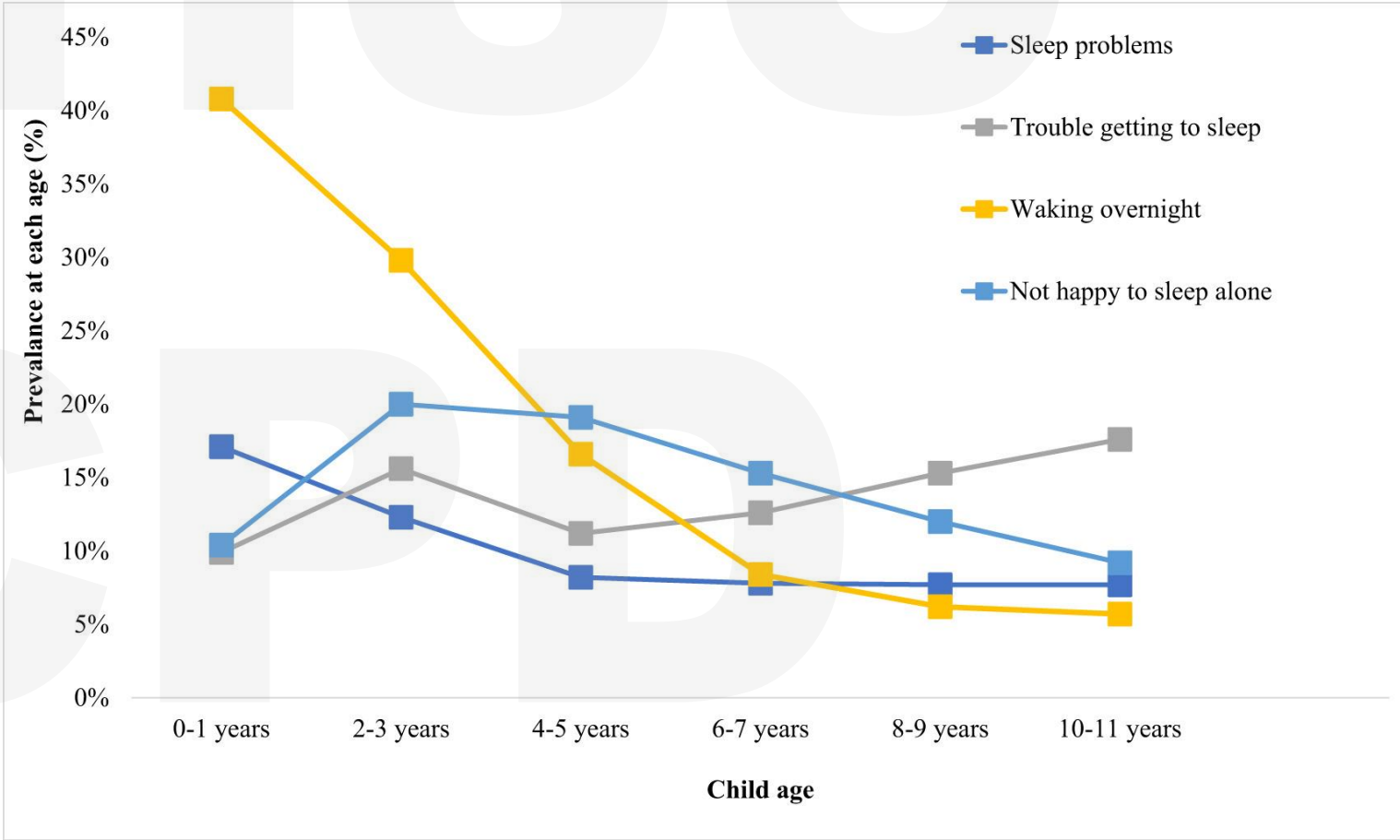
ELSEVIER

Sleep Medicine
Volume 63, November 2019, Pages 5-8

Brief Communication

Child sleep behaviors and sleep problems from infancy to school-age

Ariel A. Williamson [a b], Jodi A. Mindell [b c], Harriet Hiscock [d e f], Jon Quach [g h]



Sleep History: Daytime Sleep

- Morning: Wake time and readiness
- Falling asleep in unexpected situations?
- Fatigue
- Nap: frequency, timing, and duration
- Time and activities in bed awake
- Other: headaches, irritability…

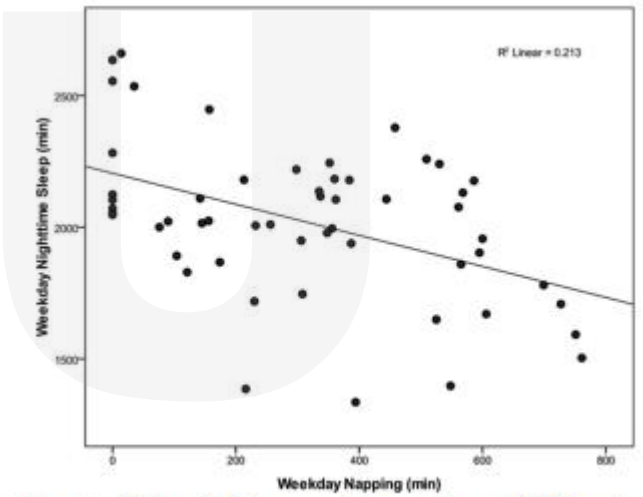


Figure 1. Relationship between weekday napping and nighttime sleep.

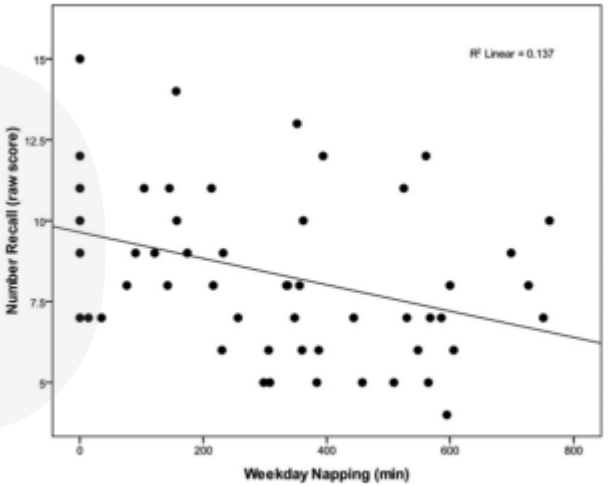


Figure 2. Association between daytime napping and auditory attention (Number Recall).

ORIGINAL ARTICLE

The Effects of Napping on Cognitive Function in Preschoolers

Lam, Janet C. MD*; Mahone, E. Mark PhD†‡; Mason, Thornton B.A. MD, PhD§; Scharf, Steven M. MD, PhD¶

Author Information

Journal of Developmental & Behavioral Pediatrics 32(2):p 90-97, February 2011. | *DOI:* 10.1097/DBP.0b013e318207ecc7

Sleep History: Night sleep

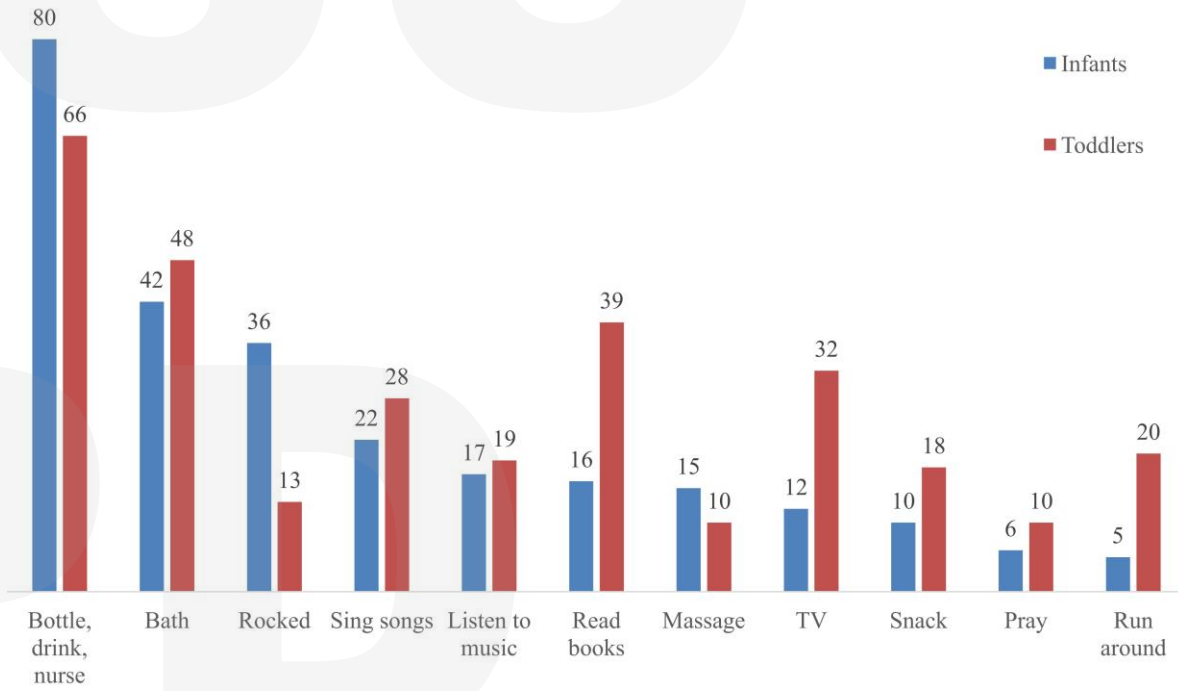
- Bedroom environment
- Routine – timing, activities, and duration
- Time in bed + Sleep onset
- Caregiver observations
- Night wakings: timing, duration
- Continence
- Other: nightmares, night terrors, other parasomnias
- Weekends?

