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TITLE: Tailored Behavioral Intervention for Insomnia in Children with Autism Spectrum Disorder

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14. ABSTRACT Children with Autism Spectrum Disorder (ASD) often have <u>chronic insomnia</u> . Based on the idea that a subset of children with ASD are in a hyper-aroused state, we developed a Tailored Behavioral Intervention (TAB) for insomnia that includes positive routines, a calming module (developed to decrease arousal levels) and faded bedtime protocol that would supplement the Standard Care (SC) established by the ATN: Sleep Tool Kit. The TAB developed for this study is novel and includes a detailed Calming Module with 12 soothing and relaxing activities to choose from and Performance feedback procedures (PFP) . Based on a child's arousal profile, 4-5 activities can be tailored and incorporated into an evening routine, to decrease their arousal level and help them fall asleep. PFP , highly effective feedback consultative strategies, that ensures a high degree of plan fidelity, is being used to support parents.					
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1. **INTRODUCTION:**

Children with Autism Spectrum Disorder (ASD) often have chronic insomnia. Based on the idea that a subset of children with ASD are in a hyper-aroused state, we developed a **Tailored Behavioral Intervention (TAB)** for insomnia that includes positive routines, a calming module (developed to decrease arousal levels) and faded bedtime protocol that would supplement the **Standard Care (SC)** established by the ATN: Sleep Tool Kit. The TAB developed for this study is novel and includes a detailed **Calming Module** with 12 soothing and relaxing activities to choose from and **Performance feedback procedures (PFP)**. Based on a child's arousal profile, 4-5 activities were tailored and incorporated into an evening routine, to decrease their arousal level and help them fall asleep. The purpose of this pilot study is to determine the feasibility of implementing a **TAB and SC n=20** or **SC only n=20** protocol for children with ASD and insomnia. We plan to evaluate the recruitment, randomization, retention, and implementation of these interventions by a multi-disciplinary team with parents of a child with ASD (2) complete a comparative cost analysis of the interventions, in terms of training and parent resources needed to teach the interventions, measure fidelity and collect data on the primary outcome, sleep, as measured by actigraphy.

2. **KEYWORDS:** Autism, Sleep , Insomnia, Tailored Behavioral Interventions

3. **ACCOMPLISHMENTS:**

What were the major goals of the project?

One of our goals was to train nurses and occupational therapists on

1. Sleep in Autism Spectrum Disorder and implementing the ATN : Sleep tool kit
2. Calming Module: 12 relaxing and soothing activities
3. Performance feedback procedures (PFP).
4. Implementing the TAB and SC with families in their home with fidelity

Objectives: (1) determine the feasibility of implementing randomized control trial of a TAB and SC n=20 or SC only n=20 protocol for children with ASD and insomnia. We plan to evaluate the recruitment, randomization, retention, and implementation of these interventions by a multi-disciplinary team with parents of a child with ASD (2) complete a comparative cost analysis of the interventions, in terms of training and parent resources needed to teach the interventions, measure fidelity and collect data on the primary outcome, sleep, as measured by actigraphy

Methods: Children Ages 6-10 with ASD and insomnia, stable medical conditions and daytime behaviors. Baseline sleep history, 10 days of Actigraphy, diary, questionnaires including: Sensory Profile, Children's Sleep Habits Questionnaire, Pediatric Anxiety Rating Scale. A multi-disciplinary team develops an arousal profile for each child. The SC is conducted by the nurse or OT. 40 Families will be randomized to either TAB and SC or SC only. The TAB group receives 8 (1hr) home based sessions with PFP. All measures and fidelity checks will be repeated for both groups at 4 and 8 weeks post intervention along with a Parent Acceptability Survey.

What was accomplished under these goals?

We received regulatory approval from The Children's Hospital of Philadelphia, University of Pennsylvania and Dept. of Defense. We had our regulatory approval renewed on 04-07-2015 at CHOP. We originally hired 3 nurses, 1 occupational therapist and 1 research coordinator for study. One nurse started a full time job in May and we hired and trained another nurse in July 2014. To date we completed 9 training sessions: 6 sessions in 2013 7/23, 8/13, 8/20, 9/10, 9/24 and 10/01 for staff on sleep tool kit, calming module and performance feedback process and 3 sessions in 2014 to train Dr. Kerns and Stefanie Zavodny BSN, RN 7/10, 7/17 and 7/31/2014.

We met with Biostatistician and discussed protocol and cost-analysis aim and strategies for data collection 10/4/2013 and 11/5/2013, 12/4/2013, 2/4/2014, 4/10/14, 6/24/14, 8/26/14 10/20/14, 2/9/15. Our Biostatistician has had a medical leave of absence for a serious illness but will be returning to work in October. We will resume analysis in 10/15. Data Safety Monitoring Committee meetings have been taken place every two months. No adverse events, no family complaints, protocol is acceptable to families.

Forty families were enrolled. 7.5% of the families dropped out, one child was placed in residential living, one family moved out of state, one child was 1 out of 11 children and mother was overwhelmed and changed her mind. Two children had adequate sleep and did not meet criteria for insomnia based on 10 nights of actigraphy and sleep questionnaire results. 35 families were randomized either to TAB $n=18$ or SC $n=17$. All families participated after randomization. Protocol was very acceptable to families with a 6.5 mean on the Acceptability Survey (Likert scale 1- 7). 38% of the families needed to reschedule home visits and could only accommodate 1 home visit a week extending the intervention across the 8 week period. Data collection at week 4 was not feasible for these families. All participants tolerated the actigraph. Based on actigraphy subjects in TAB ($n=12$) group significantly increased sleep minutes from baseline to 8 weeks (mean 43.15, SD 37.80, $p = 0.016$), while subjects in SC ($n=13$) group did not (sleep minutes (mean -2.80, SD 37.78, $p = 1.00$).

What opportunities for training and professional development has the project provided?

Our team has met bi-weekly as a multi-disciplinary team to discuss the study cases at The University of Pennsylvania, School of Nursing or Drexel University. Autism Institute. Our nursing students, occupational therapist and behavioral psychologist presented three poster presentations at the International Meeting for Autism Research in Salt Lake City. These professionals were able to engage with colleagues during their poster sessions and discuss their research and multidisciplinary roles.

How were the results disseminated to communities of interest?

We have filed for a 6 month no cost extension to complete analysis and manuscript preparation. We are still in analysis and publication preparation. We plan on submitting six publications and one book chapter.

We have been discussing our research process with our mentor Dr. Beth Malow the director of the Sleep initiative of the ATN. She is very excited to see the final analysis and perhaps incorporate the calming module for this study into the ATN Sleep tool Kit

What do you plan to do during the next reporting period to accomplish the goals?

We plan on meeting weekly with our biostatistician and team to discuss analysis and cost analysis and manuscript preparation.

4. IMPACT:

What was the impact on the development of the principal discipline(s) of the project?

We are still analyzing data.

What was the impact on other disciplines?

We are still analyzing data.

What was the impact on technology transfer? N/A

What was the impact on society beyond science and technology?

We are still analyzing data

5. CHANGES/PROBLEMS:

No changes to approach

Actual or anticipated problems or delays and actions or plans to resolve them

We have filed for a 6 month no cost extension to complete analysis and manuscript preparation.

We plan to be weekly with our biostatistician to discuss analysis and manuscript preparation

Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents : None

Significant changes in use or care of human subjects: None

Significant changes in use or care of vertebrate animals: N/A

Significant changes in use of biohazards and/or select agents: N/A

6. PRODUCTS:

Publications, conference papers, and presentations

Journal publications. Not yet

Books or other non-periodical, one-time publications. Not yet

Other publications, conference papers, and presentations.

Poster Presentations:

International Meeting For Autism Research (IMFAR), 2015 Salt Lake City Utah

1. Pilot Study of a Tailored Behavioral Intervention for Insomnia in Children with Autism Spectrum Disorder
2. Performance Feedback Procedures for Sleep Protocol
3. Tailored Behavioral Intervention (TAB) for Insomnia in Children Autism Spectrum Disorders: Comparative Cost Analysis of TAB and Sleep Tool Kit vs Sleep Tool Kit only

Website(s) or other Internet site(s)

Not at this time .

