Sleep Health and m-Health Interventions in Pediatric Chronic Conditions

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Objectives

> Describe common sleep problems

> Identify the current gaps in pediatric sleep interventions

> Describe community-based participatory approaches in the development and testing of interventions to improve sleep in children

> Describe current mHealth pediatric sleep interventions

> Discuss recommendations

Conflicts of Interest

Why Focus on Sleep?

Why Focus on Sleep?

> Major public health concern

> One of the top 5 complaints presented to primary care clinicians
   - Infants up to 40%
   - Preschool 25% to 30%
   - School-age & Adolescents 10% to 60%

> Up to 30% of children and 66% of adolescents experience Insomnia symptoms

Owens J & Chervin R (2019); Dewald-Kaufmann, de Bruin, Gradisar (2019)

Consequences of Sleep Deficiency

- Co-morbid with acute & chronic illnesses
- Developmental transitions
  - Age, work, family

- Self-imposed due to unhealthy lifestyle choices

- Physiologic & behavioral consequences
  - ↓ Quality of Life
  - Health consequences
    - Mental health
    - Obesity
    - Inflammation

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Cognitive Behavioral Therapy for Insomnia (CBT-I)

> First line of therapy for pediatric insomnia.
- Targets both behavioral and cognitive components
- Few RCTs in school-age children and adolescents

> Face-to-face or telephone sessions can produce significant improvement in sleep duration, patterns, and behaviors.
- 2 to 6 sessions

Åslund et al., *J Clin Sleep Med*. 2018; Hiscock et al., *British Med J*, 2015; Meltzer & Mindell, *J Ped Psychol,* 2014

Systematic Review of CBT-I in Children

Characteristics of the Intervention

	Components/Modules						
	Sleep Education	**Sleep Hygiene**	**Sleep Restriction/ Bedtime Fading**	**Stimulus Control**	**Cognitive Therapy**	**Relaxation/ Mindfulness**	**Other**
Blake et al., 2016	X	X		X		X	CBT-a
Cain et al., 2011	X	X				X	
Clarke et al., 2015	X	X	X	X	X		CBT-d
de Bruin et al., 2015	X	X	X	X	X	X	
Moseley et al., 2009	X	X	X	X	X		
Paine et al., 2011	X	X	X				

CBT-a = cognitive behavioral therapy for anxiety, CBT-d = cognitive behavioral therapy for depression.

Key Findings: Significant differences in total sleep time and sleep onset latency posttreatment favoring the sleep-specific CBT-I as compared to wait-list and active control groups.

- effect sizes for actigraphy and self-reported sleep onset latency 0.4 and 0.81
- effect size for WASO 0.5

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Limitations of Current RCTs in Children

> Primarily conducted in adolescents
  – Child report of sleep and daytime function

> Small sample sizes

> High risk of bias due to lack of blinding
  – Attention control groups

> Heterogeneity in participants, treatment regimens and delivery

> Longer follow up periods

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Gaps In Sleep Interventions

> Lack of pediatric providers trained in how to manage behavioral sleep problems.

> Long waiting times and referrals.
  – Cost and time
  – Missed work and school

> Stakeholders (e.g., parents and children) are not involved in developing of the intervention.

> Few interventions incorporate shared-management skills (activation, motivation, self-efficacy)

> Few sleep interventions focus on marginalized communities.

Smith et al., *Sleep Health,*2019; Caldwell et al., *J Ped Health Care,* 2019; Schwichtenberg et al., *Slp Med Rev,*2019; Honaker et al., *Sleep Med Rev,* 2015

mHealth/ eHealth

> Use of mobile technology to improve sleep
  – Mobile applications
  – Web-based applications
  – Text messaging

> Few studies have examined mHealth to improve sleep in children.

