



Improving Sleep in Navajo Caregivers and Their Young Children with Developmental Disabilities

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PURPOSE

This study explored the feasibility and acceptability of a tailored sleep health education intervention for caregivers of children with developmental disabilities (DD) in the Growing in Beauty early intervention program on the Navajo Nation.

SUMMARY

Caregivers reported an increase in their average sleep duration, a decrease in sleep onset at bedtime, and improved physical and mental health-related quality of life (HRQoL). They also increased their knowledge of sleep disorders and healthy sleep practices. Many caregivers reported better sleep quality in their children with earlier bedtimes and less night waking.

IMPLICATIONS

“Now that I am sleeping more, I feel better, and I have more energy to play with my child during the day (caregiver participant, 2018).”

Parenting a child with a DD can be demanding, and these caregivers are at risk for poor sleep quality and inadequate sleep quantity that can affect health and well-being. Education and support to improve sleep can impact a caregiver’s capacity to parent their child with DD.

INTRODUCTION

Racial and ethnic minorities in the United States, particularly those who are low income, are at greater risk for short sleep duration and poor sleep quality, and this can contribute to adverse health outcomes and exacerbate health disparities.¹ Families who have fewer economic resources may live in tighter living quarters that create challenges in maintaining sleep environments that are quiet, dark, and a comfortable temperature—conditions conducive to good quality sleep.² Also, bedtime practices that promote sleep, such as consistent bedtime routines, are less likely to occur in a family who lives in poverty or overcrowded housing conditions.³

Families who have children with DD are also at risk of having inadequate sleep or poor sleep quality. Many children diagnosed with DD have significant medical or behavioral needs.⁴ These needs may require that the child’s caregiver attend to the child throughout the night. Months or years of interrupted and unpredictable sleep can result in chronic sleep loss that can significantly influence the physical and mental health of the caregiver.⁵

Educational interventions that encourage healthy sleep practices for both adults and children arose from the growing awareness of the importance of sleep in health maintenance and child development. However, increased knowledge of healthy sleep practices does not always transfer to long-term positive changes in sleep behaviors.⁶ Non-pharmacological interventions for adults without diagnosed sleep disorders and young children are most successful if they combine educational approaches with tools and supports for behavioral change.^{6,7A} A key element in many sleep interventions is changing behaviors through the implementation of individually-tailored strategies and addressing barriers to healthy sleep.⁸



Bridge Brief

FEATURED STUDY

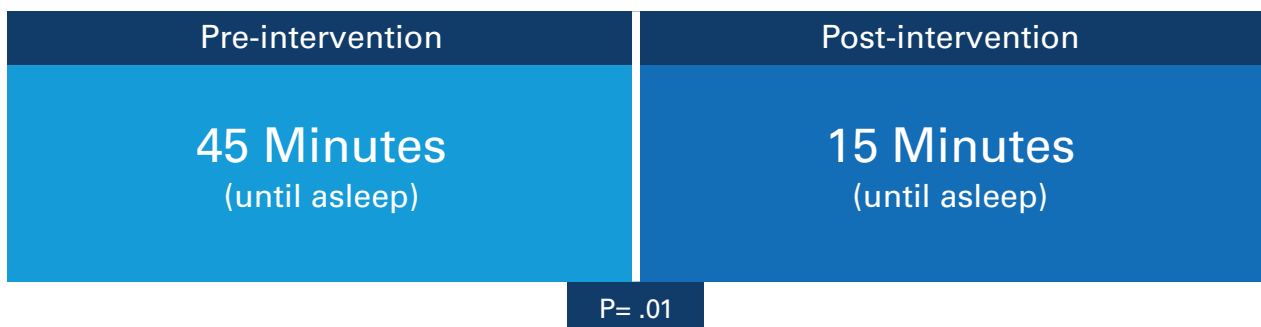
This study targeted fifteen caregivers of babies and toddlers with DD enrolled in Growing in Beauty, the Part C early intervention program on the Navajo Nation, an extremely rural area in Northern Arizona. This mixed-method pilot study utilized repeated measures and caregiver interviews to evaluate changes in caregiver and child sleep quality and sleep quantity. Also, caregivers responded to open-ended questions regarding barriers and facilitators to healthy sleep.

Available sleep education materials were adapted with consultation from Navajo Early Intervention Developmental Specialists on cultural and linguistic content. Stories from Navajo cultural resources that supported the adoption of healthy lifestyles were included. This intervention consisted of two educational modules presented to the primary caregiver during two home visits. The modules presented information on common sleep disorders (e.g., sleep apnea, insomnia, night waking in children) and deterrents to healthy sleep (e.g., electronics before bed, lack of exercise, excessive daytime napping). Strategies for better sleep were discussed, including bedtime routines, relaxation, and fading parent presence at bedtime. The modules addressed sleep issues and sleep strategies for adults and children. Caregivers developed a Sleep Plan with one or more goals for themselves and for their children that would improve sleep quality and sleep quantity. The PI provided follow-up and support for goals on the Sleep Plan for 6 to 8 weeks through phone calls or texting.

The reported sleep duration of caregivers as recorded on their sleep diaries increased from 5.82 hours (SD 1.85) pre-intervention to 7.83 hours (SD 1.86) post-intervention ($p=.005$). Moreover, a decrease in self-reported sleep onset, on average, improved significantly from 45 minutes to 15 minutes ($p=.01$). A significant difference in caregiver HRQoL was also noted, with better physical health ($p=.001$) and mental health ($p=.002$) reported following the intervention. The nighttime sleep duration for the targeted children in the intervention increased from 9.56 hours (SD 1.23) pre-intervention to 10.29 hours (SD 1.18) post-intervention ($p=.007$). A significant relationship between caregiver and child sleep was also supported. A decrease in the number of child night wakings ($M=.40$, $SD=.76$) was associated with an increase in caregiver sleep duration ($M=1.63$, $SD=1.93$), $t(12)=2.36$, $p=.04$).