ELSEVIER
Sleep Medicine Reviews
Volume 40, August 2018, Pages 93-108

Theoretical Review

Benefits of a bedtime routine in young children: Sleep, development, and beyond

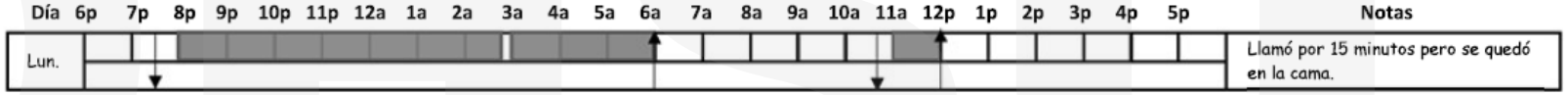
Jodi A. Mindell [a b], Ariel A. Williamson [b c]



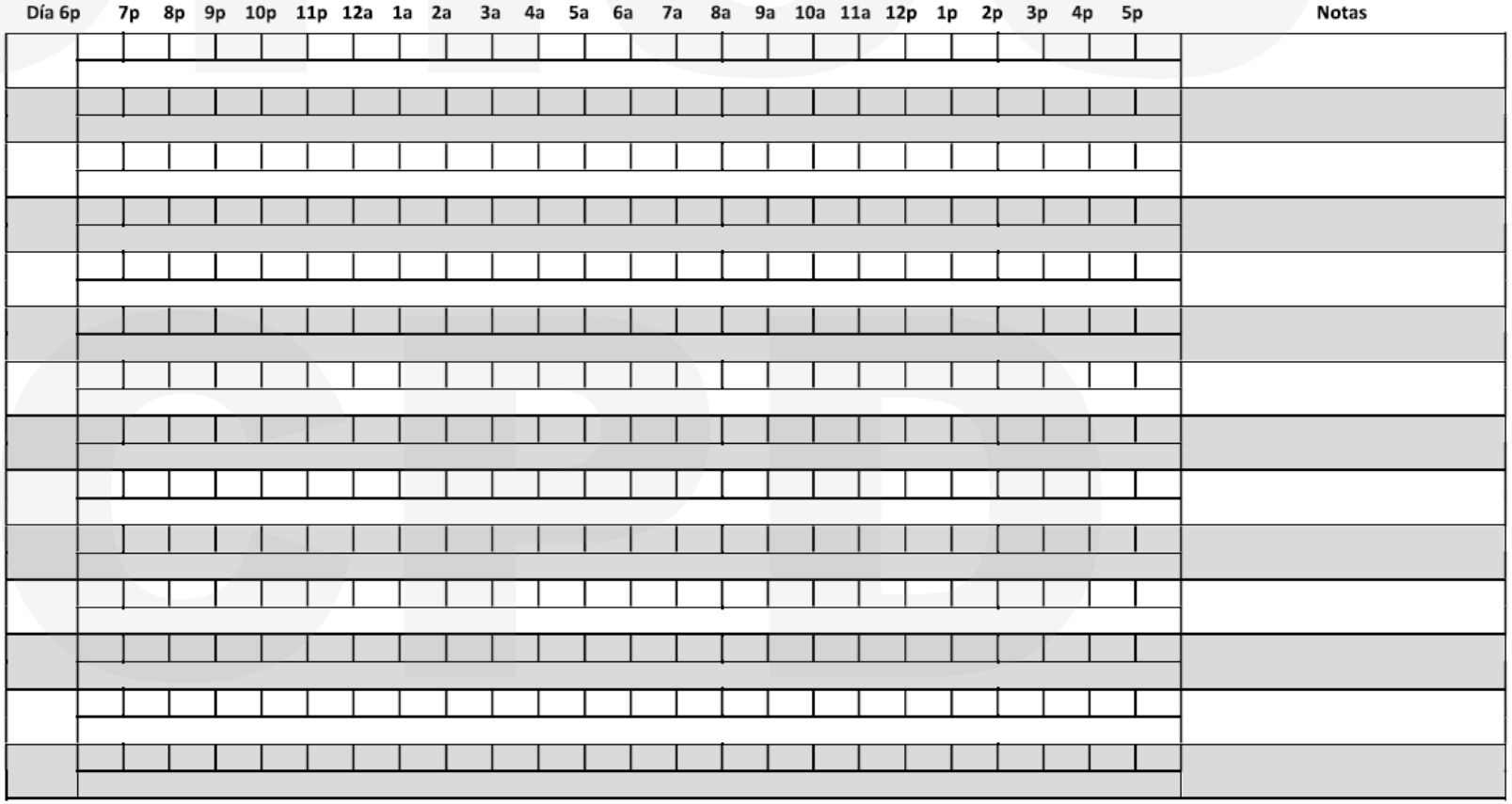
Sleep Tracking

Indicaciones: Llene cada mañana al despertar. No hay problema si usa horas aproximadas.

EJEMPLO: Se va a la cama a las 7:30 p.m.; se duerme a las 8 p.m. Se despierta por 15 minutos llamando al cuidador/a. Se despierta a las 6 a.m. Se toma una siesta de 11 a.m. a 12 p.m.



Equivalencias: ↓ = Se metió en la cama ↑ = Se salió de la cama Sombree todo el tiempo que se pasó dormido/a, siestas incluidas



Solo para uso del personal. Profesional médico/a: Apunte el número de expediente médico si se necesita escanear para el historial.

OHSU Pediatric Sleep Clinic 12/2022
503-494-8023

Sleep Questionnaires

Considerations

- Age
- Time
- Domains
- Reporter

Sleep Medicine Reviews 57 (2021) 101425

Contents lists available at ScienceDirect

Sleep Medicine Reviews

journal homepage: www.elsevier.com/locate/smrv

CLINICAL REVIEW

Pediatric sleep health: It matters, and so does how we define it☆

Lisa J. Meltzer [a, *], Ariel A. Williamson [b, c], Jodi A. Mindell [b, d]

Table 3
Examples of subjective pediatric questionnaires and the domains of sleep health measured.

Subjective Measures	Satisfaction	Alertness/Sleepiness	Timing	Efficiency	Duration	Behaviors	Age	Items	Reporter
Children's Sleep Habits Questionnaire [118]	✓	✓	✓	✓	✓	✓	2–10 yrs	33/45	Parent
Children's Report of Sleep Patterns [119–121]	✓	✓	✓	✓	✓	✓	8–18 yrs	60	Self
School Sleep Habits Survey [122]	✓	✓	✓	✓	✓	✓	13–19 yrs	45	Self
Brief Infant Sleep Questionnaire [123, 124]	✓		✓	✓	✓	✓	0–3 yrs	13/25[a]	Parent
BEARS [113]		✓	✓		✓	✓	2–18 yrs	7–8	Parent/Self
PROMIS Pediatric Sleep Disturbance [168]	✓						8–18 yrs	4/8/15	Self
							5–18 yrs	4/8/15	Parent-proxy
Sleep Disturbance Scale for Children [114]		✓			✓		6–15 yrs	27	Parent
Modified Epworth Sleepiness Scale [169]/Epworth Sleepiness Scale for Children and Adolescents [170]		✓					12–18 yrs	8	Self
							2–18 yrs	8	Parent-proxy
Pediatric Sleep Questionnaire [171]		✓					2–18 yrs	22	Parent
Pediatric Daytime Sleepiness Scale [172]		✓					11–15 yrs	8	Self
PROMIS Pediatric Sleep Related Impairment [168]		✓					8–18 yrs	4/8/15	Self
							5–18 yrs	4/8/15	Parent-proxy
Morningness-Eveningness Questionnaire for Children [173]			✓				11–12 yrs	10	Self

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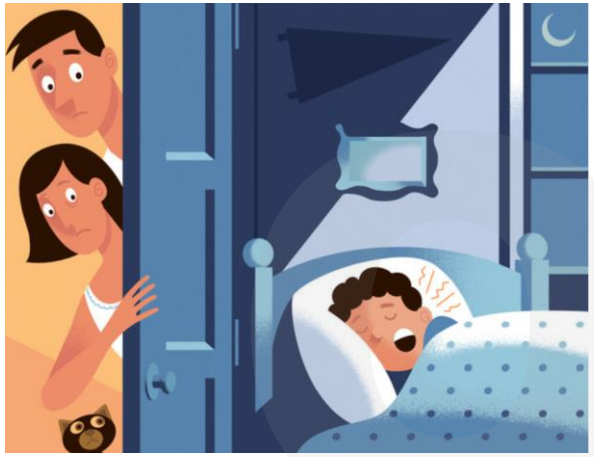


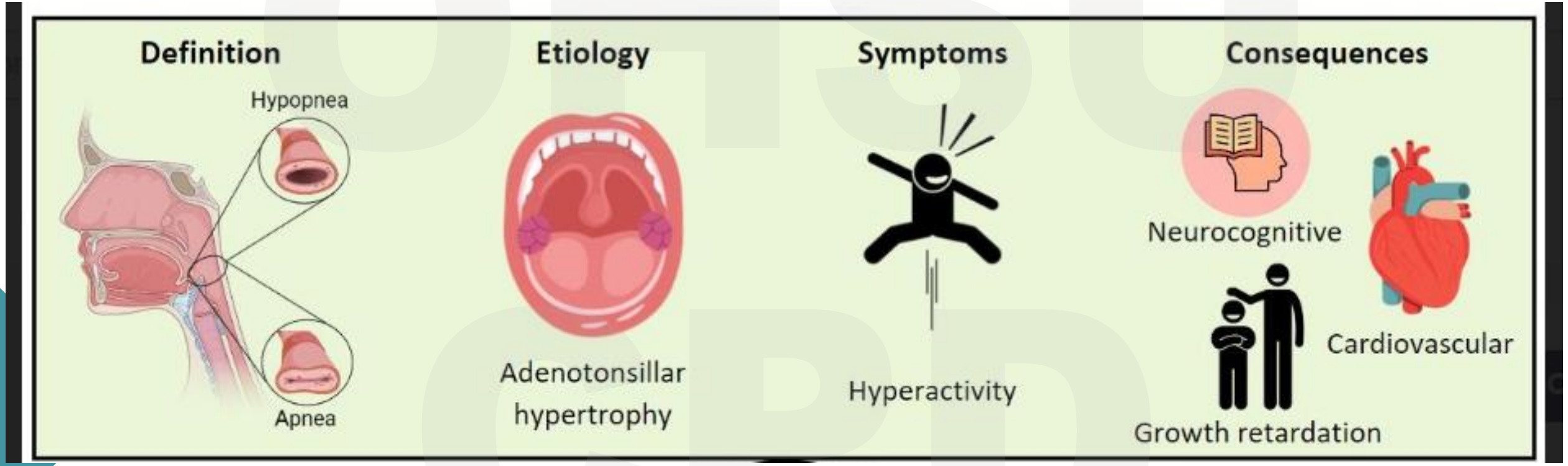
Obstructive Sleep Apnea

Disorder of breathing during sleep that causes:

Prolonged partial or complete upper airway obstruction.

Disrupts gas exchange and sleep patterns.

OBSTRUCTIVE SLEEP APNEA



Biomedicines 2023, 11, 1708.

https://pubmed.ncbi.nlm.nih.gov/37371803/

EPILEPSY

Sleep, especially deep NREM Sleep increases interictal epileptiform activity.

Sleep increases certain seizure types and the rate of generalization of partial seizures.

Sleep disorders, particularly sleep apnea, exacerbate seizures.

Seizures, in turn, can disrupt sleep structure, particularly rapid-eye-movement sleep.

CLINICAL REVIEW

Sleep disruption in children and adolescents with epilepsy: A systematic review and meta-analysis

Alice A. Winsor [a, b, *], Caroline Richards [b], Stacey Bissell [b], Stefano Seri [c], Ashley Liew [d], Andrew P. Bagshaw [a, b]

[a] Centre for Human Brain Health, University of Birmingham, UK
[b] School of Psychology, University of Birmingham, UK
[c] Birmingham Children's Hospital, Birmingham Women's and Children's Hospital NHS Foundation, UK
[d] Evelina London Children's Hospital, South London and Maudsley NHS Foundation Trust, University of Warwic

Sleep Medicine Reviews 57 (2021) 101416

- Relative to healthy children, children with Epilepsy:
  - Reduced sleep time, sleeping on average 34 mins less
  - More night waking, parasomnias and sleep disordered breathing
  - Children with drug resistant epilepsy appear to be most vulnerable to sleep disturbances, although the relative contribution of anti-epileptic medications or recurrent seizures is not clear.

