Title: Behavioral Randomized Clinical Trial of Sleep Intervention to Improve Sleep in Sleep-Disordered Children with Down Syndrome and Their Parents

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Introduction: Sleep is an important concern among children with Down syndrome (DS), with 31-54% experiencing some form of sleep problem, ranging from obstructive sleep apnea (OSA) to behavioral sleep problems (Stores & Stores, 2012). Polysomnography (PSG) records show that while 1/3-2/3 of children with DS suffer from OSA, many children with DS (52-69%) experience behavioral sleep problems that may be missed by PSG (Bull, 2011). Exacerbating the concern for undetected sleep problems is the finding that inadequate sleep in children with DS can lead to a variety of problems with behavior and executive functioning in this population (Esbensen & Hoffman, 2018; Esbensen et al, 2018). Nonetheless, minimal work has been done targeting the treatment of behavioral sleep problems and the impact on improving outcomes for children with DS. Thus, the purpose of this study was to design and test the efficacy of a manualized behavioral sleep treatment (BST) for children with DS and behavioral sleep disorders, with a focus on improving child and parent sleep.

Method: Data were collected on 30 parents and their child ages 6-17 years who had a diagnosis of DS and at least one behavioral sleep disturbance. Further inclusion criteria for the child included a mental age of at least 36 months and English as a primary language in order to complete an assessment battery. Participants were randomly assigned to one of two groups: the BST or the enhanced standard of care condition (CON). The BST condition (n=16) included five weekly parent therapy sessions which emphasized behavioral principles and visual supports targeting behavioral sleep problems in children with DS. The CON condition (n=14) involved treatment as usual enhanced with four educational sessions on non-sleep related topics relevant to families of children with DS. Sleep outcomes were gathered by parent report. The impact on sleep was assessed comparing scores at pre-treatment, post-treatment, and a 12-week follow-up to the treatment, using scores from the Child Sleep Habits Questionnaire (CSHQ) subscales of Bedtime Resistance, Night Waking and Total score, and the Pittsburgh Sleep Quality Index (PSQI) subscales of Sleep Disturbance, Sleep Latency and Total score.

Result: We hypothesized that the BST would show greater and sustained reductions in child and parent sleep outcomes than the CON condition. Regarding child sleep, we identified no statistically significant group differences. Yet, both the BST and the CON conditions saw significant reductions in repeated measures from pre- to post- to follow-up testing in the CSHQ measure of bedtime resistance (F = 7.22, p = .002), night wakings (F = 4.17, p = .020), and the total score (F = 4.46, p = .016). Regarding parent sleep, we again identified no statistically significant group differences on hypothesized subscales. A significant change in repeated measures was found from pre- to post- to follow-up testing in the PSQI measure of sleep latency (F = 3.98, p = .024). Parental sleep latency worsened from pre- to post-test for both BST and CON, yet returned to baseline levels by follow-up for BST.

Discussion: Though there were no statistically significant differences between the two groups, these findings are promising as they reveal that child sleep improved after therapist intervention. However, as no waitlist group were included, it is yet to be determined if both treatment conditions were effective or were representative of a placebo effect (time and attention of a therapist) in improving child sleep among sleep-disordered children with DS and parental sleep. During this short intervention, sleep latency worsened by post-test in both groups, perhaps reflective of parents spending more time at night working on child sleep problems. And although both BST and CON demonstrated improvements in child sleep, only the BST condition returned parental sleep to baseline levels of sleep latency by follow-up. A waitlist control condition is currently being conducted to strengthen these findings and to further test the effectiveness of BST for children with DS and behavioral sleep disorders.

References: