Parental Experiences Establishing Sleep Routines in Young Children with Autism

Introduction: Sleep-related disturbances are prevalent among children with Autism Spectrum Disorder (ASD). Reports indicate that 44% to 83% of children with ASD have some issue involving sleep (Richdale & Prior, 1995). Compared with their typically developing counterparts, children with ASD are more likely to present with significant sleep-disrupting behaviors such as frequent night-time wakings, bedtime resistance, difficulties falling and staying asleep, and/or waking up excessively early. Children with problematic sleep behaviors will affect parents, siblings, or other caregivers; the lack of quality sleep within the household can cause discord within family dynamics and increase parental stress. There are currently few studies that focus on the overall well-being and subjective experiences of parents in helping the child with ASD go to sleep. This descriptive qualitative pilot study explored parents’ experiences developing behavioral interventions, coping strategies, and perceptions of parental self-efficacy regarding sleep-related issues affecting their child with ASD.

Methods: Five parents were recruited from the San Jose State University Occupational Therapy Pediatrics clinic and from a local clinic in the San Jose area. Parents who met the inclusion criteria were administered the Children’s Sleep Habits Questionnaire (CSHQ), a 45-item questionnaire that assesses the overall severity of the sleep-related issues in school-aged children. The investigators then administered a semi-structured and open-ended interview consisting of 16 questions to capture the experience of managing bedtime routines in children with ASD. These questions were designed by the investigators to explore several aspects of the parental experience including: the child’s bedtime routines, common difficulties, support systems, feelings of stress and/or fatigue, effects on occupation, and levels of parenting confidence. Interviews were transcribed and coded by the investigators, and several themes emerged from these parents’ experiences.

Results: Scores from the CSHQ indicated that all five children of the participants had moderate to severe sleep problems. Saturation of data was not achieved due to the small sample size. The investigators developed four prominent themes focused around the original research question: 1) Parental routines and beliefs, 2) Sleep strategies, 3) Parental well-being and stress, and 4) Parental self-efficacy. Parents’ responses were unanimous in expressing the belief that consistency in routine was most helpful in managing sleep routines. Parents mostly used strategies featuring sensory-based approaches. There was also an increase in parental stress when the child’s sleep problems were seen as inconsolable. Despite heightened levels of stress, the participants overall expressed no change in their confidence in parenting skills and were hopeful that their children's sleep behaviors were capable of change.

Discussion: Themes suggest that parents of children with ASD address sleep problems in similar ways. Each family has experienced difficulties in managing sleep problems in their children with ASD, which have a significant impact on the family and their occupations. The parents in this study describe how their beliefs affected how they developed routines in order to establish sleep routines, the strategies they used to put their child to bed, the parents’ own well-being and stress, and how these factors affect their confidence in parenting their child. Limitations of this study include its small sample size, narrow demographics in terms of gender, constraints in time to analyze data, and the level of truthfulness and accuracy of responses from participants.