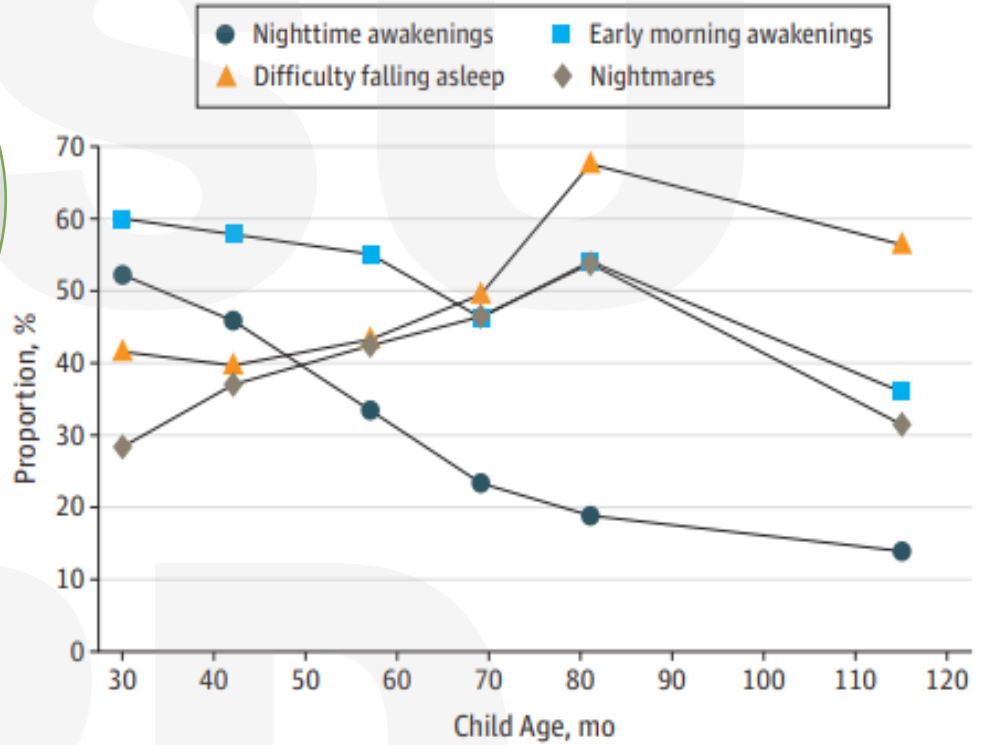
Atopic Dermatitis

Pruritis often worst at night: SCRATCHING

Difficulty falling asleep

Disruption in ongoing sleep

Figure 2. Proportion of Children With Active Atopic Dermatitis Experiencing Sleep-Quality Disturbances by Child Age



Proportion of children with active atopic dermatitis reporting each of the 4 sleep-quality disturbances based on cross-sectional data at different child ages.

JAMA Pediatr. 2019;173(5):e190025. doi:10.1001/jamapediatrics.2019.0025
Published online March 4, 2019.

JAMA Pediatrics | Original Investigation

Association of Atopic Dermatitis With Sleep Quality in Children

Faustine D. Ramirez, BA; Shelley Chen, BS; Sinéad M. Langan, FRCP, MSc, PhD; Aric A. Prather, PhD; Charles E. McCulloch, PhD; Sharon A. Kidd, MPH, PhD; Michael D. Cabana, MD, MPH; Mary-Margaret Chren, MD; Katrina Abuabara, MD, MA, MSCE

JAMA Pediatr. 2019;173(5):e190025. doi:10.1001/jamapediatrics.2019.0025
Published online March 4, 2019.

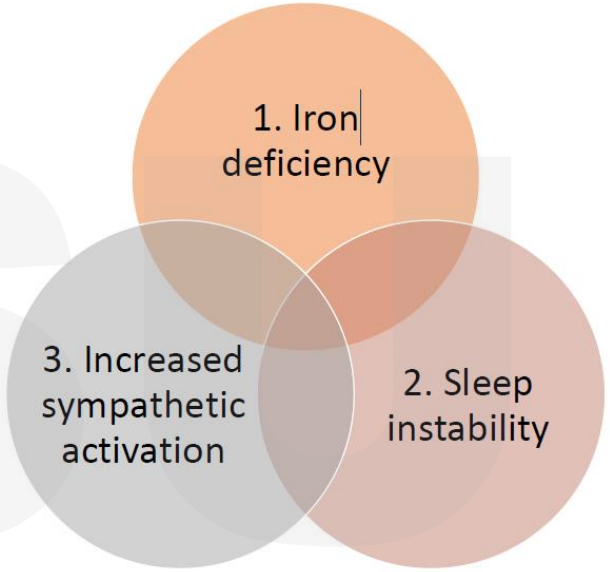
Longitudinal cohort from 1990 to 2008: 4938 children (35.3%) with Atopic Dermatitis:

Children with active Atopic Dermatitis:

More likely to report worse sleep quality at all time points, with a nearly 50% higher odds of experiencing more sleep-quality disturbances.

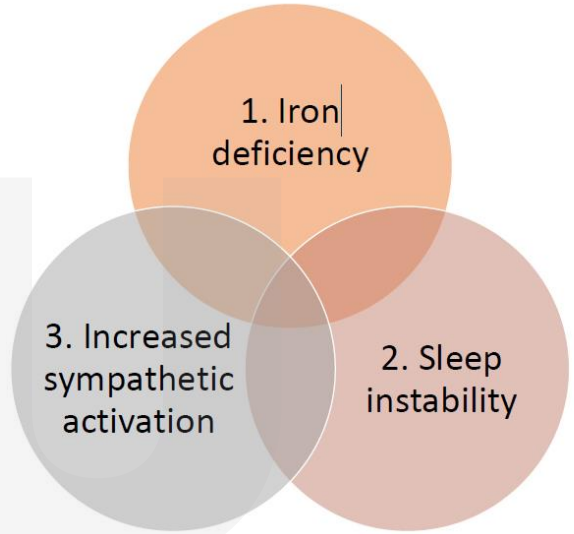
Children with more severe active disease and with comorbid asthma or allergic rhinitis had worse sleep quality.

RESTLESS SLEEP



- Restless sleep is a frequent parental concern.
- Seen more commonly in patients with ADHD, Atopic Dermatitis, Iron Deficiency Anemia.

RESTLESS SLEEP DISORDER



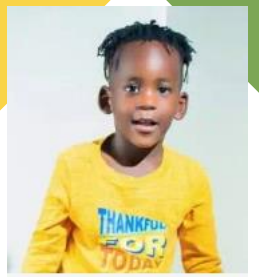
Differential Diagnosis

	RSD	RLS	PLMD
Clinical presentation	Restless sleep Daytime impairment	Urge to move legs Sleep-onset insomnia Daytime impairment	Periodic leg movements of sleep Daytime impairment
Diagnosis	Clinical + PSG	Clinical	Clinical + PSG
PSG findings	Body movement index > 5 per hour	May or may not have elevated PLMI	PLMI > 5
Pathophysiology	Sleep instability Iron deficiency Sympathetic activation	Dopamine dysfunction Iron deficiency	Unknown (probably shared with RLS)

Abbreviations: PLMI, PLMS index; PSG, polysomnogram; RLS, restless legs syndrome; RSD, restless sleep disorder.

Diagnosis is based on clinical history *and* objective findings on Sleep Study.

Case Example



Dravet Syndrome Foundation

21 month old male with Dravet Syndrome with disrupted sleep, mouth breathing, choking and gasping during sleep.

Worsening sleep after Clobazam dose increased. Now weaning Clobazam, Levetiracetam and starting Flenfluramine.

Started Melatonin 1 mg, now waking less frequently.

Sleep study at 22 months:

Negative for obstructive sleep apnea, normal oxygen and C02 levels.

Abnormal background on EEG with diffuse slowing and superimposed beta activity (beta activity can be seen due to medication effect such as benzodiazepines or barbiturates. Diffuse slowing is suggestive of encephalopathy of various etiologies).

Increased Periodic Limb Movements, majority not associated with arousal from sleep.

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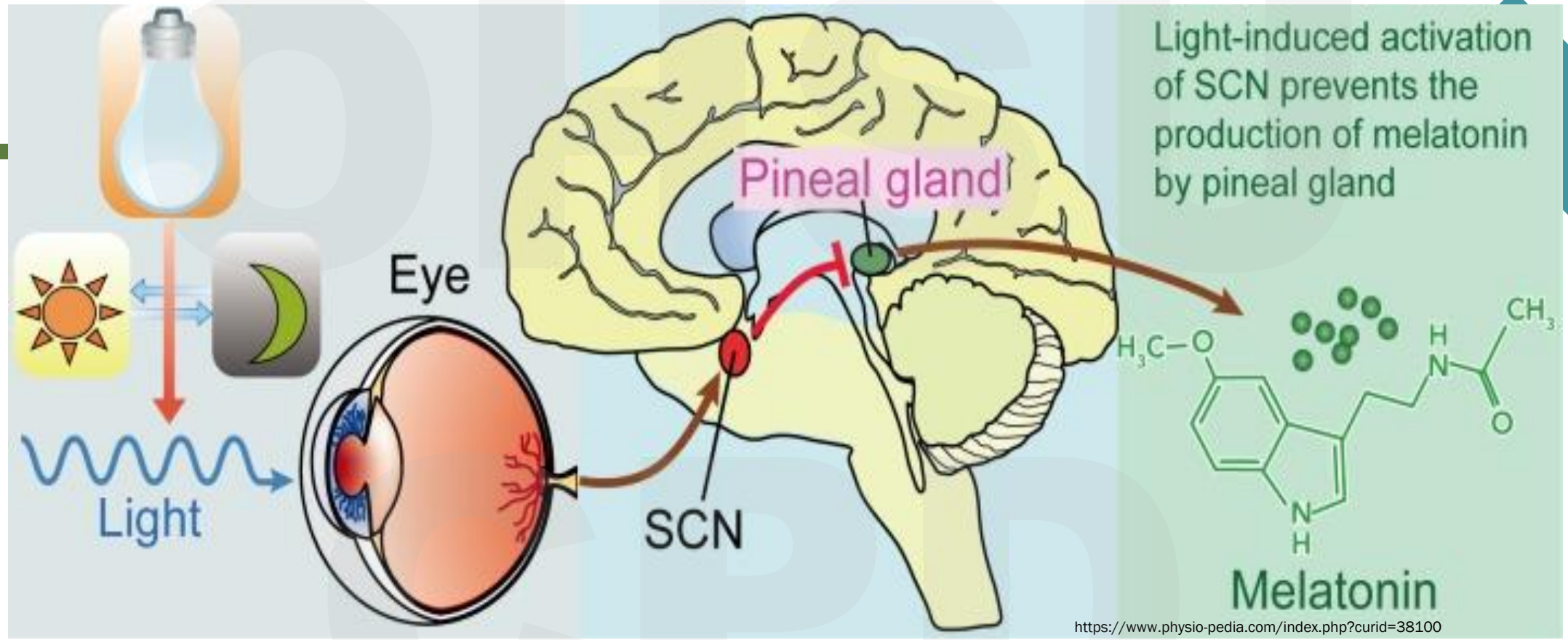
- DISCUSSION OF OFF-LABEL MEDICATIONS.
- THERE ARE NO FDA APPROVED MEDICATIONS FOR PEDIATRIC INSOMNIA.

