INVESTIGATION OF TWO METHODS FOR TREATING SLEEP PROBLEMS AMONG CHILDREN WITH CHARGE SYNDROME

Benjamin A. Kennert

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Department of Psychology

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ABSTRACT

Sleep problems are common among children, especially those with developmental disabilities, visual impairments, and behavioral problems. Among children with CHARGE syndrome, caused by a genetic mutation on the *CHD7* gene, recent research indicates a particularly high prevalence of clinically-relevant sleep problems for this group. In particular, the most common types of sleep problems among these children are those related to sleep initiation and maintenance.

While sleep problems are prevalent among children with CHARGE syndrome, there exists little research on intervention strategies to improve sleep, especially with regard to problems of sleep initiation and maintenance, specifically among this population. The present study used an explorative survey with parents of children with CHARGE syndrome in order to identify the types of sleep problems and the interventions most commonly used among this population. Two small sample studies were then employed to investigate the treatment utility of the two most common intervention strategies identified in the explorative survey, as implemented by parents in the child's home, using non-concurrent multiple baseline design across participants.

Results indicated that the use of positive bedtime routines with scheduled bedtimes and wake times (partial circadian rhythm management or CRM), melatonin treatment, and the combination of these two strategies, may be viable treatment options for increasing total nighttime sleep and improving sleep onset problems among children with CHARGE syndrome, although effect sizes were often small. The two treatments combined were shown to improve these sleep outcomes additionally after either positive bedtime routines with scheduled bed and

wake times or melatonin treatment were used alone. Parents were able to implement these strategies effectively with brief instruction, suggesting these strategies are useful without the need for direct intervention from professionals. However, more investigation is needed to determine factors resulting in differential results across participants, and to generalize findings to the rest of the population of children with CHARGE syndrome.