Technologies or techniques

None

Inventions, patent applications, and/or licenses

NoneOther Products

None

PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Example:

Personnel	Role	Percent Effort	Organization
Margaret C. Souders PhD	PI	20%	UPenn
Alex Hanlon PhD	Biostatistician	5%	UPenn
Connor Kerns PhD	Psychologist	5%	Drexel Univ.
Stefanie Zavodny	Study Nurse and coordinator	10%	UPenn
Jordana Popovich	Study Nurse and coordinator	10%	UPenn
Alexandra Ellison CRNP	Study Nurse	10%	UPenn
Whitney Eriksen RN	Study Nurse	10%	UPenn
Rebecca Sinko OT	Occupational therapist	10%	Jefferson Univ.
James Connell PhD	Consultant		Drexel Univ.
Roseann Schaaf PhD	Consultant		Jefferson

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

"Nothing to Report."

What other organizations were involved as partners?

"Nothing to Report."

7. **APPENDICES:** *Attach all appendices that contain information that supplements, clarifies or supports the text. Examples include original copies of journal articles, reprints of manuscripts and abstracts, a curriculum vitae, patent applications, study questionnaires, and surveys, etc. Reminder: Pages shall be consecutively numbered throughout the report. DO NOT RENUMBER PAGES IN THE APPENDICES.*

Pilot Study of a Tailored Behavioral Intervention for Insomnia in Children with Autism Spectrum Disorder

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Abstract

Chronic insomnia is a common problem in children with Autism Spectrum Disorder, possibly related to arousal dysregulation. We developed a Tailored Behavioral Intervention (TAB) that includes positive routines based on evening schedule, calming activities based on a child's arousal profile, and faded bedtime protocol with performance feedback. Parent reports and Actigraphy provided measures of a child's sleep prior to, during, and following the intervention. Preliminary results suggest that sleep improvements are significantly greater for children who received the TAB plus Standard Care (1 hour Sleep Tool Kit), compared to those who received Standard Care alone. Our findings suggest that sleep behaviors and sleep quality can be successfully modified using an intensive, family-based approach by a multidisciplinary team.

Background

ASD represents one of the most devastating neurobiological disorders of pre- and postnatal brain development. Prevalence is estimated at 1 in 68 children in the US. Children with ASD exhibit varying degrees of impairment within core domains: impairments in social interaction and communication, and stereotypic behaviors.

Chronic severe insomnia has a prevalence of 60-80% in ASD and has significant detrimental effects on cognitive development, behavior, and mood. The cause of sleep disturbances in ASD is likely multi-factorial and subject to many possible biological, behavioral, and cultural mechanisms. The predominant sleep disorder identified in children with ASD is Behavioral Insomnia of Childhood. However, despite the use of robust behavioral strategies and strong bedtime routines by caregivers, their children continue to have insomnia. We hypothesize that a subgroup of children with ASD may experience a hyper-aroused state that may be linked to insomnia and anxiety. In order to develop more precisely targeted sleep treatments for children with ASD, this arousal/anxiety phenomenon must be specifically addressed.

Objectives:

1. To determine the feasibility and acceptability of implementing the TAB plus Standard Care vs. Standard Care-only protocols. Evaluations include the recruitment, retention, randomization and training required to implement this intervention by a multi-disciplinary team.

2. To determine the effectiveness of the TAB plus Standard Care vs. Standard Care-only protocols in improving sleep in children with ASD, as measured by objective and subjective methods.

Enrollment for the larger RCT feasibility study is anticipated to be 40 families. Twenty-five families are currently enrolled. Study completion is anticipated for Summer 2015. The following illustrates the results to date.



Picture used with permission

Methods

Sample:

- Children aged 6 to 10 years
- Recruited on an ongoing basis through the Center for Autism Research (CAR), Autism Treatment Network (ATN) at The Children's Hospital of Philadelphia (CHOP), Autism Match
- Inclusion criteria: Confirmed ASD diagnosis, insomnia, stable medical and behavioral condition

Measures:

- **Children's Sleep Habits Questionnaire (CSHQ)**
 - Structured parent report with 48 items and eight subscales related to common sleep behaviors in children
 - Cut-off total score of 41 (sensitivity of .80 and a specificity of 0.72)
- **Actigraphy (ACT)**
 - Records accelerations greater than 0.01 gr
 - Digitized motion data is stored on the ActiGraph
 - Evaluated with the Sadeh sleep algorithm
 - Worn inside a small pocket sewn on a T-shirt sleeve
 - Data recorded for 5-7 nights (baseline, Week 4, Week 8)
- **Sleep Diary**
 - Record of parent perception of child's sleep and wake patterns during ACT data collection
- **Fidelity Checklist**
 - Adherence to the protocol of the ATN Sleep Tool Kit.
 - Screen for Child Anxiety Related Disorders (SCARED)
 - Structured parent report of anxiety symptoms
 - Pediatric Anxiety Rating Scale (PARS)
 - Clinician-rated instrument for assessing severity of anxiety symptoms
- Acceptable consistency, test-retest, validity, inter-rater reliability
- **Sensory Profile Short (SPS)**
 - Parent report of behaviors associated with abnormal responses to stimuli.
- Reliability of .90, discriminate validity > .95%.
- **Parental Acceptability Survey**
 - Collected at Week 10

Procedures:

- **Standard Care:**
 - ATN Sleep Tool Kit (sleep hygiene and limit setting)
 - One-hour education
 - Two Home Visits: fidelity checks
- **Tailored Behavioral Intervention:**
 - Standard Care
 - Positive routines (evening routines, antecedent strategies)
 - Detailed calming activities
 - Soothing and relaxation techniques
 - Faded bedtime protocol
 - Nine Home Visits: fidelity checks, parental support and feedback

Preliminary Results

Table 1. Description of Sample

Characteristic	TAB (N=13) N (%)	Control (N=11) N (%)	Total (N=24) N (%)
Child gender			
Male	11 (85)	12 (100)	23 (95)
Female	2 (15)	0 (0)	2 (8)
Mean child age (range 6-10)	6.3	7.5	7.0
Child race			
Caucasian	9 (69)	7 (64)	16 (66)
African American	1 (8)	2 (17)	3 (12)
Other	4 (30)	2 (18)	6 (25)
Parent's Education Level			
GED/high school	4 (31)	2 (17)	6 (24)
Some college	2 (15)	2 (17)	4 (16)
Bachelor's degree	2 (15)	3 (27)	5 (20)
Graduate degree	2 (15)	4 (36)	6 (25)
Marital status			
Married	9 (69)	6 (55)	15 (62)
Single	2 (15)	4 (36)	6 (25)
Families with more than one child	9 (69)	10 (91)	19 (78)
Child's medications			
Melatonin	5 (38)	7 (64)	12 (50)
Alpha-2 agonist	4 (31)	2 (18)	6 (25)
Stimulant	1 (8)	3 (27)	4 (16)
SSRIs	2 (15)	1 (9)	3 (12)
Antipsychotics	2 (15)	0 (0)	2 (8)
Other	3 (23)	0 (0)	3 (12)

The intervention significantly decreased sleep duration ($M = 27.11$ minutes), wake minutes ($M = 55.91$ minutes), and activity mean ($p < .05$) for children in the TAB plus Standard Care, compared to those receiving Standard Care alone. The intervention significantly increased sleep minutes ($M = 32.88$ minutes; $p < .05$).

Both groups showed decreases in sleep latency (time to fall asleep), but those receiving the TAB plus Standard Care showed significantly greater improvement. Following intervention, the TAB group fell asleep 15 minutes faster than pre-intervention, and 11 minutes faster than the control group post-intervention. The mean sleep latency at week 8 in the TAB group ($M = 18.91$ minutes) indicates that the intervention was successful in treating insomnia.

Total CSHQ score decreased significantly in the TAB group, with no significant changes noted in the control group. Parents in the TAB group reported significantly fewer night wakings than the control group. Significant decreases are also noted in the TAB group in the total CSHQ score and the bedtime resistance and parasomnia subscales, but these changes were not significantly different from the control group.

Many children in the sample were taking more than one medication during the study, with nearly half of the children taking melatonin (48%). Actigraphy measures indicate that the children in the TAB group had worse sleep than the control group at baseline.