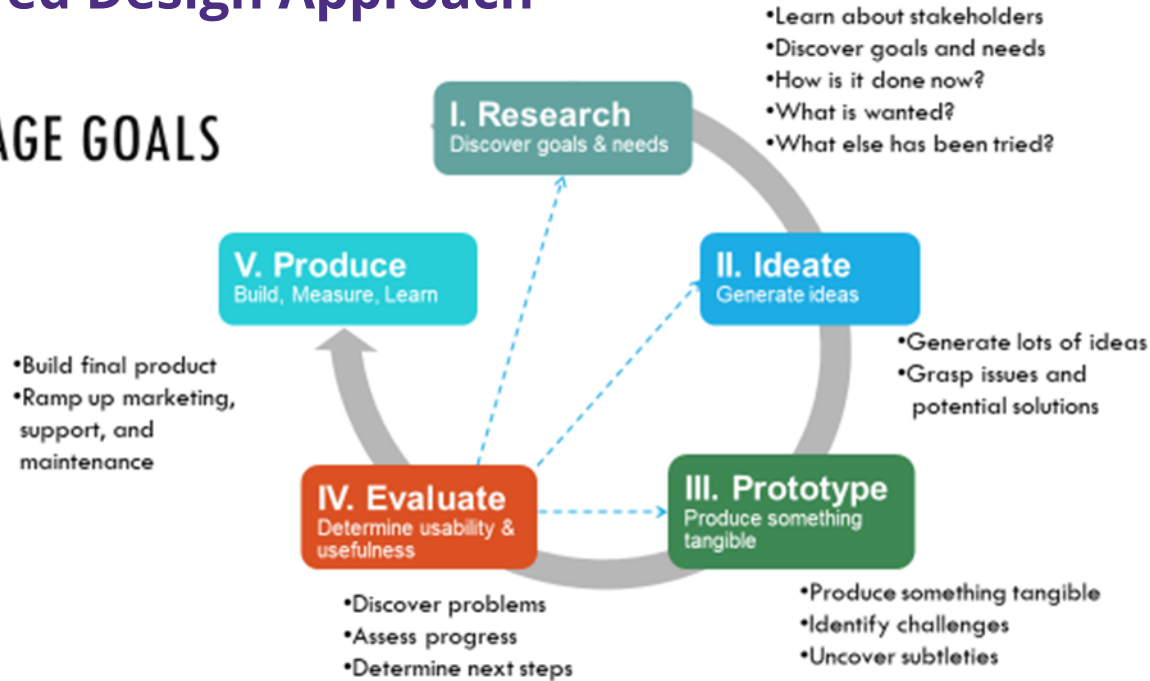Tan-MacNeill, et al., *Res Dev Disabilities*, 2020; Leichman, et al., *Behav Ther*, 2020; Ward, et al., *Nursing Outlook,* 2020; Sonney, et al., *J Clin Sleep Med,* 2020; Corkum, et al., *JMIR*, 2018; Corkum, et al., *JMIR 2018*; Ritterband et al., *Annals Behav Med,* 2009

Shared Management

> Caregivers are an essential component of the care of the child.
  - Activation
  - Motivation
  - Self-efficacy

> Empower both caregivers and children to set goals and problem solve.

> mHealth interventions have been shown to improve patient activation and engagement, making them a possible solution to improve outcomes.

> Few studies evaluate the use of mHealth in the parent-and-child dynamic to better understand optimal use of mHealth for both parts of this dynamic.

Palermo T, et al., *Contemp Clin Trials*, 2018; Badawy, et a., *JMIR*, 2018; Fisher et al, *J Pediatr Pscyhol*, 2018; Haas, et al., *J Pediatri,* 2017; Grey M, et al., *Nurs Outlook,* 2015.

Integration of Technology to Improve Sleep

User Centered Design Approach

STAGE GOALS

I. Research
Discover goals & needs

- Learn about stakeholders
- Discover goals and needs
- How is it done now?
- What is wanted?
- What else has been tried?