MELATONIN



Production and secretion begin in the evening and peak during the night between 2:00 and 4:00 AM

Melatonin production becomes regular at **3 months** of age.

Exogenous Melatonin does not affect sleep architecture (Bruni et al., 2015).

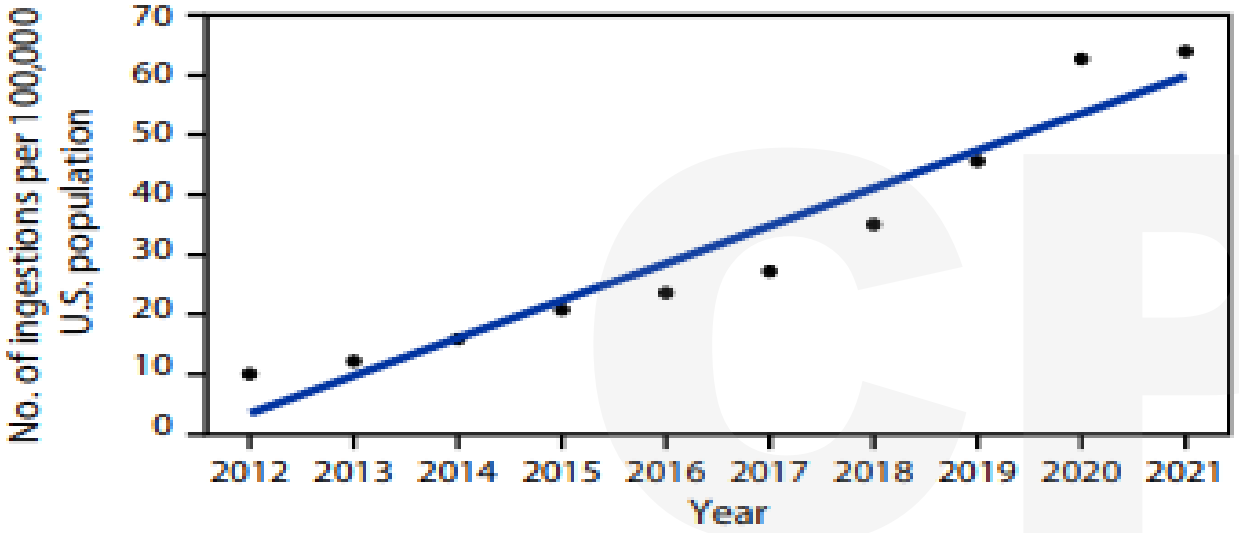
MELATONIN INGESTIONS

Centers for Disease Control and Prevention
MMWR
Morbidity and Mortality Weekly Report
Weekly / Vol. 71 / No. 22
June 3, 2022

Pediatric Melatonin Ingestions — United States, 2012–2021

Karima Lelak, MD[1]; Varun Vohra, PharmD[2]; Mark I. Neuman, MD[3]; Michael S. Toce, MD[3]; Usha Sethuraman, MD[1,4]

FIGURE 1. Rate* of pediatric† melatonin ingestions reported to poison control centers, by year§ — United States, 2012–2021



* Ingestions per 100,000 population, based on U.S. Census Bureau Annual Estimate.
† Aged ≤19 years.
§ Linear trend, p<0.001.

- 260,435 pediatric melatonin ingestions were reported to National Poison Data System from 2012-2021.

4.9% of all pediatric ingestions in 2021 compared with 0.6% in 2012.

JCSM
Journal of Clinical Sleep Medicine

SCIENTIFIC INVESTIGATIONS

Melatonin Natural Health Products and Supplements: Presence of Serotonin and Significant Variability of Melatonin Content

Lauren A.E. Erland, MSc; Praveen K. Saxena, PhD

Gosling Research Institute for Plant Preservation, Department of Plant Agriculture, University of Guelph, Guelph, Ontario, Canada

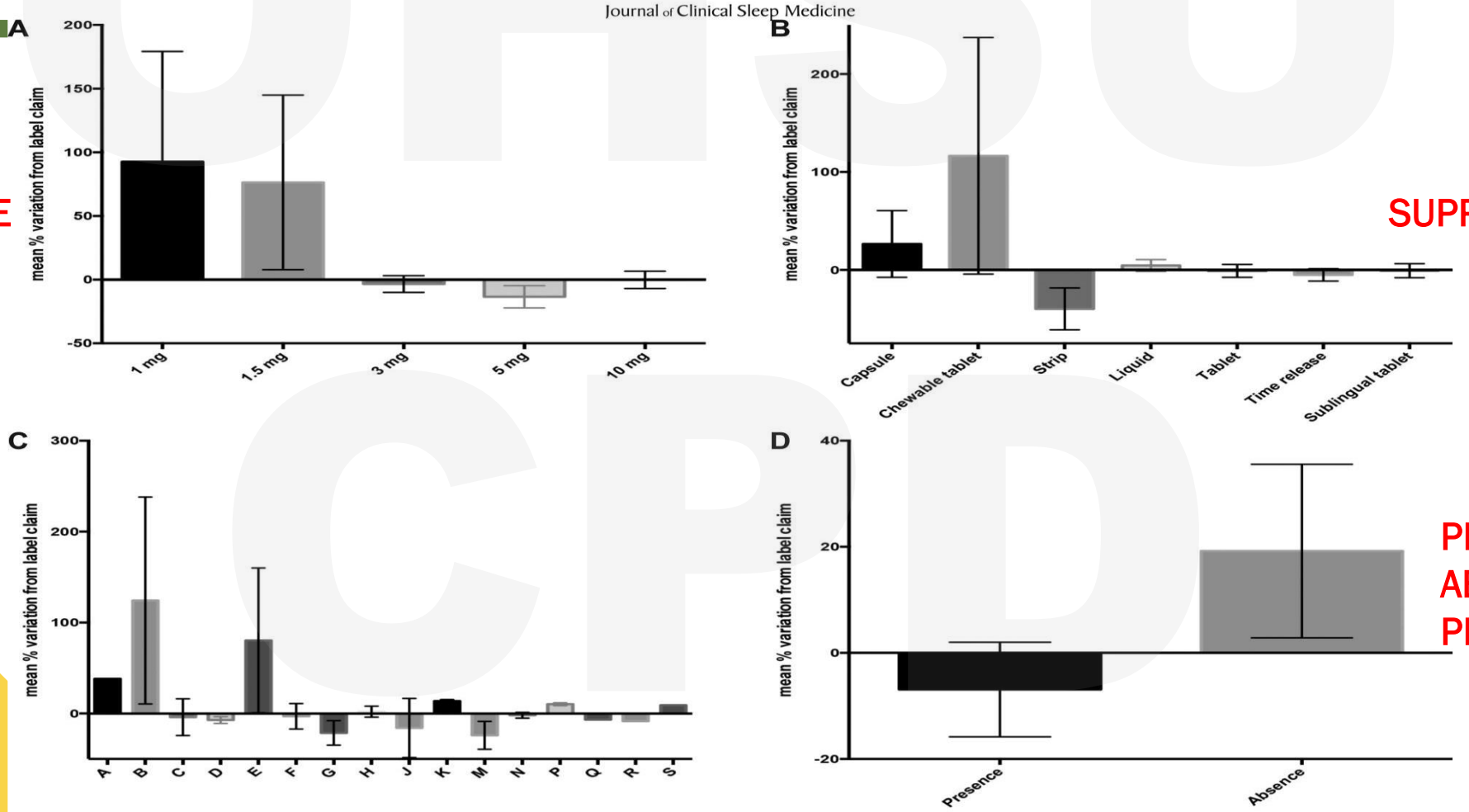
MEAN PERCENT VARIABILITY ACROSS MELATONIN SUPPLEMENTS

LABEL CLAIM VALUE

SUPPLEMENT TYPE

BRAND

PRESENCE OR ABSENCE OF OTHER PLANT EXTRACTS



Erland LA, Saxena PK. Melatonin natural health products and supplements: presence of serotonin and significant variability of melatonin content. J Clin Sleep Med. 2017;13(2):275–281.

MELATONIN EVIDENCE:

Dose 1–10 mg given 30– 60 min before bedtime alone or in combination with cognitive-behavioral therapy is effective in insomnia of children with:

Autism Spectrum Disorder (Cortesi, Giannotti, Sebastiani, Panunzi, & Valente, 2012; Goldman et al., 2014)

Angelman syndrome (Andersen, Kaczmarska, McGrew, & Malow, 2008; Braam, Didden, Smits, & Curfs, 2008)

Rett syndrome (McArthur & Budden, 1998)

ADHD, but did not improve core symptoms (Cortese et al., 2013); RCT showed efficacy in reducing sleep latency in ADHD children with sleep onset delay caused by methylphenidate (Mohammadi et al., 2012)

Smith–Magenis syndrome (De Leersnyder et al., 2001)

MELATONIN EVIDENCE:

- Prolonged release melatonin – improved night wakings in neurodevelopmental conditions.[4-5]
- Prolonged release melatonin may be more efficacious for night wakings given its longer duration of action and showed efficacy in an open label trial[6] and in randomized clinical trials[7-8]
- Minimal adverse effects and pubertal development was not delayed in children followed over 2 years. [9]
- Previous reports of poor seizure control and poor asthma control have not been confirmed.

1Anderson 2008; 2Rossignol 2011; 3 Cortesi 2011; 4Giannotti 2006; 5Cortesi 2012; 6Leersnyder, 2011; 7Gringras, 2017; 8Maras, 2018, 9Malow, 2020

MELATONIN DOSING

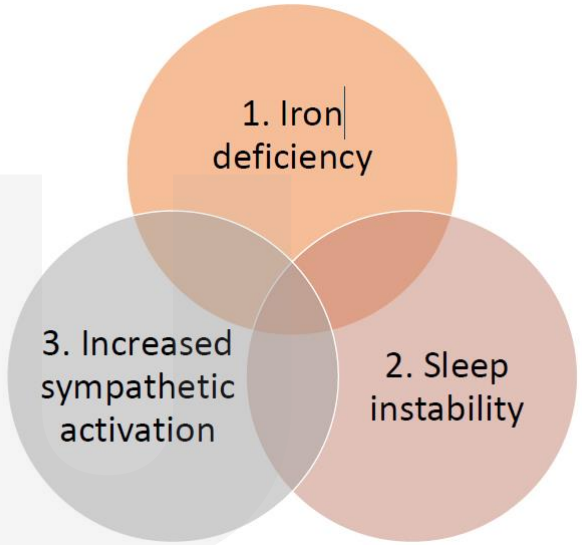
QualitySupplements

- Melatonin 3 mg Tablets – NatureMade
- Melatonin 5 mg Tablets – NatureMade
- Melatonin 5 mg Fast Dissolve Tablets – Natrol

https://www.quality-supplements.org/usp_verified_products?search_api_fulltext=melatonin

- 30 minutes prior to sleep for hypnotic effect
- Maximum dose: <40 kg: 3 mg
- >40 mg 5 mg
- **Side effects:** Headaches, confusion, dizziness, cough, and rashes have been reported, but these common symptoms are likely to be coincidental or caused by impurities in the unregulated formulations of melatonin. Most commonly reported is vivid dreams.