Table 2: Actigraphy Data

Actigraphy Measure	TAB (N=13)	Control (N=11)	TAB-SC P-values
	Baseline-Week 0	Baseline-Week 8	Difference (P-value)
Start time (Child in bed)	9:13PM-9:28PM	9:00PM-9:54PM	+54 min (NS)
End time (Parent reports child wakes up)	7:09AM-6:55AM	6:55AM-6:45AM	+12 min (NS)
Duration (min)	506.41-509.30	507.13-504.37	-2.78 (NS)
Activity mean (Nighttime movements)	32.32-21.91	28.09-24.97	-2.78 (NS)
Wake minutes (Time awake during night)	162.36-106.45	125.05-116.10	-3.55 (NS)
Sleep minutes (Time asleep)	434.04-402.93	470.36-478.27	+7.91 (NS)
Sleep latency (min)	34.23-13.01	35.11-31.01	-4.50 (0.004)

Table 3: CSHQ Data

CSHQ Measure	TAB (N=13)	Control (N=11)	TAB-SC P-values
	Baseline-Week 0	Baseline-Week 8	Difference (P-value)
Bedtime resistance	10.42-8.25	10.09-9.16	-0.91 (NS)
Sleep onset delay	1.92-1.58	1.75-1.45	-0.27 (NS)
Sleep duration	5.83-5.33	5.90-4.35	-0.64 (NS)
Sleep anxiety	7.17-6.50	6.16-7.09	-1.09 (NS)
Night wakings	5.56-4.25	5.83-5.32	0.00 (NS)
Parasomnias	10.42-8.25	10.55-10.18	-0.36 (NS)
Sleep-disordered breathing	3.42-3.50	3.62-4.09	-0.27 (NS)
Daytime sleepiness	11.67-11.50	12.09-11.09	-0.55 (NS)
Total score	55.00-48.42	56.99-52.55	-3.55 (NS)

Conclusions

Discussion:

Results demonstrate that the TAB plus Standard Care shows a greater improvement in several measures of sleep than Standard Care alone. For many reasons, including cultural, psychological, environmental, and practical considerations, parent perceptions and subsequent parent reports of children's sleep have limitations. However, Actigraphy allows for an objective measure of sleep and wake times within specific timeframes.

The TAB group showed significantly greater improvements over the control group in the Actigraphy measures of duration, activity mean, wake minutes, and sleep latency. The decrease in sleep latency is clinically significant in the TAB group, with the average sleep latency at week 8 no longer meeting criteria for insomnia.

Further, the TAB intervention improved parents' perceptions of their children's sleep, with no significant changes noted in the control group.

Implications:

The intensity of the Tailored Behavioral Intervention (9 Home Visits vs. 2 Home Visits) paired with the multi-disciplinary approach appears to address the variety of factors contributing to insomnia in children with ASD. An extended timeframe allows for the development of trust between the family and the team, the development of a cohesive, individualized, yet structured approach to the intervention, and feedback opportunities for both families and team members.

Acknowledgments
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University of Pennsylvania School of Nursing

Performance Feedback Procedures for Sleep Protocol

James E Connell, PhD, NCSP, BCBA-D & Margaret C. Souders PhD CRNP
AJ Drexel Autism Institute and University of Pennsylvania School of Nursing

Introduction

- Performance feedback is a standardized feedback loop that includes graphic presentation of intervention implementation fidelity, problem-solving and frequent meetings to ensure that evidence-based interventions are implemented the way they were designed.
- Taken from IO Psychology (Balcasar et al., 1985), performance feedback was adopted in school settings to ensure that students were receiving high quality evidence-based programs (Noell et al., 1997). The procedures were refined, and culminated in randomized controlled trial (Noell et al., 2005) which demonstrated the overwhelming and positive effect of performance feedback on the implementation of evidence-based interventions in school settings, compared to no consultation and standard educational practice.
- Performance feedback has since been shown effective in other community settings including behavioral health agencies and home settings (Connell, 2010). The Connell (2010) study did not follow the procedures outlined by Noell et al., (2005) in that home visit frequency was not optimal. The results indicated that the parents did implement the intervention, however they did not complete the treatment fidelity checklist. The following study addresses that limitation by increasing home visit frequency to determine if more frequent visits increase implementation checklist completion.

Study Aims

1. Increase home performance feedback sessions to match recommendations in Noell et al., (2005).
2. Determine if increased visits increasing implementation checklist completion.
3. Determine if implementation fidelity improves intervention outcomes.

- Balcasar, R., Hopkins, B. L., & Suarez, Y. (1985). A critical objective review of performance feedback. *Journal of Organizational Behavior Management*, 7, 65-89.
- Connell JE (2010). Applications of performance feedback: Consultation in the home. *International Journal of Behavioral Consultation and Therapy*, 6, 17-23.
- Noell, G. H., Witt, J. C., Gilbertson, D. N., Ranior, D. D., & Freeland, J. T. (1997). Increasing teacher intervention implementation in general education settings through consultation and performance feedback. *School Psychology Quarterly*, 12, 77-88.
- Noell GH, Witt JC, Slider NJ, Connell JE, Williams KL, Rosetier JL, Koenig JL (2005). Treatment implementation following behavioral consultation in schools: A comparison of three follow-up strategies. *School Psychology Review*, 34, 87-106.
- Pellecchia M, Connell JE, Eisenhart D, Kane M., Schoener C, Turkel K, Riley M, & Mandell DS. (2011). Group Performance Feedback: Consultation to increase Classroom Team Data Collection. *Journal of School Psychology*, 49, 411-431.

Methods

Sample

- Children aged 6 to 10 years, recruited through the Center for Autism Research (CAR), Autism Treatment Network (ATN) at The Children's Hospital of Philadelphia (CHOP), Autism Match
- Inclusion criteria: Confirmed ASD diagnosis, insomnia, stable medical and behavioral condition
- Table 1. Study sample

Characteristic	TAG (N=13) N (%)	Control (N=12) N (%)	Total (N=25) N (%)
Child gender			
Male	11 (85)	12 (100)	23 (92)
Female	2 (15)	0 (0)	2 (8)
Mean child age (range 6-10)	8.3	7.5	7.9
Child race			
Caucasian	6 (46)	7 (58)	13 (52)
African American	1 (8)	2 (17)	3 (12)
Other	4 (30)	3 (24)	7 (28)
Parent's Education Level			
GED/high school	4 (31)	2 (17)	6 (24)
Some college	2 (15)	2 (17)	4 (16)
Bachelor's degree	5 (38)	3 (25)	8 (32)
Graduate degree	2 (15)	5 (42)	7 (28)
Marital status			
Married	6 (46)	8 (67)	14 (56)
Single	5 (38)	4 (33)	9 (36)
Families with more than one child	9 (69)	10 (83)	19 (76)
Child's medications			
Melatonin	5 (38)	7 (58)	12 (48)
Alpha-2 agonist	4 (31)	6 (50)	10 (40)
Stimulant	1 (8)	2 (17)	3 (12)
SSRI	2 (15)	1 (8)	3 (12)
Antipsychotics	3 (23)	0 (0)	3 (12)
Other	3 (23)	0 (0)	3 (12)

Measures

***see Zavodny et al poster for more detail

Children's Sleep Habits Questionnaire (CSHQ)

Actigraphy (ACT)

Sleep Diary

Fidelity Checklist

Adherence to the protocol of the ATN Sleep Tool Kit.

Adherence to the individualized behavior plan.

Screen for Child Anxiety Related Disorders (SCARED)

Pediatric Anxiety Rating Scale (PARS)

Sensory Profile Short (SPS)

Parental Acceptability Survey

Procedures

Standard Care

- ATN Sleep Tool Kit (sleep hygiene and limit setting)
- One-hour education
- Two Home Visits: fidelity checks

Tailored Behavioral Intervention

- Standard Care
- Nighttime routines (evening routines, antecedent strategies)
- Detailed calming activities
- Soothing and relaxation techniques
- Faded bedtime protocol
- Nine Home Visits: fidelity checks, parental support and feedback

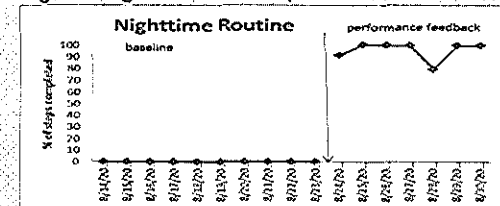
Performance Feedback

- Fidelity Check list for positive routines and faded bedtime
- Graphic presentation of steps missed and steps completed
- Problem-solving process
- Intervention modification, or recommitment to intervention
- Frequent visits

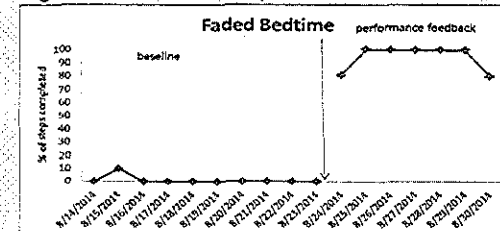
Results/Discussion

- Implementation fidelity during baseline data collection was zero for each of the two interventions targeted, night time routines (Figure 1) and faded bedtime (Figure 2) for the first two weeks of the intervention. The implementation checklists and parent report indicated that none of the steps in each of the interventions were completed, with one exception in the faded bedtime intervention. Performance feedback began by planning two trips to the home each week.