II. Ideate
Generate ideas

- Generate lots of ideas
- Grasp issues and potential solutions

III. Prototype
Produce something tangible

- Produce something tangible
- Identify challenges
- Uncover subtleties

IV. Evaluate
Determine usability & usefulness

- Discover problems
- Assess progress
- Determine next steps

V. Produce
Build, Measure, Learn

- Build final product
- Ramp up marketing, support, and maintenance

Explore

> Identify stakeholders
- Patients
  > Children
  > Older Adults
- Caregivers
  > Parents
  > Spouses
- Healthcare Providers
  > Nurses
  > Doctors
- Community
  > Community health navigators

OBSERVE

> Participatory Design
 – Incorporate stakeholders throughout the design process
 – Example:
   > Sticky Note Exercise
   > Facilitator
   > RAs for notetakers

Prototypes
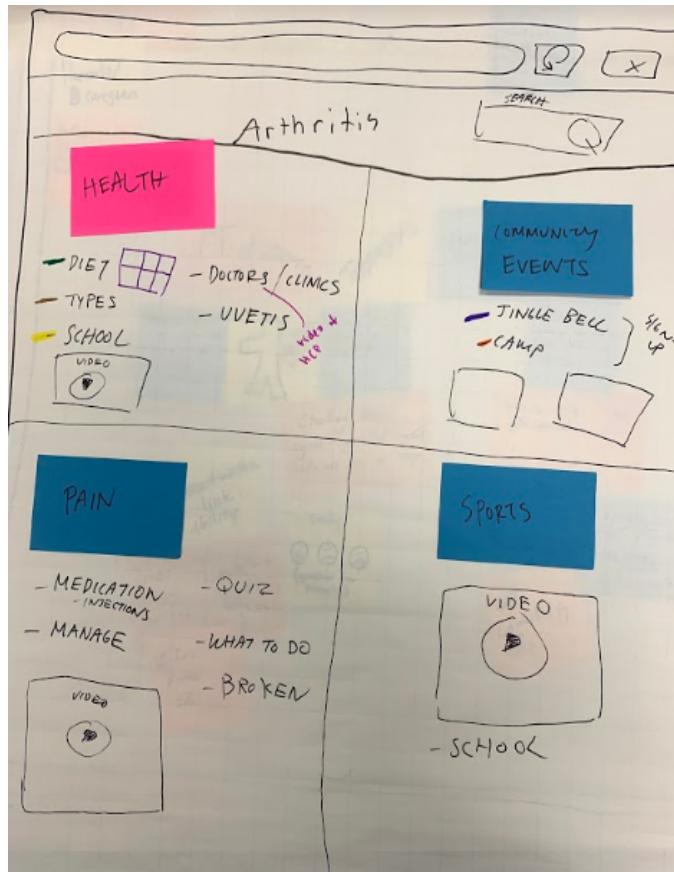
Participatory Design

EXPLORE

> Prioritize features
  – How important is the feature
  – How well the need is met by existing solutions

Welcome to SLEEPSMART

Sleep Shared-Management Intervention for Children with Juvenile Idiopathic Arthritis

1) Sleep Education
2) Recognizing stress and negative emotions
3) Operant strategies I (reinforcing behaviors)
4) Positive Reinforcement
5) Modeling
6) Communication
7) Lifestyle
8) Relapse Prevention

Ward et al., *Nurs Outlook*, 2020

Key Components of Behavioral Sleep Interventions

Cross-Cutting Modules				Common Transdiagnostic Sleep-Circadian Problems	Treatment Module
Case Formulation	Education	Behavior Change & Motivation	Goal Setting	Establishing regular sleep-wake times	Core Module 1
				Learning a wind-down routine	Core Module 1
				Learning a wake-up routine	Core Module 1
				Improving daytime functioning	Core Module 2
				Correcting unhelpful sleep-related beliefs	Core Module 3
				Improving sleep efficiency	Optional Module 1
				Reducing time in bed	Optional Module 2
				Dealing with delayed or advanced phase	Optional Module 3
				Reducing sleep-related worry/vigilance	Optional Module 4
				Maintenance of behavior change	Core Module 4

The above with a highly trained SLEEP COACH

Chen et al., *JMIR,* 2019

Weekly Email

Hello and welcome to your first week of the SleepSmart study; we are so excited that you are taking part!