Through interviews, caregiver participants identified four primary barriers to healthy sleep: responsibilities, environmental conditions, caregiver physical and mental health, and harmful habits. Participants indicated that responsibilities that included child care, jobs, and school were sometimes a barrier to healthy sleep, usually in preventing adequate sleep duration. Some caregivers discussed the needs of their child with DD as requiring more time and attention, sometimes during the night. Monitoring feeding pumps, coping with seizures, and tending to problem behaviors were situations that required caregivers to forego sleep. Environmental conditions were also a factor in getting good quality sleep. Some of the families lived in homes with extended family members. This sometimes resulted in overcrowded conditions where the caregiver had limited control over the

Self-Reported Sleep Onset of Caregivers

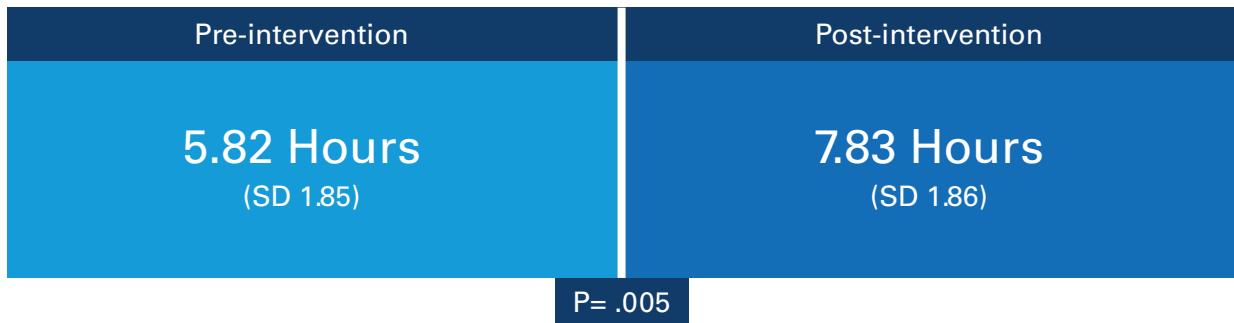




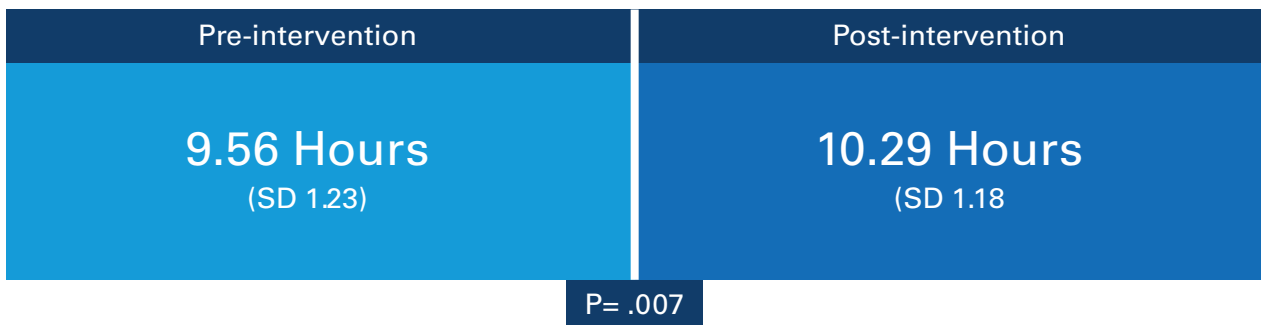
environment. Many of the homes on the Navajo Nation do not have central heating or cooling, resulting in uncomfortable temperatures for sleeping or disruption of sleep to tend to a wood stove. The extreme rurality of the Navajo Nation can create an additional barrier to adequate sleep, as families may be required to travel long distances for school, jobs, or medical appointments. Some caregivers indicated that falling asleep and staying asleep were challenging due to their worries about their child with DD, as well as concerns about other family members, bills, and health. Habits that are harmful to sleep were also a stated barrier by the caregiver participants. Common habits included overconsumption of caffeine, screen time before bed, and inadequate exercise during the day.

Many caregivers participating in this intervention stated that their sleep improved and that this helped them to “feel better.” Participants indicated that relevant information directed toward specific challenges contributed to meeting their goals. For example, caregivers reported that learning strategies that would help to quiet their minds enabled them to fall asleep at bedtime and return to sleep during the night. Information that targeted specific age-related challenges with sleep was beneficial, such as strategies for toddler self-soothing at bedtime. Caregivers also stated there were challenges in following their Sleep Plan, including getting buy-in from other members of the household in making changes for healthier sleep.

Reported Sleep Duration of Caregivers



Nighttime Sleep Duration for the Targeted Children





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BEST AVAILABLE EVIDENCE

Relevant education and tools to support behavioral change are key components in successful interventions. Caregiver participants in this study acknowledged that developing personalized goals assisted them in making changes in their daytime habits and bedtime routines that were helpful to both their own and their children's sleep. As in research with other tailored health promotion interventions, personal contact through home visits and texting may have contributed to better compliance by the participants.⁹

IMPLICATIONS FOR PRACTICE

Caregivers are critical supports for their children with DD. Caregivers of children with DD, particularly those who have limited economic resources and who live in rural locations, are at risk for poor sleep that can affect their physical and mental health as well as their capacity to parent their child. Supports for caregivers' health and well-being are critical components of programming to improve the quality of life of children with DD and their families.

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