- Figure 1. Night time routine implementation adherence



- Figure 2. Faded bedtime implementation adherence



- Actigraph data collected before baseline, near the end of baseline, and at the end of the intervention clearly demonstrates significantly more sleep minutes, decreased sleep latency and increased sleep efficiency. The data suggests that as implementation fidelity increased, intervention effectiveness also increased. This study extends Connell (2010) by demonstrating the more frequent visits increase fidelity, which may the result in better participant outcomes.

Measure	Baseline	Week 6	Week 8
Starting Time	20:13:32	20:05:23	20:09:23
Ending Time	6:07:40	5:18:47	5:48:02
Midpoint	1:10:25	0:47:33	1:12:45
Duration	294:9	343:4	350:38
Activity Mean	27.52	35.77	33.00
Activity Median	5.2	4.8	5.38
Activity SD	56.67	20.11	31.01
Wake Minutes	117.6	90.6	65.38
Sleep Minutes	477.3	443.6	465
% Sleep	80.29	81.57	87.34
Sleep Efficiency	80.9	81.77	86.92
Sleep Latency	26.7	13.6	11.25

Tailored Behavioral Intervention (TAB) for Insomnia in Children Autism Spectrum Disorders: Comparative Cost Analysis of TAB and Sleep Tool Kit vs Sleep Tool Kit only

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Introduction

Chronic, severe insomnia occurs in 60-80% of children with Autism Spectrum Disorder (ASD). With significant detrimental effects on cognitive development, behavior, daily functioning and mood, chronic insomnia poses unique and significant challenges to individuals with ASD. The cause of sleep disturbances in ASD is likely multi-factorial and subject to many possible biological, behavioral, and cultural mechanisms.

An emerging hypothesis for insomnia in individuals with ASD centers on imbalances in brain and neurological systems that prevent sufficient or consistent regulation of anxiety and fear stimuli, as well as sensitivity thresholds to environmental stimuli. This arousal dysregulation may contribute to difficulties in initiating and maintaining sleep and daytime behavior. Based on the theory that a subgroup of children with ASD are in a hyper-aroused state, we developed a Tailored Behavioral Intervention (TAB) that addresses both the internal and external factors that may threaten sleep. The TAB includes three components: (A) positive evening routines, (B) a calming module developed to decrease arousal levels, and (C) a faded bedtime protocol. The TAB is a novel protocol that includes a detailed calming module of 12 soothing and relaxing activities, selected with the parents and children with ASD for an individualized routine.

Based on a child's individual arousal/anxiety profile and family goals, four to five activities are selected for use in the child's tailored evening routine to decrease a child's arousal/anxiety level and promote sleepiness. In conjunction with a faded bedtime protocol, which uses stimulus control to pair sleepiness with bedtime and bedroom, the child engages in calming, positive activities outside the bedroom until the child is sleepy. Initial bedtime is identified by sleep diary and actigraphy data, and is slowly faded forward over time to reach the ideal bedtime and increase sleep duration.

The TAB requires a multi-disciplinary team to implement the in-home intervention. Intensive training of team members includes Performance Feedback (PFB), an innovative method to support and guide the family in implementing their individualized TAB routine that ensures a high degree of intervention fidelity, as well as fundamentals of sleep, sleep measures, the TAB protocol, family advocacy and the ecological approach employed in this family-centered study.

Here, we focus on the third and final aim of the study, to assess the comparative costs of training the multi-disciplinary team on the study program for the TAB and the Standard Care (SC) protocol of the Sleep Tool Kit developed by Dr. Beth Malow. The Sleep Tool Kit is a standardized manual for educating families on sleep hygiene and basic behavioral strategies.

Aims

The specific aims of this project are to:

1. Determine the feasibility, acceptability and fidelity of implementing the TAB and SC vs. SC only Protocol. We plan to evaluate the recruitment, retention, randomization, and training required to implement this novel intervention by a multi-disciplinary team with parent(s) of a child with ASD.
2. Estimate the effects of the TAB and SC in relationship to sleep parameters and arousal/anxiety symptoms
3. Complete a comparative cost analysis of the two interventions, TAB and SC. Specifically, we propose to assess the comparative costs in terms of training and staff and family resources needed to teach the interventions to ensure fidelity.

Team and Training

Our multi-disciplinary team is comprised of:

- Sleep Expert Nurse Practitioner: Dr. Souders
- Neuropsychologist: Dr. Guy and Dr. Kerns
- Behavioral psychologist: Dr. Connell
- Four Registered Nurses
- One Occupational therapist

Consultants to the study protocol include:

- Dr. Beth Malow, ASD and Sleep expert
- Dr. Roseann Schaaf, Sensory Integration expert

Training Program (40 hours)

Classroom Curriculum

Curriculum addresses:

- 1) Sleep in ASD
- 2) Use of Actigraphy
- 3) Ecological Approach
- 4) Sleep Tool Kit education and training
- 5) TAB Protocol Training
- 6) PFB Education and Training
- 7) Family advocacy and mental illness

Home Training

- 1) One in-home case with support from Sleep Expert
- 2) One in-home case with PFB supervision from Behavioral Psychologist

Methods

Sample: N = 40

- Children aged 6 to 10 years
- Recruited on an ongoing basis through the Center for Autism Research (CAR), Autism Treatment Network (ATN) at The Children's Hospital of Philadelphia
- Inclusion criteria: Confirmed ASD diagnosis, insomnia, stable medical and behavioral condition

Measures:

Children's Sleep Habits Questionnaire (CSHQ)

- Structured parent report with 48 items and eight subscales related to common sleep behaviors in children
- Cut-off total score of 41 (sensitivity of .80 and a specificity of 0.72)

Actigraphy (ACT)

- Records accelerations greater than 0.01 gr
- Digitized motion data is stored on the Actigraph
- Evaluated with the Sadeh sleep algorithm
- Worn inside a small pocket sewn on a T-shirt sleeve
- Data recorded for 5-7 nights (Baseline, Week 4, Week 8)

Sleep Diary

- Record of parent perception of child's sleep and wake patterns during ACT data collection

Fidelity Checklist

- Adherence to the protocol of the ATN Sleep Tool Kit Screen for Child Anxiety Related Disorders (SCARED)
- Structured parent report of anxiety symptoms
- Pediatric Anxiety Rating Scale (PARS)
- Clinician-rated instrument for assessing severity of anxiety symptoms

- Acceptable consistency, test-retest, validity, inter-rater reliability

Sensory Profile Short (SPS)

- Parent report of behaviors associated with abnormal responses to stimuli

- Reliability of .90, discriminate validity > .95%

Parental Acceptability Survey

- Collected at Week 10

Procedures:

Standard Care:

- ATN Sleep Tool Kit (sleep hygiene and limit setting)
- One-hour education
- Two Home Visits with fidelity checks

Tailored Behavioral Intervention:

- Standard Care, plus...
- Positive routines (evening routines, antecedent strategies)
- Detailed calming activities
- Soothing and relaxation techniques
- Faded bedtime protocol
- Nine Home Visits with fidelity checks, feedback and parental support

Results

Cost Analysis:

Standard Care

- Training: 8 hours = \$320
- Parent Education Session = \$130
- Intervention: 2 Home Visits = \$260
- Cost through 1st case = \$710
- Cost for subsequent cases = \$390

TAB Intervention

- Training: 40 hours = \$1560
- Intervention
- Parent Education Session = \$130
- 11 Home Visits = \$1430
- Expert Consultation = \$1200
- Case Supervision (1st case only) = \$1430
- Cost through 1st case = \$5750
- Cost for following cases = \$2760

Conclusions

Discussion:

Preliminary Results (N = 24) suggests that the TAB plus Standard Care shows a greater improvement in sleep than Standard Care alone (Sleep Minutes: TAB = 32.88, SC = 7.91; Wake Minutes: TAB = -55.91, SC = -9.85; Sleep Latency: TAB = -15.32, SC = -4.50). Mean Sleep Latency following the TAB intervention no longer met criteria for insomnia (> 30 minutes), but did not significantly change for those receiving Standard Care.

Cost Analysis: Following training and initial case supervision costs, the TAB intervention cost \$2,760 to implement per case compared to Standard Care cost of \$390. Given our preliminary findings, this translates to costs of \$83.84 to increase sleep by one minute, \$49.36 to decrease wake by one minute, and \$180.15 to decrease sleep latency by one minute with the TAB intervention (SC: \$49.30/min, \$39.59/min and \$86.67/min, respectively). However, the direct and cost benefits to sleep consolidation and increases in sleep minutes observed in the TAB, but not the SC, group are not included herein and cannot be understated.