This week you will be learning all about sleep. Below are outlined the steps for you to complete for this week's learning module. Please note that *it is up to you, as parent and child, if you would like to go through the lesson (Step 1) together or separately.*

Steps for Child

1) Sleep Education Lesson
   a) Go to the Sleep Education lesson page on the SleepSmart website.
   b) Click through the slides to learn "all about sleep."
   c) Take the 5 question quiz to see what you've learned.

2) This Week's Activities
   a) Under "For Kids" in the "Weekly Activities" activities, you will find the 4 worksheets that you need to complete for this week.
   b) Click on the button with each worksheet's name. You can then either print it out and fill it in by hand, or you can complete the worksheet on your computer.
   c) Once you've finished, give your completed worksheets to your parent so that they can upload them onto the REDCap site on this child link.

Steps for Parent

1) Sleep Education Lesson
   a) Go to the Sleep Education lesson page on the SleepSmart website.
   b) Click through the slides to learn "all about sleep."
   c) Take the 5 question quiz to see what you've learned.

2) This Week's Activities
   a) Go to this link on the REDCap website.
   b) Follow the instructions to answer the questions related to the "Pros and Cons of Changing Sleep Habits."
   c) Upload your child's worksheets from this week.
   d) Click "Submit" and your weekly learning module is complete!

Please remember if at any time you need support from our team, you can email us at sleepsmartstudy@uw.edu. Thank you again for your participation in this study!

Sincerely,
The SleepSmart Study Team

Sleep Education

About this Lesson

In this week's lesson you will learn about the importance of sleep, different types of sleep, and sleep biology and rhythms. The lesson will include:

1. A video slideshow
2. An interactive quiz
3. Activities to complete this week
4. Handouts with additional information about sleep

As part of this lesson, we want you to be reflecting upon your sleep-related behaviors, thoughts, feelings, and consequences at bedtime, during the night, on waking, and during the day sleep habits and struggles.

Pros & Cons of Changing Sleep Habits

There are advantages and disadvantages to making any change in your life. Think about the changes you might make to help your child's sleep habits. What are some pros and cons?

1) **Pros?**

_____

Expand

2) **Cons?**

_____

Expand

3) **Please upload the Session 1 Assignment Sheet here**

⬆ Upload file

Better Nights Better Days (BNBD)- ADHD

> **Primary Aim**: To determine the effect of a distance BNBD intervention on children's sleep onset latency, bedtime resistance, and sleep duration as measured by parent report.

> **Secondary Aims:**

  – To evaluate change in sleep as measured by actigraphy,

  – To evaluate whether children with ADHD responded similarly to the distance sleep intervention as typically developing (TD) children

  – To determine whether changes in sleep resulted in changes in daytime functioning

Corkum P, et al., *J Ped Psych, 2016*

Better Nights Better Days Intervention with Sleep

Intervention sessions.

Session	Topic overview
Sleep information	Characteristics of sleep; types of sleep problems, sleep need; how sleep problems develop; impact and treatment of sleep problems
Healthy sleep practices	Daytime and bedtime routines; sleep hygiene/healthy sleep practices; sleep scheduling (including napping) and sleep routines
Independent settling at bedtime	Settling at bedtime; parents choose a sleep intervention that best fits their needs from 3 intervention strategies: controlled comforting, camping out, and bedtime fading
Night waking, napping, and early morning awakenings	Applying strategies to night waking; applying strategies to early morning awakenings; applying strategies to napping
Looking back and ahead	Relapse prevention; looking back at goals and progress; common pitfalls/roadblocks; what to expect at new developmental milestones; dealing with other sleep problems; making a plan

Sleep Coach
- 5 weekly telephone calls (30 to 45 minutes)
- parent manual

Better Nights Better Days -Study Eligibility

Child		
Inclusion	• Age 5 to 12 years • Child experience trouble falling asleep, with/without bedtime resistance →SOL >25 minutes & occurring >3 times per week • Duration of sleep problem >1 month, with impairment to daily functioning	
Exclusion	• + Sleep apnea screening • Moderate/severe cognitive impairment • Neurological disorder (epilepsy) • Mental health disorder (anxiety, depression) other than ADHD • Participation in behavioral sleep intervention over the last 6 months • Co-sleeping	