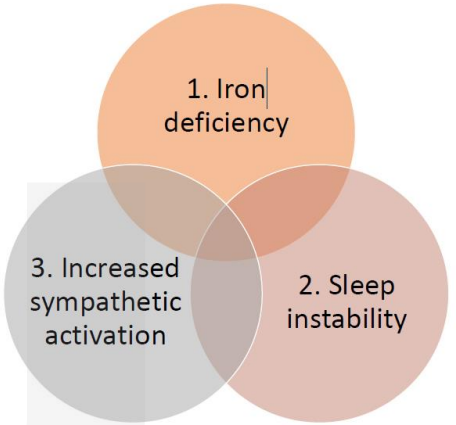
Iron Supplementation



- Goal Ferritin above 50.
- Oral and IV Iron has shown clinical improvement with fewer movement and less sleepiness.
- Oral iron 3 mg elemental iron/kg/day or 65mg/day for three months. Can dose every other day.
- Optimize absorption with concurrent vitamin C, avoid dairy/antacids.

DelRosso et al Sleep Med Clin 16 (2021) 381–387
DelRossoL et al Sleep Medicine 87 (2021) 114-118

Iron Supplementation



- Unpleasant taste, patients with poor absorption
- Many preparations available that may be better tolerated: (Nova Ferrum liquid, Celebrate Iron Chewables, Lifeable Iron Gummies).
- Constipation, GI upset, nausea, teeth staining with liquid.
- Repeat ferritin 3 months after supplementation.

HYDROXYZINE

- First generation anti-histamine
- Rapidly absorbed and have rapid onset of action.
- Effects on sleep architecture appear to be minimal.
- Consider use in children with comorbid atopic dermatitis for disturbed sleep due to itch.

HYDROXYZINE

- Half life: 6-24 hours
- Not habit forming
- Tolerance increases with increased use
- Paradoxical reactions (~10%)

CLONIDINE

Centrally-acting alpha-2 adrenergic agonist that inhibits sympathetic outflow, and also has sedative effects.

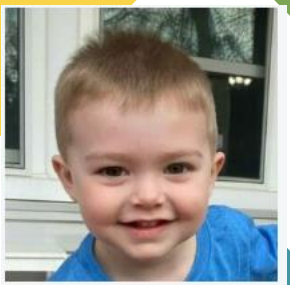
- **Autism Spectrum Disorder:** open-label study of 17 children (ages 4-16 years) prescribed clonidine for sleep onset insomnia or night wakings (0.05 to 0.1 mg). All with sleep onset delay improved and 16/17 with night wakings improved.[1]
- In **neurodevelopmental disorders,** 6 children (ages 4-15 years) had fewer night wakings and longer sleep duration with 0.15-0.225 mg/daily (2 divided doses).[2]
- Retrospective review of 62 children and young adults (ages 6-24 years) showed decrease in Pittsburgh Sleep Quality Index (PSQI) scores, especially sleep latency and subjective sleep quality. Dose not specified.[3]

•1 Ming, 2008; 2Ingrassia, 2005; 3Jang, 2022

CLONIDINE

- Immediate release: rapidly absorbed
- Onset of action within one hour and peak effects 2-4 hours
- Mid-sleep awakening may occur as blood levels drop during the night.
- Narrow therapeutic index: risk for overdose
- Side effects: pallor, tachycardia, hypotension, irritability, dizziness, nausea, and increased night wakings. Rebound hypertension on withdrawal. Blood pressure monitoring after starting and every three months.

Case Example



Benton

Dravet Syndrome Foundation

Returned 10 months later:

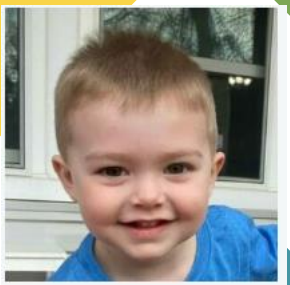
Takes 2 mg melatonin around 10-10:30 pm.

Falling asleep quickly, but waking between 1:30-3:30 am, falls back to sleep at 7 am. Shares bed with parents.

Falls asleep mostly on his own but wakes up screaming, climbing around in bed.

Is itchy at night.

Case Example



Dravet Syndrome Foundation

Goal bedtime: 8:30 pm

Increase Melatonin to 3 mg

Due to comorbid eczema: trial of hydroxyzine and referral to Dermatology

Continue supplemental iron; Ferritin with next lab draw.

Referral to Behavioral Sleep Psychology

Goal to minimize middle the night reinforcement if patient is awake.

Referral to CDRC Equipment Clinic for safety sleeper bed.

Follow up in 8 weeks.

Home Medical Beds

“Our beds offer unparalleled safety features that prevent elopement and entrapment, such as opening only from the outside and a coverlet sheet. Crafted with care, each bed model enhances sleep for both families and their loved ones.”

Home Medical Beds

- More recent requests due to direct marketing through social media
- Cubby Beds, Sleep Safe, Beds by George
- Doernbecher CDRC Equipment Clinic (referrals for wheelchairs, mobility equipment
- Physical Therapy Equipment Evaluation considered letter of medical necessity
- Can take at least three months, and can be very difficult to be approved by insurance

Case Example Follow Up

Jo Jo

Dravet Syndrome Foundation

Two Months Later:

Marked improvement in sleep onset and sleep consolidation with hydroxyzine and melatonin.

One nap per day
ABA therapy starting shortly
Upcoming CDRC Equipment Clinic Appointment
Upcoming Behavioral Sleep Medicine appointment

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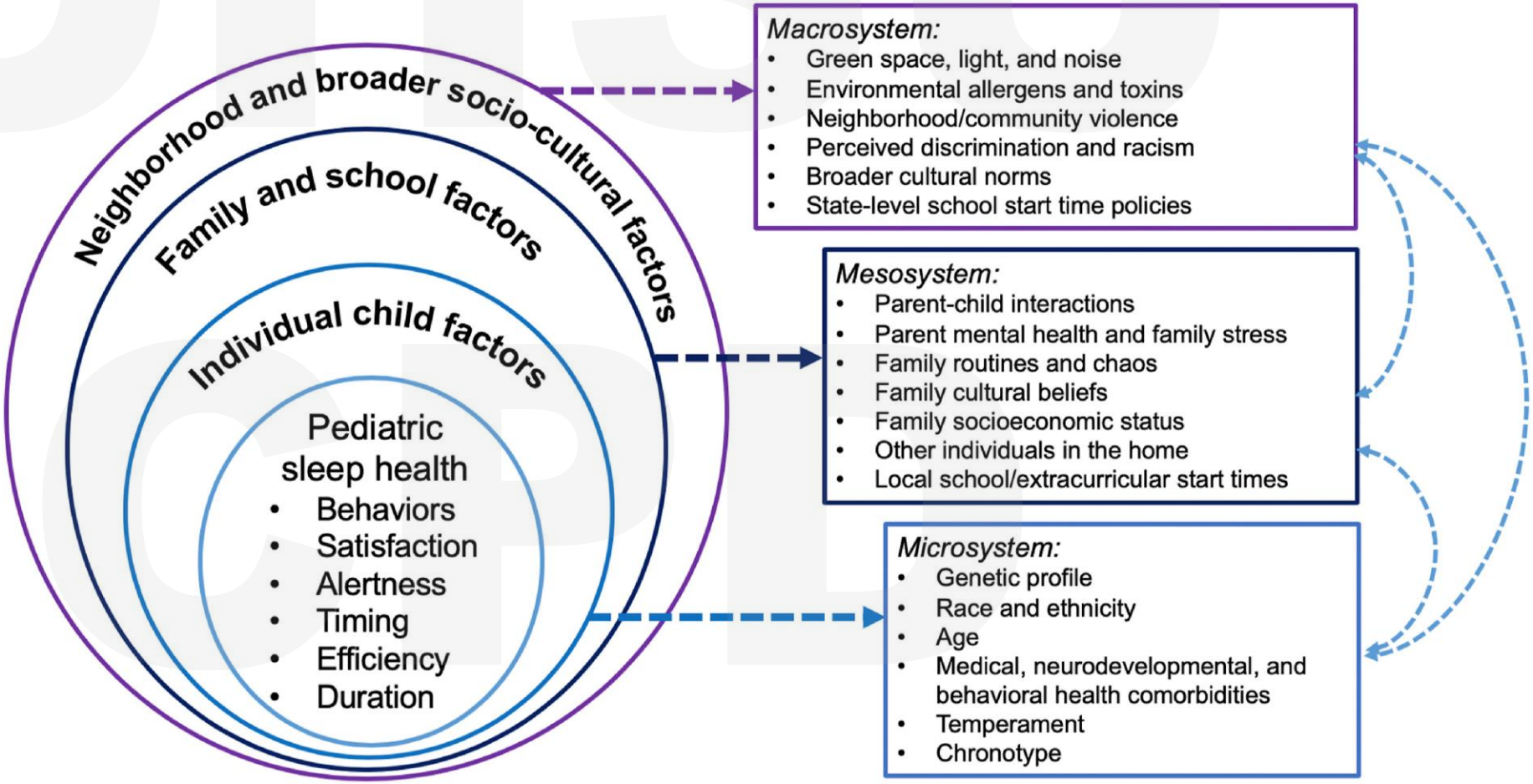
Socioecological framework

Sleep Medicine Reviews
Volume 57, June 2021, 101425

Clinical Review

Pediatric sleep health: It matters, and so does how we define it ☆

Lisa J. Meltzer [a], Ariel A. Williamson [b c], Jodi A. Mindell [b d]