Implications:

The intensity of TAB (11 Home Visits vs. 2 Home Visits) paired with the multi-disciplinary approach appears to address the variety of factors contributing to insomnia in children with ASD. An extended time frame allows for development of trust between the family and team, and development of a cohesive, individualized, yet structured intervention that results in significantly improved measures of sleep in the child and perceptions of child's sleep by the parents.

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Calming Module for Insomnia

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1. Observing Your Breath Exercise

Breathing exercises have been found to be calming and help with relaxation. This activity can be performed alone with your child or with the whole family. The activities are described for an individual lying on his/her back, but can be adapted if lying on side or stomach.

1. Find a quiet spot and get into position.

Find a quiet, calm environment in which to do the breathing exercises.

Lie down on a comfortable flat surface. If you lie on your back, you may want to place a pillow underneath your head or knees.

2. Observe your breath.

Allow your body to relax into the ground. Relax your muscles, letting your arms and legs drop loosely away from your body.

Gently, slowly breathe in (count to 2 or 3).

Gently let out the breath (count to 3 or 4).

Repeat this for a total of 5 breaths.

Take a 30 second break and breathe at your own pace.

3. Watch your body as you breathe.

As you breathe in, watch as your belly grows.

As you breathe out, watch as your belly goes down.

Repeat this for a total of 5 breaths.

Take a 30 second break and breathe at your own pace.

4. Feel your breath.

Place your hands on your belly. (Hands should be placed around the belly button.)

As you breathe in, feel your belly rise (as air fills your lungs and your diaphragm pulls down).

As you breathe out, feel your belly fall (as air leaves your lungs and your diaphragm relaxes).

Repeat this for a total of 5 breaths.

Take a 30 second break and breathe at your own pace.

5. Time your breath.

Breathe in to the count of 2 or 3.

Breathe out to the count of 3 or 4.

Repeat this for a total of 5 breaths.

Take a 30 second break and breathe at your own pace.

Alternative exercises

If your child prefers to move around, have him/her walk around a room or outdoor space breathing in for every 2 or 3 steps and out for 3 or 4 steps. After doing this for 5 breaths, slow the pace of the steps and work to reduce the number of steps to have 1 breath in for 1 step and 1 breath out for 1 step. Alternatively, using a medium-sized blown-up ball, like a beach ball, toss the ball back and forth with your child breathing out as you throw the ball and breathing in as you catch it.

If your child has a favorite animal, pretend to be that animal assuming a comfortable position. For example, alligators lie quietly and very still on their stomachs. Have your child feel his/her stomach push against the ground as he/she breathes in, and less resistance as he/she breathes out.

Using the "Simon Says" game structure, walk your child (or have your child walk you) through the breathing exercises. For example: "Simon says to put your hands on your belly and feel as your belly grows as you breathe in and falls as you breathe out".

References

Linehan, M.M. (1993). *Skills training manual for treating borderline personality disorder*. The Guilford Press.

2. Progressive Muscle Relaxation

Progressive muscle relaxation is an exercise that allows your child to focus on his/her body through systematic tensing and relaxation of major muscles. This helps to release tension in the body and decrease stress.

Find a cool, calm area in which to perform this activity. You may find that you want to create a soothing environment with calming music or smells, but these are not necessary to do the exercise.

How to tense and relax your muscles

When tensing the muscle, you want to feel a moderate to strong squeeze in that area. For example, when tensing your toes, you will feel them tighten and squeeze against one another and possibly curl toward your foot.

Tense each muscle for 3 to 5 seconds, then allow the muscle to relax.

When relaxing the muscle, allow all tension to flow from that area. Muscles should be loose and feel floppy.

Muscle relaxation should be done in a systematic, progressive manner from one end of the body to the other. You may find that you and your child enjoy one direction best.

You can pair the tension-relaxation cycle with your breath, squeezing the muscle as you breathe in and hold the breath for a moment, and relaxing the muscle as you breathe out.

You can start by tensing muscles for 3 seconds and building to 5 seconds over time.

1. Get comfortable.

You can do this exercise lying down on a comfortable surface, sitting in a chair, or sitting on the floor while leaning against a wall or couch.

2. Observe your breath.

Allow yourself to sit for a moment observing your breath. Count to 5 or 10 breaths in your head while you simply relax.

3. Toes

Squeeze and tighten your toe muscles for 3 seconds. Feel the tension as your toes curl up against each other and your foot. Allow your toes to relax and wiggle out.

4. Ankles

Flex your feet tightly up towards your shin for 3 seconds. Feel as your toes are reaching upwards to your shins. Relax and roll out your ankles.

5. Calves

Tighten the upper portion of your calves by tightening at the knees or pushing your feet into the ground if you are sitting. Hold for 3 seconds. Relax the muscle. Shake out at the knees if you are still feeling tension.

6. Thighs

Squeeze your thigh muscles tightly and hold for 3 seconds. You can do this by pressing your thighs together tightly if lying down or imagining squeezing in the middle back of your thighs if you are sitting. Relax your thighs and take a deep breath.

7. Hips and Bottom

Tighten your bottom muscles. Allow the squeeze to wrap around and expand to your hip muscles. Hold this for 3 seconds and relax, blowing your breath out slowly as you gently relax your muscles. Take a few moments to breathe gently and allow your mind to settle.

8. Tummy

Tighten the muscles in your tummy. If you are in a sitting position, crunch over your tummy. If you are lying down, raise your shoulders and upper back slightly off the ground. Hold this position and squeeze for 3 seconds. Gently relax your muscles, resuming your previous comfortable, relaxed position. Take a deep breath and feel your belly stretch out after being so tight.

9. Shoulders/Upper Arms

Raise your shoulders up toward your ears, squeezing the muscles together. Imagine you are trying to touch your shoulder to your neck or ears. Hold this for 3 seconds and relax your shoulders down to a normal position. Next, push your shoulders back and squeeze your shoulder blades together. Hold this for 3 seconds and relax your shoulders forward.

10. Arms

Tighten your arm muscles by flexing your upper arms. Imagine showing someone your 'strong man/woman' pose. Squeeze and hold for 3 seconds. Relax and shake out your upper arms. Next, tighten your middle and lower arms by bending at the elbow and squeezing your lower arm to your upper arm. Hold for 3 seconds and relax your arms down, allowing the tension to flow out of your arms. Take a moment to relax and breathe at your own pace.

11. Wrists

Flex your wrists inward toward your arm with your hand in a fist. Focus on stretching and squeezing at the wrist and not squeezing your fist too tightly. Hold for 3 seconds and relax your wrist. Slowly roll out your wrists in circles.

12. Hands/Fingers

Squeeze your hands into fists. You may curl your fingers under, or allow them to press against the palm of your hand. Hold the squeeze for 3 seconds, then relax your hand. You can wiggle your fingers and imagine any tension flowing out of your fingertips.

13. Face

Tighten your forehead and face muscles by squeezing in your face toward your nose. Pull your eyebrows down and in, your lips up to your nose and cheeks toward the center of your face. Hold for 3 seconds and then relax your face muscles.

Squeeze and stretch your cheek muscles by smiling a really big smile. Allow the feeling and happiness of your smile to fill your entire face and body, pulling it all the way down to your toes. Take a deep breath and relax, allowing your smile to slowly relax into a neutral face position.

References

Linehan, M.M. (1993). *Skills training manual for treating borderline personality disorder*. The Guilford Press.

3. Qigong Massage

Qigong is more than just a massage. It is based on ancient Chinese medicine and the belief that energy flows through the body in channels. Diseases and impairment happen when this flow of energy is disturbed, interrupted, or turned off. Qigong opens up the channels to allow the healing and balancing energy flow again.

A series of scientific studies over the past 10 years looked at the effects of Qigong on children with autism. These studies found that children whose parents had treated them with Qigong every day for 5 months showed significant improvement in their sensory responses (touch, textures), socialization skills, bowel movements, and sleep. The studies showed that children improved very quickly and began to tolerate and even enjoy touch even in the most sensitive areas such as ears, fingers, and toes. One study found that all children in the study with sleep problems had almost normal sleep patterns after 5 months of Qigong.

Qigong for the home is a pattern of 12 movements that include patting, shaking, or pressing different spots on the body. The first 3 movements open up the flow of energy to the brain and the senses. The 4th movement helps with balance and coordination. The next 3 movements help with social interaction, speech, and self-regulation, while the next 2 regulate energy and digestion. The last 3 movements should calm your child and help with sleep.

The whole massage takes about 15 minutes and should be done every night.