Methods

> Sample: 61 children (n=31 ADHD)
  – 5 to 12 years of age
> Sleep – actigraphy (SOL, duration), CSHQ
> Single Center, parallel group RCT
  – Randomized to intervention (n=30) or waitlist control (n=31)
> 5-week telephone intervention with sleep coach

Baseline Assessment → **Intervention (5 weeks)** → **2-month Post-Intervention** → **6-month Post-Intervention**

Corkum P, et al., *J Ped Psych, 2016*
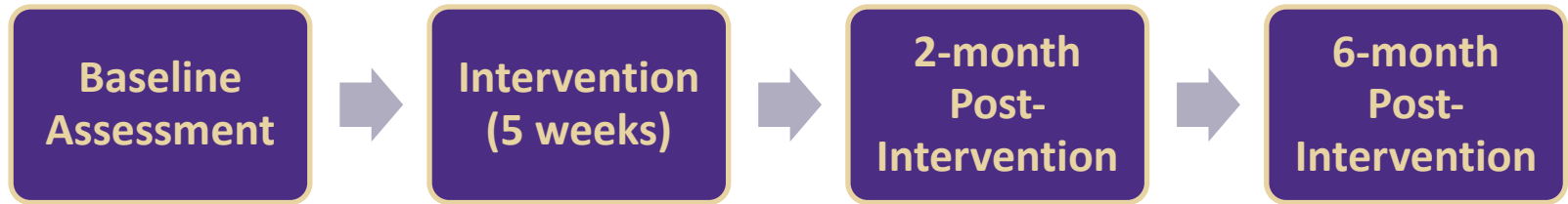
Demographics

	Intervention (n=31)	Waitlist Control (n=30)	p value
Age (months, SD)	108.0 (23.6)	110.6 (23.7)	.67
Sex (female, %)	16 (51.6%)	17 (56.7%)	.69
Ethnicity	25 (80.6%)	28 (90.3%)	.14
ADHD diagnosis	12 (38.7%)	10 (33.3%)	.66
Meds for ADHD (yes, %)	8 (67%)	6 (60%)	.59

Results

> Significant improvement for parent ratings on the CSHQ in the intervention group at 2- and 6-months post-intervention

  – SOL, bedtime resistance, and sleep duration

  – effect sizes small to moderate

> Actigraphy no differences over time

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Limitations

> Low adherence to actigraphy

> Lack of child report measures of sleep and daytime functioning
  – sleep hygiene

> Shared Management measures
  – self-efficacy, motivation

Revised Better Nights Better Days

> Developed to determine its effectiveness on children's sleep and psychosocial functioning

> **Parent-guided e-Health intervention** to treat behavioral insomnia
  – Accessible program to empower parents to implement strategies independently
  – ADHD, Typically Developing, Neurodevelopmental Disorders

> Based on evidence-based practices and tailored content
  – participants create personalized sleep routines, set individualized goals, and receive custom feedback on progress
  – age-specific information delivered primarily through videos and interactive elements to engage and encourage parents
  – access to built-in tools and supports, such as sleep diaries and goal setting and tracking, provides feedback on participants' progress.

Tan-MacNeill et al., *Res Dev Disabil*, 2020; Corkum P, et al., *JMIR,* 2018; Corkum, et al*., J Ped Psych*, 2016

Better Nights Better Days

> The purpose of the RCT trial is to evaluate the effectiveness of BNBD, an eHealth intervention for insomnia in children 1 to 10 years of age.

– RCT across Canada

– Canadian Institutes of Health Research

> **Implementation and sustainability**

– Who does this intervention work for?

https://betternightsbetterdays.ca/information-media

Better Nights Better Days -Study Eligibility

	Child	Parent
Inclusion	• Age 1-10 years • Speak/understand English • Internet access • Insomnia (sleep onset disturbance)	• Caregiver of a child • Read/understand English & French • Internet access • Reside in Canada
Exclusion	• + Sleep apnea screening • Medical and/or mental health disorder (developmental disability, medication for ADHD)	• Bedsharing with the child

Corkum P, et al., *JMIR, 2018*

Web-Based Sleep Intervention for Kids and Parents (SKIP): A Pilot Study

> **A Shared Management Pilot Study**

> Develop and pilot test SKIP, a web-based tailored intervention for sleep deficiency in 6-to-11 year-old children with asthma and their parents.