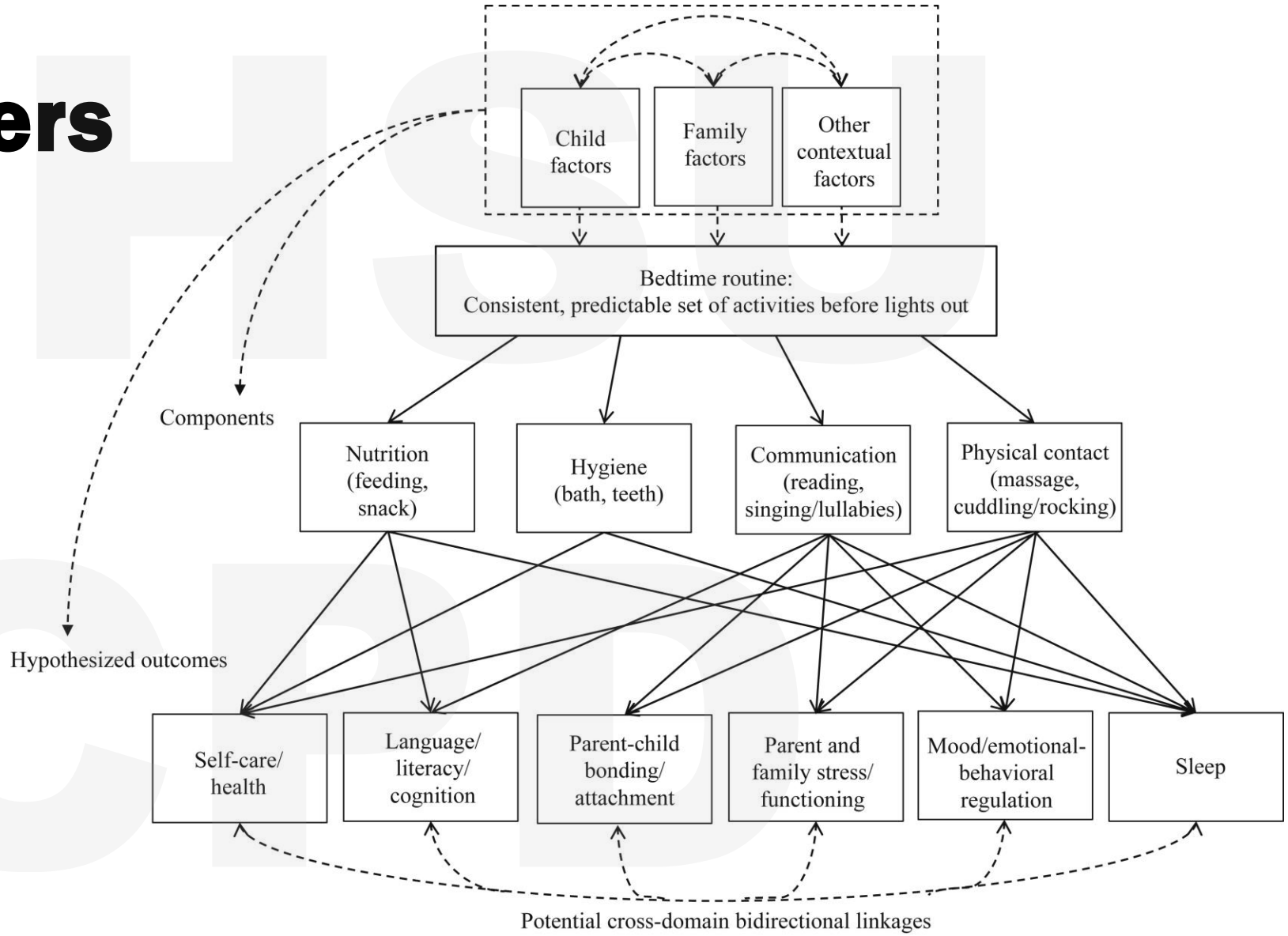
Context Matters

Sleep Medicine Reviews
Volume 40, August 2018, Pages 93-108

Theoretical Review

Benefits of a bedtime routine in young children: Sleep, development, and beyond

Jodi A. Mindell [a b], Ariel A. Williamson [b c]



Take Home Message

Consider

- Cultural factors
- SES
- Parent Stress
- Family roles/beliefs
- Social support
- Readiness

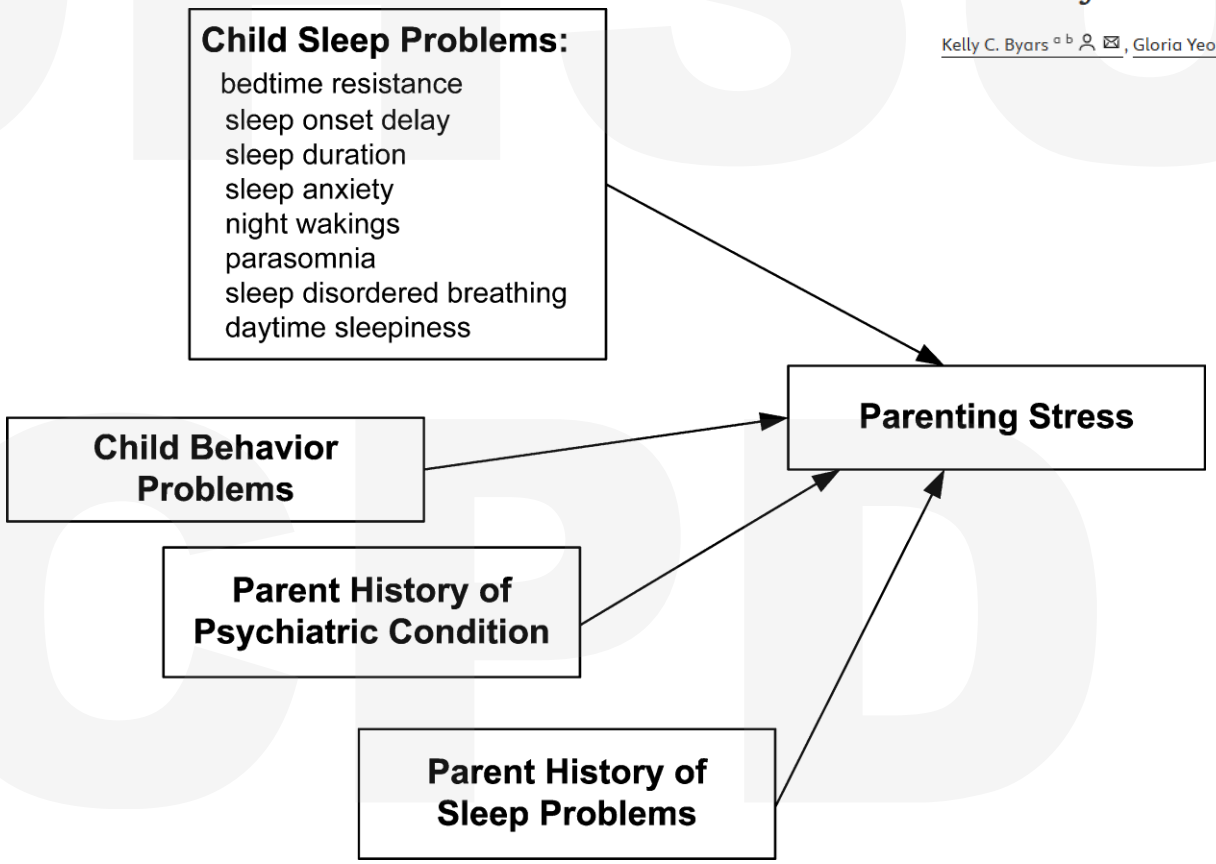
ELSEVIER

Sleep Medicine
Volume 12, Issue 9, October 2011, Pages 898-905

Original Article

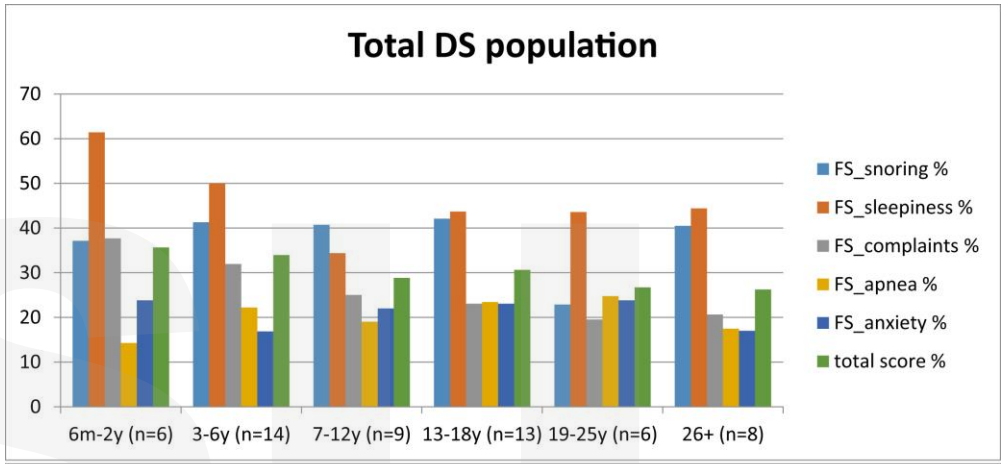
Parental functioning and pediatric sleep disturbance: An examination of factors associated with parenting stress in children clinically referred for evaluation of insomnia

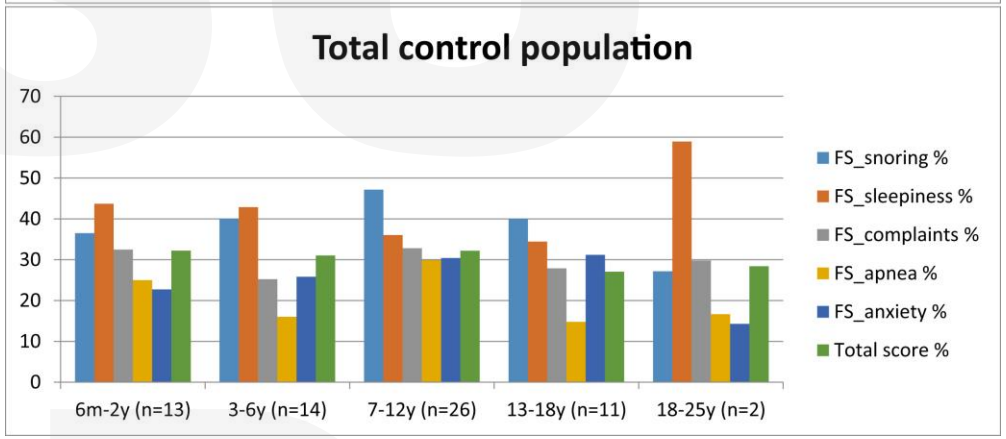
Kelly C. Byars [a b], Gloria Yeomans-Maldonado [b], Jennie G. Noll [b c]



Case Example

- Family goals:
  - Reduce waking and duration
  - Transfer to own bed/room
- Factors to consider
  - Family structure: other children, employment (late shift)
  - Existing services
  - Daytime activity
  - Anxiety
  - Safety concerns





European Journal of Paediatric Neurology
Volume 23, Issue 1, January 2019, Pages 61-69

Original article

More daytime sleepiness and worse quality of sleep in patients with Dravet Syndrome compared to other epilepsy patients

An-Sofie Schoonjans [a], Shauni De Keersmaecker [b], Maxime Van Bouwel [b], Berten Ceulemans [a]

OBJECTIVES

1. Obtain full sleep history in medically complex patient.
2. Appreciate medical comorbidities that contribute to sleep disruption.
3. Review off label medications that may be helpful for insomnia
4. Recognize systemic factors within families that impact sleep
5. Identify potential behavioral interventions to address sleep challenges.