If you are interested in trying Qigong with your child, we have a book and a DVD for you to get to know this method.

1. Find a quiet spot where your child can sit or lie comfortably and you can move around your child.
2. **Qigong Movement 1: The child lies on his/her belly (face down), sits up, or stands, depending on which position is tolerated.**
 - a. With one hand, pat on the top of the child's head.
 - b. Continue patting down the center back of his/her head and on the base of the head.
 - c. Continue patting down the neck and spine.
 - d. Pat down the middle of the back of each leg toward the feet.
 - e. Pat the heels.
 - f. Repeat a. through e. at least 3 times.
3. **Qigong Movement 2: The child lies on his/her belly, with the head down or turned on its side.**
 - a. Pat the top of the child's head with both hands, one hand to the left and one to the right of the midline.
 - b. Continue patting down the neck and spine with both hands; one hand to the left and one to the right of the midline.
 - c. Continue patting down the middle of the back of each leg; one hand on each leg.
 - d. Pat the heels.
 - e. Repeat a. through d. at least 3 times.

4. **Qigong Movement 3: The child lies on his/her back, face up.**
 - a. Pat the top of the child's head with both hands.
 - b. Continue patting down the sides of the head until you reach the ears. Use one hand on the right and one hand on the left side.
 - c. Cup both ears loosely and pat with your fingers behind the ears.
 - d. Continue patting down the sides of the head and neck, and the tops of the shoulders.
 - e. Continue tapping down the sides of the body, hips and legs until you reach the ankles.
 - f. Repeat a. through e. at least 3 times.
5. **Qigong Movement 4: The child lies on his/her back, face up. Begin on one side, and then move to the other side.**
 - a. Cup one ear loosely and pat with your fingers behind the ear.
 - b. Continue patting down the side of the neck and the top of the shoulder.
 - c. Pat down the arm to the back of the hand.
 - d. Repeat a. through c. at least 3 times for each arm.
6. **Qigong Movement 5: The child lies on his/her back, face up. Begin on one side, and then move to the other side.**
 - a. Take the child's hand between the thumb and forefinger of both hands, with one hand grasping between the 2nd and 3rd fingers, and the other between the 3rd and 4th fingers.
 - b. Pull gently on the arm until the arm is completely extended.
 - c. Shake arm gently while moving the arm up and down, from shoulder level to waist.
 - d. Repeat a. through c. at least 3 times for each arm.
7. **Qigong Movement 6: The child lies on his/her back, face up. Begin with one hand, and then move to the other hand.**
 - a. Hold the child's hand with one hand.
 - b. With the other hand, use forefinger and thumb to rub or press the sides of each of the child's fingers with short strokes from the base to the tip.
 - c. Repeat a. and b. at least 3 times for each hand.
8. **Qigong Movement 7: The child lies on his/her back, face up.**
 - a. Gently press down on the child's chest just under the right and left collarbones with your right and left hands.
 - b. Continue pressing down in a line toward the bottom of the rib cage.
 - c. Repeat a. and b. at least 3 times.
9. **Qigong Movement 8: The child lies on his/her back, face up.**
 - a. Gently rub your hand in large circles around the child's belly button. Rub in one direction for 9 circles.
 - b. Reverse direction and rub for 9 circles in the other direction.
 - c. Reverse direction again and rub for 9 circles in the original direction.
10. **Qigong Movement 9: The child lies on his/her back, face up.**
 - a. With one hand on each leg, pat down the middle of the legs from the top of the thighs down to the top of the feet.
 - b. Repeat at least 3 times.

11. **Qigong Movement 10: The child lies on his/her back, face up. Begin with one leg, and then move to the other leg.**
 - a. Using both hands to alternate movements, stroke slowly and evenly down one leg from behind the knee to the heel.
 - b. Repeat at least 3 times for each leg.
12. **Qigong Movement 11: The child lies on his/her back, face up.**
 - a. Use forefinger and thumb to rub or press the sides of each of the child's toes with short strokes from the base to the tip.
 - b. If the toes are too sensitive to rubbing, gently press the bottom and top of each toe.
 - c. Repeat a. or b. up to 3 times for each toe.
13. **Qigong Movement 12: The child lies on his/her back, body straight and face up.**
 - a. Take a foot in each hand with the thumb on the bottom and the other fingers curled around the top.
 - b. Gently and slowly press against the feet nine times.
 - c. Repeat several times if desired.

References

- Silva, L. (2011). *Qigong Massage for Your Child with Autism*. Singing Dragon, Philadelphia, PA. ISBN 978 1 84819 0702
- Silva, L., Cignolini, A. (2005). A medical Qigong methodology for early intervention in autism spectrum disorder: A case series. *The American Journal of Chinese Medicine*. 33(2):315-327.
- Silva, L., Cignolini, A., Warren, R., Budden, S., Skowron-Gooch, A. (2007). Improvement in sensory impairment and social interaction in young children with autism following treatment with an original Qigong massage methodology. *The American Journal of Chinese Medicine*. 35(3):393-406.
- Silva, L., Schalock, M., Ayres, R., Bunse, C., Budden, S. (2009). Qigong massage treatment for sensory and self-regulation problems in young children with autism; A randomized controlled trial. *American Journal of Occupational Therapy*. 63(4):423-432.
- Silva, L., Schalock, M., Gabrielsen, K. (2011). Early intervention for autism with a parent-delivered Qigong massage program: A randomized controlled trial. *American Journal of Occupational Therapy*, 65(5):550-559. doi: 10.5014/ajoty.2011.000661.

4. Five Senses Awareness Exercise

Five Senses Awareness Exercises are self-soothing exercises that use your five senses to allow you to be in the moment and reach a state of calmness. This exercise should take about 20 minutes (a minimum of 3 minutes per sense).

1. Create a calm, soothing, and quiet environment. Dim the lights.

Vision

2. Focus your eyes on soothing images, such as calming/non-stimulating pictures in a book, or the different features of a favorite toy stuffed animal. The goal is to have what your eyes focus on be as pleasing and calming as possible.

Describe 5 things you see. Descriptions should be informative and brief and without any emotional attributes. For example, "I see a wall painted light blue. I see the light above me has been dimmed. There is a brown teddy bear tucked in my bed."

Hearing

3. Listen to whatever sounds might be soothing, such as calm music, sounds of nature (waves, rainfall), or white noise. Close your eyes and allow your attention to focus on these sounds in your environment. Describe 4 sounds you hear. Descriptions should be informative, brief and bring attention to what sounds are happening in that moment. For example, "I hear the fan whirring in the window. I hear music playing softly."

Touch

4. Touch a texture you find soothing, such as soft pajamas, a textured blanket, or a soft, creamy lotion. With your eyes closed, allow your sense of touch to explore what is around you. Describe 3 things you feel. For example, "I feel the soft fur of my stuffed animal in my lap. I feel the scratchy wool of the carpet underneath my feet."

Smell

5. Breathe in scents that are calming and pleasant, such as a favorite lotion or perfume, or cinnamon. With your eyes closed, focus your attention to the scents in your environment. Describe 2 scents you can smell. Descriptions should be short and informative. For example, "I smell the soap I used to wash my hands after dinner. I smell the lavender lotion that mom rubbed on my shoulders."

Taste

6. Enjoy a small amount of a favorite drink, such as juice or milk, and/or eat a small snack slowly and mindfully. Describe 1 taste you are experiencing in this moment. For example, "I taste the minty toothpaste I used to brush my teeth before bed. I taste the chocolate chips in the cookie I am having as a snack."

References

Linehan, M.M. (1993). *Skills training manual for treating borderline personality disorder*. The Guilford Press.

5. Mindful Movements

These exercises are meant to bring awareness to our bodies and the movements we can make to bring ourselves a sense of calmness and peace.

You can do these exercises with your child alone or with the whole family.

They can be performed anywhere, inside or outside, wherever you feel most comfortable.