> **Study Aims:**

1: Describe the feasibility & acceptability of SKIP

2: Explore changes in sleep deficiency measures

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Study Eligibility

	Child	Parent
Inclusion	• Asthma diagnosis • Age 6-11 years • Speak/understand English • Prescription for daily asthma medication • Sleep deficient (CSHQ)	• 18+ years • Read/understand English • Reside with child (50% +) • Legal guardian • Internet access • Sleep deficient (PSQI)
Exclusion	• Traumatic brain injury • Developmental delay • ASD, ADHD, Cancer • Diagnosed sleep disorder • + Sleep apnea screening • Use sleep medication	• Diagnosed sleep disorder • Night shift worker • Use sleep medication

Methods

> May 2017 - July 2018
> Single group 8-week tailored intervention
> Study structure:

| Baseline Sleep Assessment | → | Intervention (8 weeks) | → | Immediate Post-Intervention | → | 12 Week Post-Intervention |
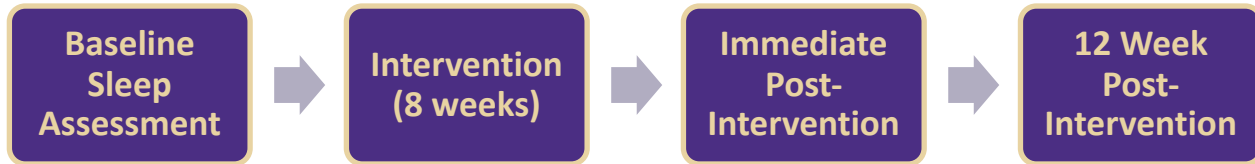
Data Sources

Parent

- **Objective**
  - Actigraphy
- **Subjective**
  - Self-report & proxy surveys
  - Sleep diaries

Child

- **Objective:**
  - Actigraphy
  - Spirometry
  - Weight, height
- **Subjective:**
  - Self-report surveys
  - Sleep diary

Dyad

- **SKIP**
  - Engagement
  - Goal-setting, progress reports
- **Semi-structured interview**

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Web-Based SKIP Intervention

> Dyads select from 3 modules

> Educational video

> Weekly activities

   – Goal setting

   – Anticipating barriers & problem solving

   – Weekly progress report (weeks 2-8)

Module Activities

Not going well

Still working on it

Met my goal!

GOALS

Anticipated
Barriers & Problem

STOP

GO

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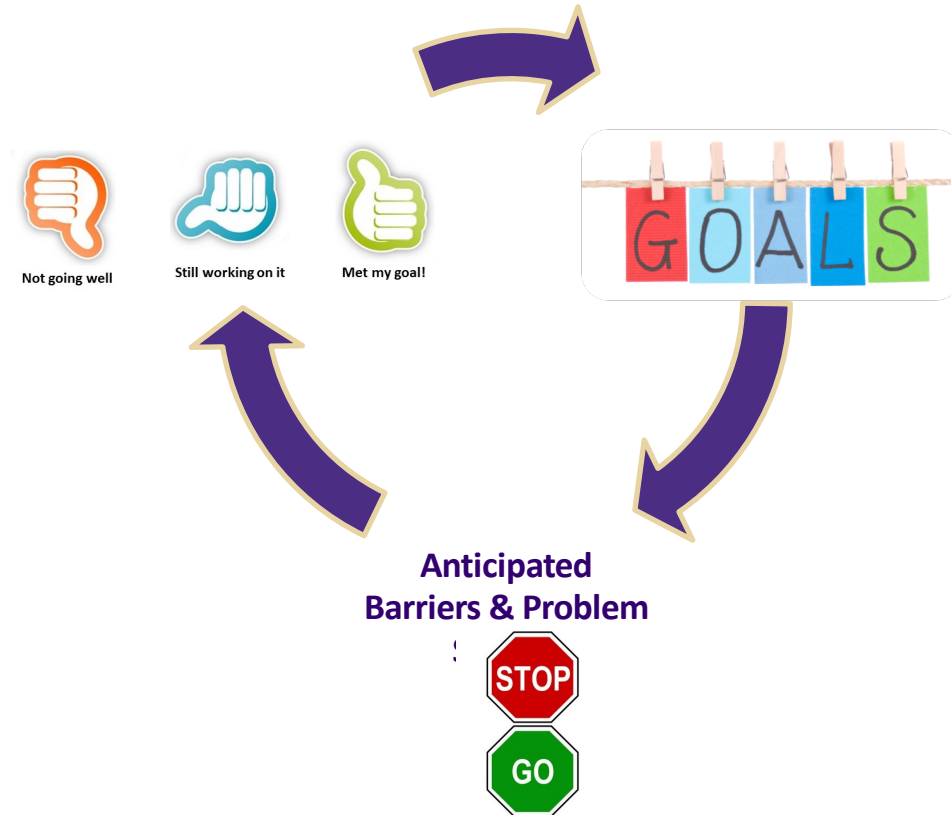
Results