Behavioral Interventions

Typical challenges:

- Delayed sleep onset
- Leaving bedroom
- Nighttime waking
- Requires caregiver present

Considerations:

- Age
- Developmental level
- Family structure
- Daytime behavior

Journal of Sleep Research

REVIEW PAPER | Full Access

Interventions to control children's screen use and their effect on sleep: A systematic review and meta-analysis

Katie B. Martin, Jana M. Bednarz, Edoardo C. Aromataris

Volume 30, Issue 3
June 2021
e13130

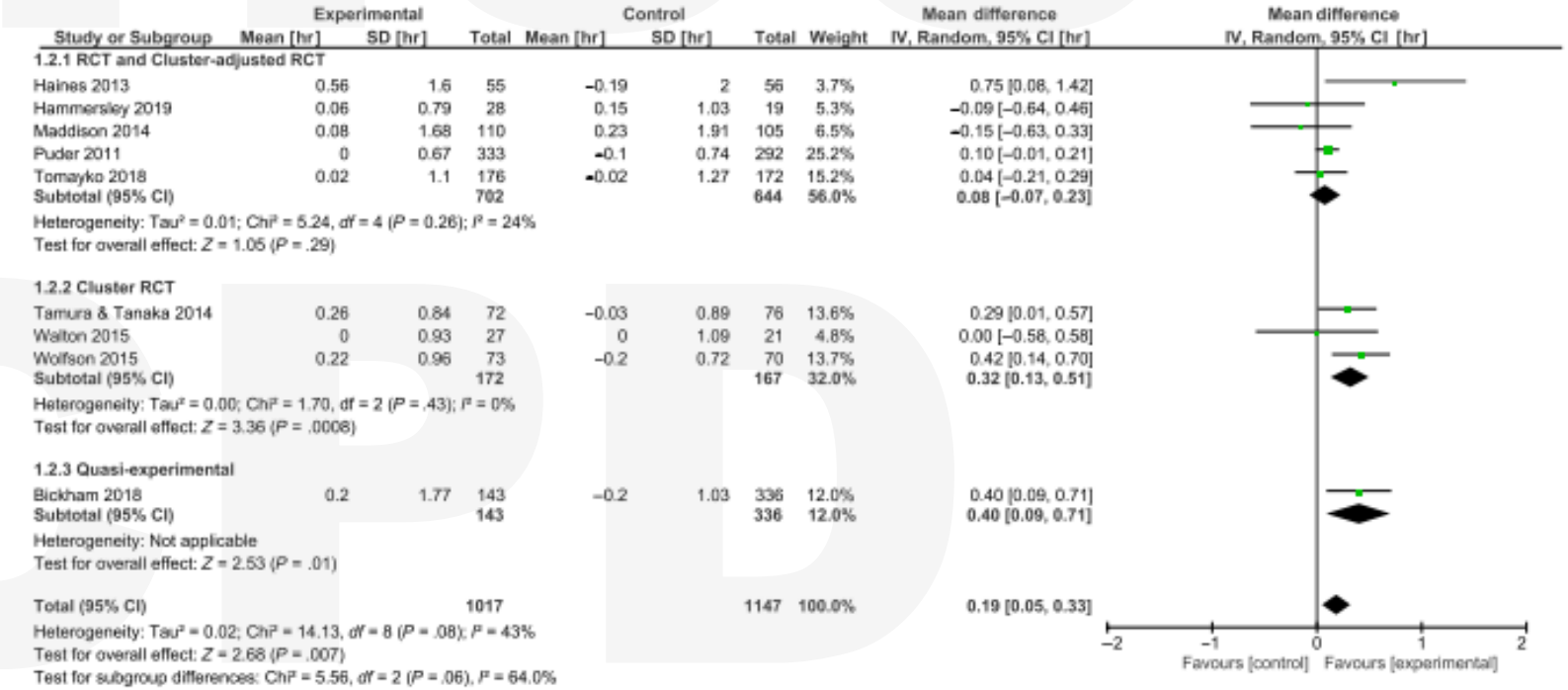


FIGURE 3 Increase in sleep duration (hr/day) from baseline following intervention, by study design

Behavioral Interventions: Bedtime Routine

- Issue: Not falling asleep consistently
- Benefits: Pattern of behaviors child will learn to connect with sleep
- Considerations:
  - All should take place outside of bed
  - Should end close to typical sleep onset

- Important components (Mindell & Williamson, 2018)
  - Same order each night
  - Several adaptive activities
  - + parent-child interaction
  - Avoid maladaptive components
  - Consider family factors

Behavioral Interventions: Faded Bedtime Routine

- Issue: Large gap between routine and sleep onset
- Benefits:
  - Routine = sleep onset
  - Less time in bed/lights out awake
- Steps:
  - Temporarily push routine and bedtime later
  - Keep same wake/nap time
  - Goal = fall asleep within 15-30 minutes
  - Gradually move toward desired sleep onset

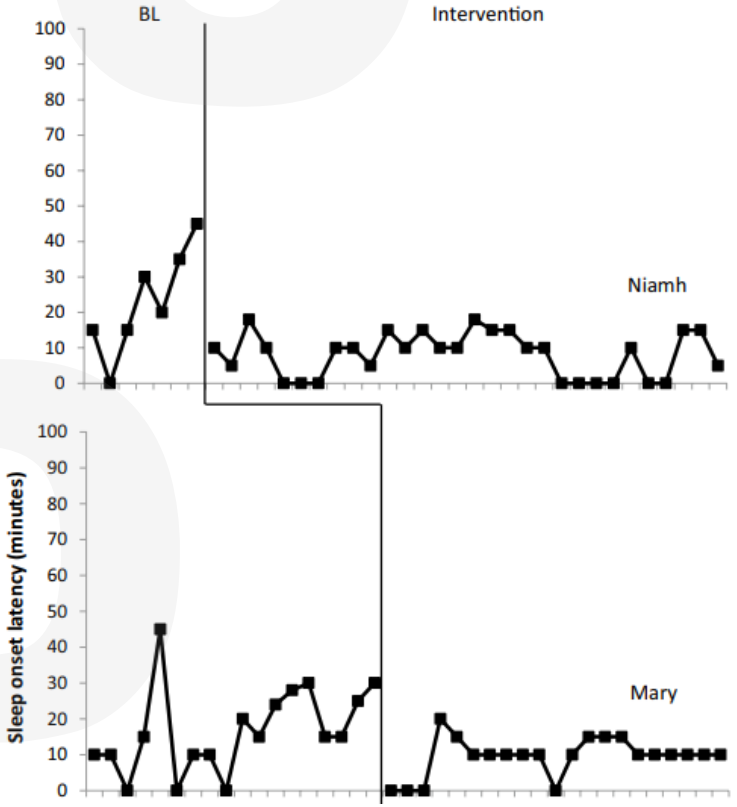
Journal of Autism and Developmental Disorders (2018) 48:1002–1019
https://doi.org/10.1007/s10803-017-3398-4

S.I. : PARENTING CHILDREN WITH ASD

Parent-Implemented Bedtime Fading and Positive Routines for Children with Autism Spectrum Disorders

Emma Delemere[1] · Katerina Dounavi[1]

Fig. 1 Sleep onset latency in minutes across nights for bed-time fading



Treating sleep onset associations and night wakings

"Whatever is needed to fall asleep is needed to get back to sleep after normal night wakings, which happen 2-6 times per night!"

Start with a bedtime routine: Move sleep onset item (feeding, TV) to beginning of routine and/or stabilize sleep onset association

Consider bedtime fading!

Choose where and how to start (gradually) removing or reducing sleep onset association (modified vs. unmodified extinction)

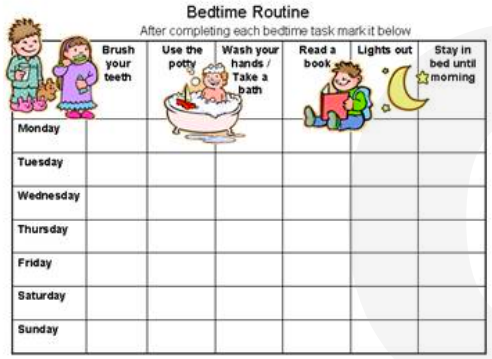
Add differential reinforcement! Address fears!

Address night awakenings once child can consistently fall asleep on their own at bedtime

Manage expectations!

Meltzer & Crabtree, 2015; Mindell, 2005

Positive reinforcement & planned ignoring



- Try a visual ***bedtime chart***
- Can add a small prize in the morning for following the routine

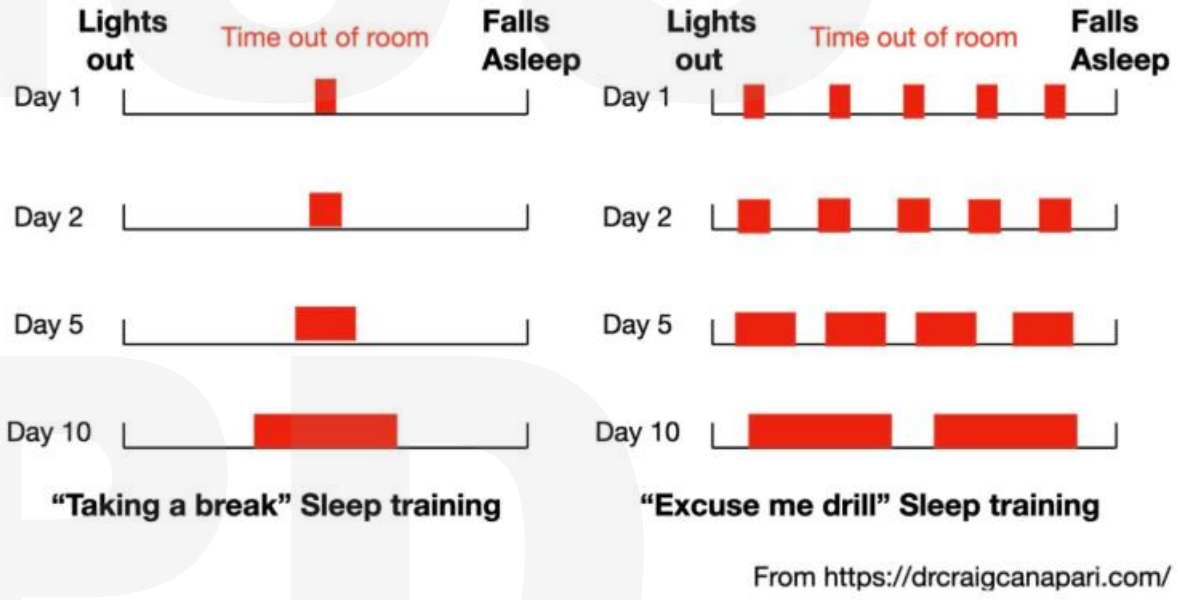
- ***Sleep fairy (or superhero)*** checks whether child stays in bed after lights out
- Child gets small prize or encouraging note in morning
- Eventually apply to night wakings

- ***OK to wake clock or light timer***
- Turns on or off when child can get out of bed
- Set for 3-5 minutes after child typically wakes
- Gradually move later

Meltzer & Crabtree, 2015; Mindell, 2005

Behavioral Interventions: Excuse Me Drill or Camping Out

- Issue: Difficulty sleeping without caregiver
- Benefits: Gradual way of child learning to fall asleep independently
- Steps: Babysleep.com



A COMPARISON OF THE EXCUSE ME DRILL AND TAKING A BREAK SLEEP TRAINING.
LIGHTS OUT: WHEN YOU TURN OUT THE LIGHTS. FALLS ASLEEP: WHEN YOUR CHILD FALLS ASLEEP
THE RED BLOCKS INDICATE WHEN YOU ARE OUT OF THE ROOM.

