The Blind Men and the Elephant: The Risk of Misdiagnosis in Children with Developmental Disabilities

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Despite scant knowledge about the impact of nonoptimal sleep on development in general [1], a spotlight on sleep in children with developmental disabilities is much-needed [2]. This Special Issue consequently provided a platform to outline and to discuss various reasons why sleep should not be overlooked when development is atypical.

In fact, the parable of the blind men and the elephant perfectly describes the state-of-art regarding sleep in children with developmental disabilities. That is, the risk of misdiagnosis is high. Firstly, intrinsic and extrinsic factors, as in typically developing children, may cause the sleep *complaint* and/or the sleep *problem* and/or the sleep *disorder*. Secondly, and pertinent to a population characterized by an atypical development, comorbidities and co-occurrences may mask the “causative” pathways. Thirdly, the perception of problematic sleeping and waking will depend on the complainant, the sufferer, and the professional. Combined these three aspects already point out that problematic sleeping and waking are possibly determining, mediating and/or moderating the developmental profile of the child. The hypotheses posed and the findings reported in this Special Issue put forward that these three aspects are possibly intertwined; hence the challenges faced with “the elephant.”

Alternatively, glancing at the pediatric sleep research literature, sleep in children with developmental disabilities is a rapidly growing field of interest [2]. Directing attention to this population from a sleep perspective may foster new insights in general. That is, we are unfortunately still ignorant to the importance of knowledge gained from “atypical” development. At the same time, we should not overlook aspects related to typical development when studying the atypical development. It is our belief that findings from a crossover perspective will not only benefit the pediatric sleep research field but foremost those involved, that is, the developing child and caregiver.

This Special Issue starts with reviewing the potential bottlenecks in the framework explaining sleep in children with developmental disabilities. The review by Stores [3] emphasized the underuse of the International Classification of Sleep Disorders or the need for a more streamlined approach in this population. An important stepping stone in the process of understanding, diagnosing, and treating problematic sleeping remains so far increasing awareness of all involved. For instance, Allen et al. [4] zoomed in on painful conditions across multiple pediatric illnesses such as migraines, cystic fibrosis, sickle cell disease, cancer, and others. The authors summarize that the pain–sleep relationship is often under-“questioned” in an acknowledged vulnerable population, that is,

children experiencing pain. In both reviews, the detrimental aspect of chronicity of problematic sleeping and waking arises. This is especially worrisome given the statement of higher rates of sleep “complaints,” “problems,” and “disorders.”

Next, in light of the sleep challenges faced when working with children with developmental disabilities, the study by Ipsiroglu et al. [5] explored alternative methods to investigate problematic sleeping. The authors focused on narratives and behavioral observations toward diagnosing Willis–Ekbom disease/restless legs syndrome and this during an office visit. Whereas Miano et al. [6] discussed a comprehensive sleep assessment including sleep questionnaires, sleep habits, a video-polysomnographic recording with full high density electroencephalography and cardiorespiratory polygraphy, multiple sleep latency test, and 1-week actigraphic recording. This assessment resulted in five sleep-defined attention deficit hyperactivity disorder phenotypes. This study is a clear example of a crossover perspective. Indeed, the overlap of significant clinical signs in development can be interpreted from a sleep–wake perspective. Lopes et al. [7], on the other hand, questioned the role of sleep in the clinical profile of depressed children. They concluded that sleep complaints reported during a clinical interview are a not-to-be-ignored risk factor for suicidal behavior in youth with major depression. Although the intersection of pathways of sleep and psychopathology has been long-standing, as per the early reports of sleep complaints within psychiatric diagnostics, the awareness of the respondent about the role of sleep in the case of developmental disabilities is less explored. Levin et al. [8] investigated, in young children with autism spectrum disorders, the parenting stress and more specifically the mother's sleep-related cognitions. That is, the bedtime settling problems, although perceived as an extra maternal burden, were not ascribed to problematic parental cognitions and/or interactions but to the pathology and/or disrupted sleep.

Each of these studies in clinical populations underscored the need to investigate from a sleep–wake perspective. This is similarly illustrated in a sample of individuals with Smith–Magenis syndrome, a genetic disorder characterized by an inversed or shifted melatonin secretion pattern and daytime somnolence. That is, Spruyt et al. [9] suggested that their endogenous melatonin, age, and gender may potentially interact yielding the severity range of sleep disturbances reported in individuals with Smith–Magenis syndrome. Their person-centered sleep treatment on the other hand may bring new insights into sleep mechanisms. Whereas, Nixon et al. [10], for instance, suggested early treatment of the obstructive sleep apnea in Down syndrome as potentially

beneficial to their adaptive functioning. Both studies may ultimately support knowledge gained on the impact of nonoptimal sleep on development.

To conclude, this Special Issue is an example of an “under construction” framework of concerns and hence findings, relating to the sleep–wake state of the developing individual as expressed by

all involved. Future research may give more clear insight and more precise diagnosis of “the elephant.”

Conflict of Interest

The authors have no conflict of interests to disclose.

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