1. Before performing the exercises, take a moment to relax and ground yourself. With your feet shoulder-width apart and knees softly bent, relax your shoulders as you take a deep breath in and out. Image an invisible thread from the top of your head gently pulling your body up to stand straight, with your neck relaxed and chin slightly tucked into your neck, shoulders gently forward. With your feet firmly placed, take 5 slow, deep breaths.
2. **Flying:** Start with your feet slightly apart and your arms loosely at your sides. As you breathe in, lift your arms (palms facing down) in front of you until they are at shoulder level, parallel with the ground. As you breathe out, allow your arms to slowly fall back down to your sides. Repeat 5 times.
3. **Reach for the Stars:** With your feet shoulder-width apart and arms by your sides, breathe in and bring your arms in front of you, reaching all the way up to the sky and stretching them above your head. Palms can be facing inward toward one another or facing forward as you reach. As you breathe out, your arms slowly go back down to your sides. Repeat 5 times.
4. **The Claw:** Still standing with your feet slightly apart and your arms at your sides, breathe in while lifting your arms out to the side with your palms facing up until they are at shoulder level. As you breathe out, bend your elbows and touch your fingertips to your shoulders. Breathe in and open your arms back out to the horizontal position. Breathing out, allow your arms to drop back down to your sides. Repeat 5 times.
5. **The Windmill:** In this exercise, we are making large circles with our arms, much like a windmill motion. As you breathe in, bring your arms in front of you between your hips with your palms together. Raising your arms and allowing the hands to separate, stretch your arms above your head as you continue to breathe in. Now, breathing out, continue the circle as your arms circle back and your fingers point to the ground. Bring your hands back in front of you with palms together in front of your hips to complete the circle. Repeat 5 times.
6. **Around the World:** With your hands on your waist and your legs straight, breathe in and bend forward at the waist, making a circle with your upper body. When you are halfway through the circle and your upper body is leaning back, breathe out and complete the circle motion. After each circle motion, begin the next circle in the opposite direction. For the first 4 breaths, you should end with your head in front of you and still bent at the waist. On your last out-breath, return to an up-right position. Repeat 5 times.
7. **The Duck Squat:** With your hands on your waist, your heels together and toes turned out to form a 'V', breathe in and rise up onto your toes. Breathe out, still on your toes, and bend your knees, sinking down to the ground with your upper body straight and centered. Go as low as you can while maintaining your balance. Breathe in and rise back up to standing, still on your tippy-toes. On the last out-breath, relax your feet back down to the ground with your heels together and toes out to form a 'V'. Repeat 5 times.

8. **The Bow:** Standing with your feet hip-width apart, breathe in and reach your arms high above your head, palms forward with fingertips reaching to the sky. As you breathe out, bend at the waist and bring your arms down to touch your fingertips to the ground and relax your neck muscles. As you breathe in again, keep your back straight as you rise up again to touch the sky. Repeat 5 times.
9. **The Flamingo:** Start with your feet together and hands on your waist. Shift your body weight so it is all on your left foot. As you breathe in, lift your right leg so it is bent at the knee and your toes are pointed down to the ground. Breathing out, stretch your right leg out in front of you so your toes are now pointed out, away from you. Breathing in, drop the lower half of your leg to the previous position. Breathing out, place your foot back on the ground so your feet are touching. Repeat this movement 5 times with each leg.
10. **Foot Painting:** The purpose of this movement is to make a circle with your leg. With your feet together and your hands on your waist, shift your weight on to your left foot. Breathing in, lift your right leg straight out in front of you and circle it to the side. Breathing out, circle it to the back and bring it down behind you, allowing your toes to touch the ground. Breathing in, lift your leg up behind you and circle it around to the side. Breathing out, continue the circle to the front, then lower your leg and put your foot on the ground, placing your weight again on both feet. Repeat this exercise 5 times with each leg.
11. **The Lunge:** To do this exercise, you need to be in a lunge position. To get in a lunge position, begin by standing with feet together. Keeping your left foot where it is, move your right foot out so your feet are wider than shoulder-width apart and turn your right foot out 90 degrees. Keeping your weight on both feet, your body will naturally turn slightly toward the right foot to find a comfortable position angled between your two feet. Put your left hand on your waist and your right arm at your side. Breathing in, bend your right knee, bringing your weight over your right foot as you lift your right arm with the palm of your hand facing outward in front of you, and stretch it to the sky. Breathe out as you straighten your knee and bring your right arm back to your side. Repeat this exercise 5 times with each leg.
12. Stand with your feet slightly apart and firmly on the ground. Breathe in and out. Feel your body relax and fill with calm.

References

Hanh, T.N. (2008). *Mindful movements: Ten exercises for well-being*. Berkley, CA: Parallax Press.

6. Moody Cow Activities

Children with ASD are often visual learners and concrete in their thinking. Thinking about thinking is a difficult concept. Dividing your thoughts into 3 components can be helpful: Emotional Mind, Reasonable Mind and Wise Mind. This activity uses a Cue Card and a Mind Jar to help your child visualize his/her emotions and the means to self-regulation.

Emotional Mind: My mind is full of angry thoughts swirling around just like the sparkles in the jar. The sparkles are bouncing all over the place. My mind is upset.

Reasonable Mind: Take a deep breath and let it out. I can think about my situation in a reasonable way. Just as the sparkles in the jar will settle down, your angry thoughts will settle down, too. As the sparkles sink to the bottom of the jar, my thoughts settle as well. As my thoughts settle, my mind becomes quiet and calm.

Wise Mind: When my mind becomes full with angry thoughts and when I am upset with emotions, I can get my Cue Card and use my Mind Jar to help me settle down.

Preparing for this activity:

1. Read Moody Cow Meditates book.
2. Make the Mind Jar.
3. Make the Cue Card.
4. Put the card and the jar in a prominent place. Make sure your child knows where it is.

Using your Mind Jar:

1. Find your Cue Card.
2. Get your Mind Jar.
3. Get comfortable.
4. Take 5 deep breaths.
5. Shake the jar.
6. Watch the sparkles swirl and settle.

References

- Linehan, M.M. (1993). *Skills training manual for treating borderline personality disorder*. The Guilford Press.
- MacLean, K.L. (2009). *Moody cow meditates*. Wisdom Publications.

7. Worry Box/Worry Doll

The Worry Box is a stress management technique that is used in cognitive behavioral therapy. It is based on an ancient Guatemalan tradition. The Worry Box is a strong technique for children with ASD because they are often visual learners and concrete in their thinking. Writing down your worries on paper and placing them in a box, closing the box and putting the box outside the bedroom can provide concrete visual support of clearing your mind of worries. If your mind can quiet, it can help you calm and decrease your arousal level. Similarly, a Worry Doll or figurine can be a repository of your child's worries.

Worry Box

1. Get a box to use for your Worry Box, for example a shoe box.
2. Gather supplies to write down your worries and decorate your Worry Box, for example paper, pen/pencil, markers, stickers, etc.
3. Decorate your box.
4. Write down your worries on small pieces of paper.
5. Put the worries in the box.
6. Put the box in a special place, outside of the bedroom.

Worry Doll/Figurine

1. Get a doll or figurine to use as a Worry Doll.
2. Tell the doll or figurine about your worries or attach paper worries to it.
3. Put the doll or figurine in a special place, outside of the bedroom.

References

Dadoly, A. (2011). *Two techniques for reducing stress*. Retrieved from <http://www.health.harvard.edu/blog/two-techniques-for-reducing-stress-201104092235>

8. Gentle Rocking

Rocking has been shown to provide vestibular sensations that trigger receptors in the inner ear that detect head movement and gravity. This can have immediate and profound effects on alertness. In general, slow, rhythmical vestibular sensations such as rocking will decrease arousal level and can be helpful to induce sleep. However, responses to vestibular sensations are individually determined based on the individual's inherent sensory responsivity and arousal level. Therefore, vestibular sensation can be calming or alerting, organizing or disorganizing. Observe your child's response to this activity and proceed accordingly.

Exercise ball

1. Find a calm, quiet spot.
Place ball on the floor. Clear the surrounding area to allow room for rocking.
2. Lean forward over the ball with your arms hanging down in front of you and your legs behind you (body in an upside-down "U" position). Head can be turned to one side for comfort. The ball should support your body. Place your hands on your child's trunk or pelvis to provide stability and to monitor the rate of movement.
3. Rock forward and back slowly for approximately 10 minutes, no faster than 1 rock per second. The rocks should be slow and rhythmical.

Rocking chair

1. Place the chair in a calm, quiet area.
2. Sit in the chair, get comfortable. Your child can sit in the chair alone or on your lap.
3. Rock forward and back slowly for approximately 10 minutes, no faster than 1 rock per second. The rocks should be slow and rhythmical.