Case Example Follow-up

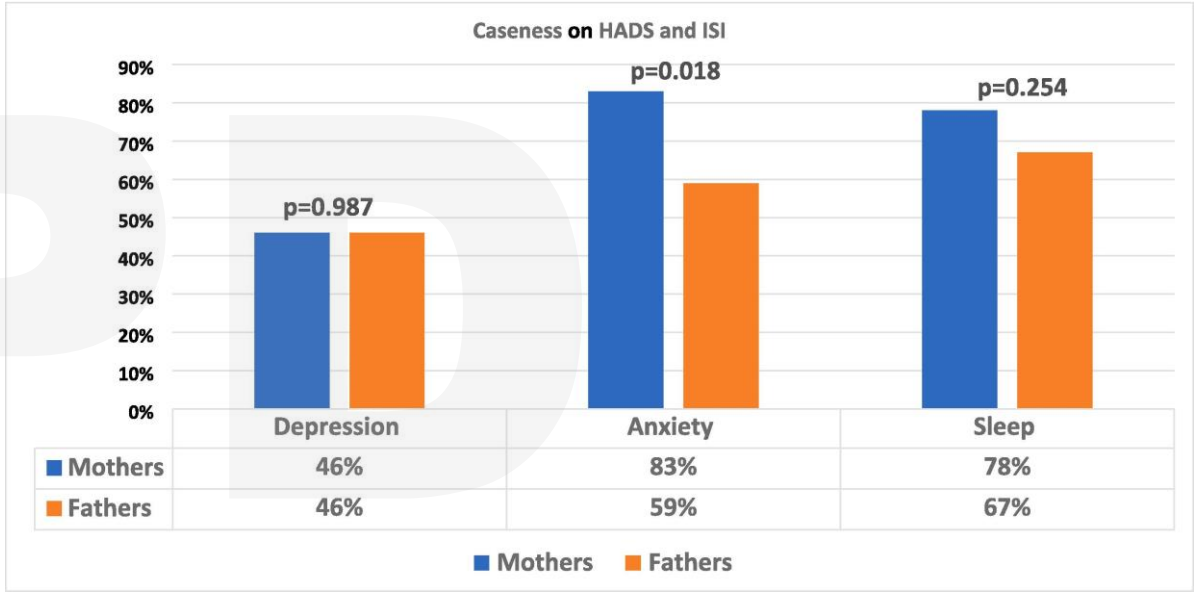
- Provided
  - Sleep tracking, resources, reinforcement
- Progress
  - Sibling in own bed, ABA, QOL
- Next steps
  - Practice routine during nap
- Barriers
  - No cubby bed/safe place
  - Revolving illness
  - Monitoring equipment delay

ELSEVIER

Epilepsy & Behavior
Volume 161, December 2024, 110102

Health-related quality of life, depression, anxiety, and sleep in mothers and fathers of children with dravet syndrome in Sweden

Colin Reilly [a b c], Björn Bjurulf [a b c], Tove Hallböök [a b c]



Case Example Follow Up

Dravet Syndrome Foundation

Follow up at three months:

Cluster of seizures caused significant sleep disruption
Needed PRN seizure medication and bridge medication

Very itchy; dermatology consult 7/2025
Hydroxyzine increased slightly; continue 3 mg melatonin (liquid)
Ferritin ordered
Awaiting cubby bed
Continues with ABA
Continues Behavioral Sleep Psychology

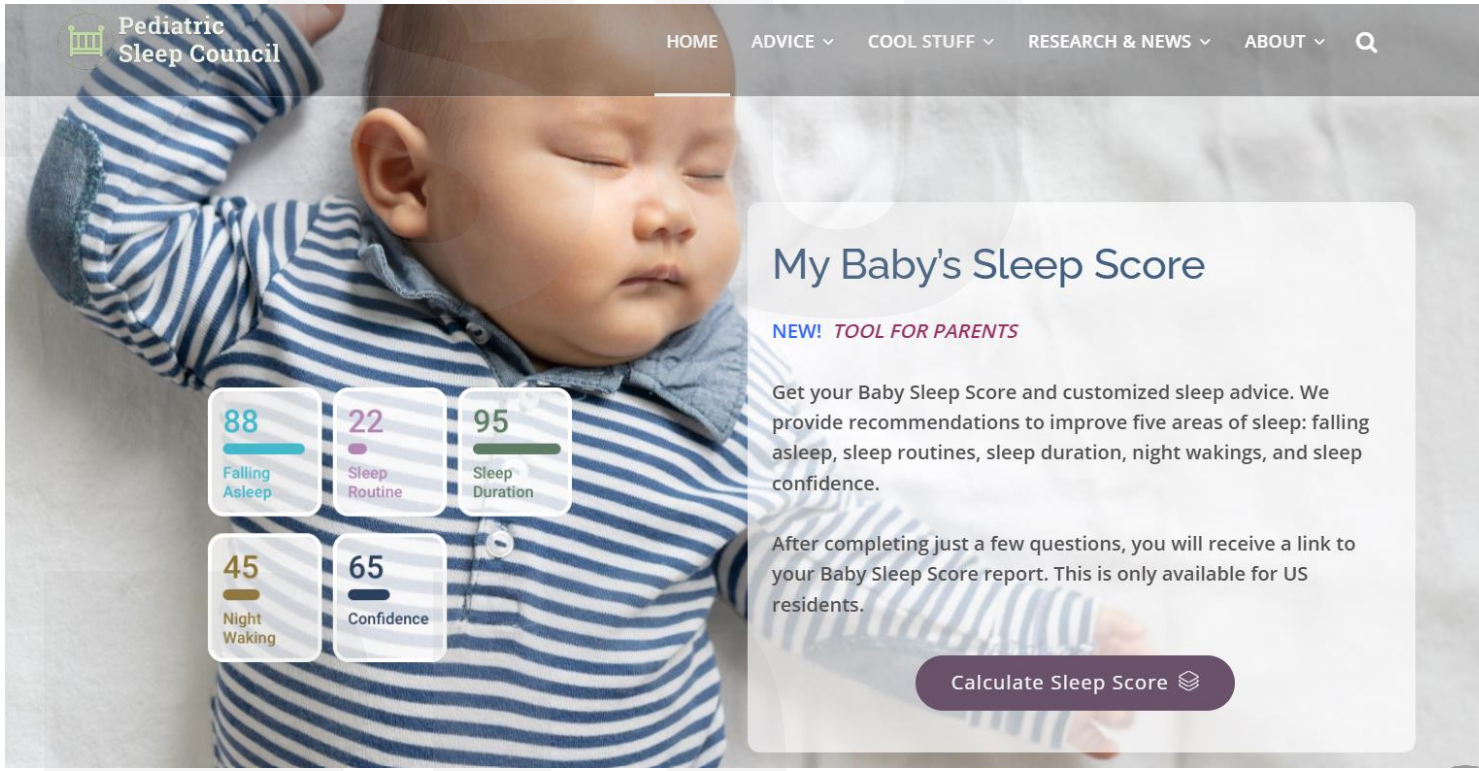
PRACTICE PATHWAY

- Screen for sleep problems as part of annual visits
- Identify medical co-occurring conditions
- Start with behavioral strategies if the family is willing/able to implement them
- Medications should be used sparingly-to facilitate behavioral strategies
- Use/choose medications to treat co-occurring conditions
- Start at low doses, avoid polypharmacy and ensure close follow-up

- Malow 2012; Buckley2021; Galion 2023

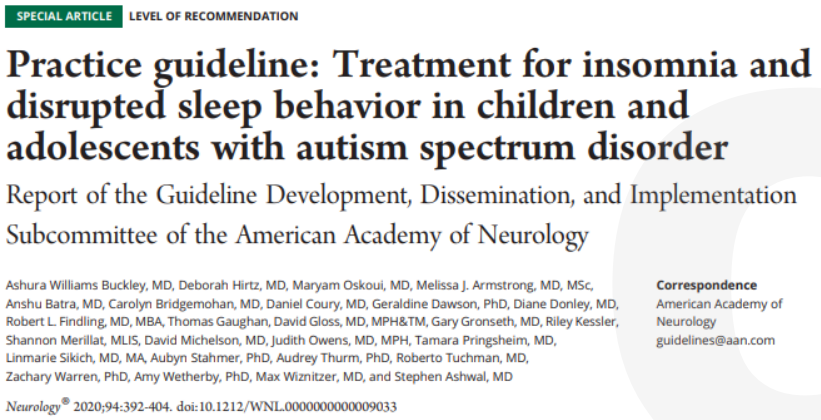
Resources

- A Clinical Guide to Pediatric Sleep: Diagnosis and Management of Sleep Problems 3rd Edition (Mindell and Owens)
- Pediatric Sleep Problems: A Clinicians Guide to Behavioral Interventions (Metzler)
- Babysleep.com



Medication Resources

https://www.aacap.org/App_Themes/AACAP/Docs/families_and_youth/med_guides/SleepDisorders_Parents-Medication-Guide-web.pdf



SPECIAL ARTICLE LEVEL OF RECOMMENDATION

Practice guideline: Treatment for insomnia and disrupted sleep behavior in children and adolescents with autism spectrum disorder

Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology

Ashura Williams Buckley, MD, Deborah Hirtz, MD, Maryam Oskoui, MD, Melissa J. Armstrong, MD, MSc, Anshu Batra, MD, Carolyn Bridgemohan, MD, Daniel Coury, MD, Geraldine Dawson, PhD, Diane Donley, MD, Robert L. Findling, MD, MBA, Thomas Gaughan, David Gloss, MD, MPH&TM, Gary Gronseth, MD, Riley Kessler, Shannon Merillat, MLIS, David Michelson, MD, Judith Owens, MD, MPH, Tamara Pringsheim, MD, Linmarie Sikich, MD, MA, Aubyn Stahmer, PhD, Audrey Thurm, PhD, Roberto Tuchman, MD, Zachary Warren, PhD, Amy Wetherby, PhD, Max Wiznitzer, MD, and Stephen Ashwal, MD

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Neurology® 2020;94:392-404. doi:10.1212/WNL.0000000000009033

https://www.neurology.org/doi/pdf/10.1212/WNL.0000000000009033

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Thank you!

- Questions?

Behavioral Interventions: Bedtime Pass

JOURNAL OF APPLIED BEHAVIOR ANALYSIS 2006, **39,** 423–428 NUMBER 4 (WINTER 2006)

TREATING BEDTIME RESISTANCE WITH THE BEDTIME PASS: A SYSTEMATIC REPLICATION AND COMPONENT ANALYSIS WITH 3-YEAR-OLDS

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