Feasibility
- Enrollment response
- 14% attrition

Acceptability
- Acceptable & helpful
- Easy to use

Efficacy
- Parent & child improvements
- Post intervention & 3 month follow-up

Efficacy Results Continued

	Outcome	Baseline Mean (SD)	3-Month FU Change (95% CI)
	Sleep Time (min)	479 (74)	7.5 (-3.5 to 18.5)
	Bedtime consistency (min)	171 (104)	**-35.2 (-42.9 to -27.5)***
	Wake after Sleep Onset (WASO, min)	109 (64)	**-37.1 (-44.5 to -29.7)***
	Sleep Efficiency (%)	82 (10)	**5.4 (4.2 to 6.5)***
	Sleep Time (min)	421 (78)	6.5 (-7.5 to 20.4)
	Bedtime consistency (min)	223 (168)	**-35.3 (-51.0 to -19.7)***
	Wake after Sleep Onset (WASO, min)	70 (40)	**-13.9 (-19.5 to -8.2)***
	Sleep Efficiency (%)	86 (7)	**2.7 (1.7 to 3.7)***

* p < .001

Implications & Next Steps for SKIP

> SKIP was feasible, acceptable and effective

> Next steps:
- Refinements
- Testing in a larger trial

Moving Forward -Recommendations

> Integration of community-based participatory approaches

> Sample

   – consideration of who is and is not included

> What interventions work for whom?

> Sharing Protocols

> Intervention Fidelity

> Validation of the technology to measure sleep

> Security & Privacy concerns

Current Research at UW School of Nursing

Center for Innovation in Sleep Self-Management

> **Online Prenatal Trial in Mindfulness Sleep Management (OPTIMISM)** Dr. Ira Kantrowitz-Gordon

> **Sleep Innovations for Preschoolers with Arthritis (SIPA)** Dr. Weichao Yuwen

> **Latino Caregivers of Children with Special Healthcare Needs** Dr. Maggie Ramirez

https://cissm.nursing.uw.edu/

Current Ongoing Studies at UW

> **Sleep Shared-Management Intervention in Children with Juvenile Idiopathic Arthritis (SLEEPSMART)** Dr. Teresa Ward

> **The Role of Sleep Deficiency in Youth with Chronic Pain** Dr. Tonya Palermo

> **Open Tools for Self -Tracking, Self-Experimentation, and Patient - Provider Collaboration in Symptom Self - Management and Clinical Care**. Dr. James Fogarty

> **Mobile Motivational Physical Activity Targeted Intervention –** Dr. Oleg Zaslavsky

> **Better Sleep for Breast Cancer Survivors: A Chat Bot Intervention** Dr. Kerryn Redding

ACKNOWLEDGEMENTS

PEDIATRIC SLEEP TEAM

Thank you!