References

- Bagatell, N., Mirigliani, G., Patterson, C., Reyes, Y., & Test, L. (2010). Effectiveness of therapy ball chairs on classroom participation in children with autism spectrum disorders. *American Journal of Occupational Therapy*, 64, 895-903.
- Mailloux, Z., & Smith Roley, S. (2010). Sensory integration. In H.M. Kuhaneck & R. Watling (Eds.), *Autism: A comprehensive occupational therapy approach* (3rd ed.) (pp.469-507). Bethesda, MD: American Occupational Therapy Association, Inc.
- Pierce C, Pecen J, McLeod K.J. (2009) Influence of seated rocking on blood pressure in the elderly: a pilot clinical study, *Biological Research for Nursing* 11(2):144-51
- Schaaf, R.C., & Smith Roley, S. (2006). *SI: Applying clinical reasoning to practice with diverse population*. San Antonio, TX: Harcourt Assessment, Inc.
- Schilling, D.L., & Schwartz, I.S. (2004). Alternative seating for young children with autism spectrum disorder: Effects on classroom behavior. *Journal of Autism and Developmental Disorders*, 34(4), 423-431.
- Snyder M, Tseng Y, Brandt C, Croghan C, Hanson S, Constantine R, Kirby L. (2001) A glider swing intervention for people with dementia. *Geriatric Nursing* 22(2):86-90.
- Wu, W.L., Wang, C.C., Chen, C.H., Lai, C.L., Yang, P.C., & Guo, L.Y. (2012). Influence of therapy ball seats on attentional ability in children with attention deficit/hyperactivity disorder. *Journal of Physical Therapy Science*, 24, 1-6.

9. Quietly Reading a Book

Reading is a common method of relaxation and distraction. It allows one to focus on reading the story, leaving less room for the mind to think about stimulating thoughts or anxieties.

1. Find a quiet, comfortable area.
2. Read a soothing book, or books, for approximately 10-15 minutes.

10. Quietly Saying Prayers

This is a time you can just relax, think back on your day, and speak of the good in your life. This practice allows you to breathe more slowly and decreases your heart rate and blood pressure. A calm environment, soothing voices, and happy thoughts distract from other, more disturbing and stressful thoughts and anxious feelings.

1. Pick a quiet, calm spot and get comfortable.
2. Think about moments in your life for which you are thankful, and use quiet voices to briefly speak about them.
3. Pray. This can be in the form of religious or spiritual prayers, or just reflections on love and beauty; whatever you choose.
4. Be thankful for the people and love in your life and briefly talk about your gratitude in quiet voices.

References

- Seeman, T., Dubin, L., Seeman, M. (2003). Religiosity/spirituality and health: A critical review of the evidence for biological pathways. *American Psychologist*. 58(1):53-63.
doi: 10.1037/0003-066X.58.1.53

11. Yoga Poses for Insomnia

1. Find a quiet, calm place with a soft surface on which to practice, such as a carpet or yoga mat.

2. **Downward Facing Dog**

- a. Begin on hands and knees, and inhale deeply through your nose.



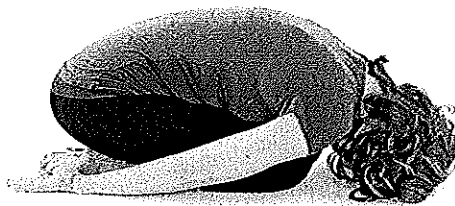
- b. Curl your toes under your feet, exhale, straighten your knees and lift your hips high towards the ceiling so that your body is in the shape of an upside-down "V". Let your head hang down as you breathe gently, looking behind you. Hold for 5 breaths. (One way to encourage kids to breathe is to have them bark like a dog.)



- c. To come out of pose, exhale and bring knees to the floor to move into Child's Pose.

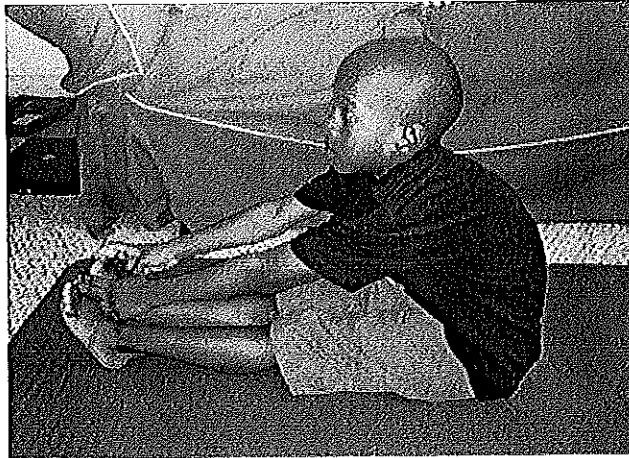
3. **Child's Pose**

- a. Kneel on the floor with your knees hip-width apart, your feet together and with the tops of your feet flat against the floor.
- b. Bring your head down to rest on the floor in front of you, exhaling.
- c. Move your arms to wherever is comfortable, whether outstretched in front of you with your palms down, or stretched back by your knees, etc.
- d. Relax and take 5 breaths.



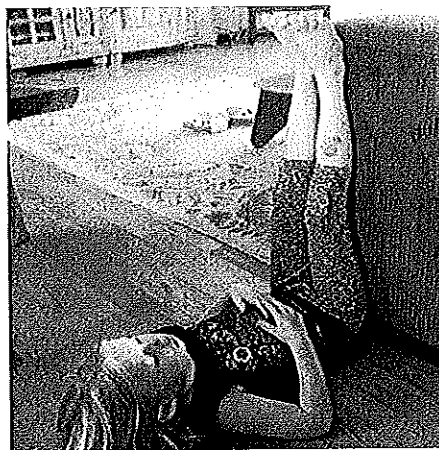
4. Seated Forward Bend

- a. Sit on the floor with your legs straight out in front of you and your back straight.
- b. Raise your arms straight up above your head as you breathe in.
- c. Exhale as you bend forward from your hips, keeping your back straight, and reach your hands to your legs (shins, feet). Focus on keeping your back straight and reaching your chin toward your toes (versus than toward your knees).
- d. Take 5 breaths.



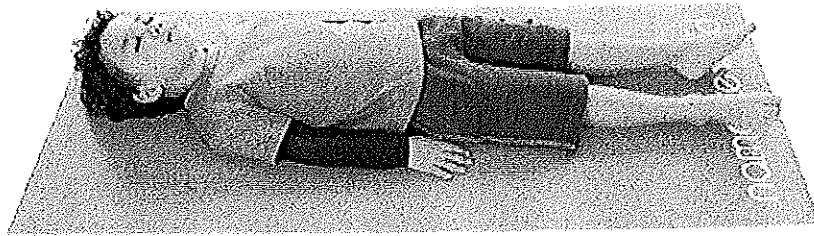
5. Legs Up The Wall

- a. Lie on the floor next to a wall (or surface you will use to raise your legs against).
- b. Exhale, and swing your legs up so they go “up the wall”. Do not lock your knees.
- c. Move your bottom so that it is against the wall (or as close to the wall as is comfortable), so your bottom and heels are flat against the wall.
- d. Place arms/hands wherever comfortable, whether up over your head, at your sides, or resting on your belly as you take 5 gentle breaths.



6. Sleeping Pose

- a. Lay down on the floor on your back with your arms outstretched by your sides.
- b. Close your eyes and breathe deeply for several minutes.



References

<http://www.namastekid.com/learn/kids-yoga-poses/table-pose/>
<http://www.namastekid.com/learn/kids-yoga-poses/downward-facing-dog-pose/>
<http://www.namastekid.com/learn/kids-yoga-poses/childs-pose/>
<http://www.artofliving.org/yoga-poses/seated-forward-bend-paschimottanasana>
http://www.google.com/imgres?imgurl=http://25.media.tumblr.com/tumblr_m8ypn7R9VT1r4ez6uo1_500.jpg&imgrefurl=http://blackyogis.tumblr.com/post/29700874662&h=358&w=500&sz=52&tbnid=sMeOgbShZtrtPM:&tbnh=90&tbnw=126&zoom=1&usg=__sCiQtIHdg1R-WqJFxFVSRYP1Xq4Q=&docid=GA1MIRT0k6LSeM&sa=X&ei=wB3QUZmaE-y20AGajIDADQ&ved=0CEAQ9QEwBA&dur=793
<http://www.cnyhealingarts.com/2011/02/07/health-benefits-of-viparita-karani-legs-up-the-wall-pose/>

12. Taking a Warm Bath

Warm baths can decrease anxiety and produce an sensation of well-being. Select a time in the evening that will allow you to directly supervise your child for 10 to 15 minutes. The bath water should be warm, not too hot or cold. Ideally, it should be at the child's body temperature 36.5 - 37.5 °C or 97.7 - 99.5 °F.

1. Prepare a warm bath.
2. Engage in relaxing play, such as with toy figurines, flotation toys, or gentle singing for 10-15 minutes. Stay with your child for the entire duration of the bath.

References

Robiner, W.N. (1990) Psychological and physical reactions to whirlpool baths. *Journal of Behavioral Medicine*, 13 (2):157-73.