

Developmental Medicine & Child Neurology

Mac Keith Press



Developmental Medicine & Child Neurology

Volume 51 Issue 2, Pages 143 - 150

Published Online: 19 Nov 2008

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ORIGINAL ARTICLE

Sleep disturbances in CHARGE syndrome: types and relationships with behavior and caregiver well-being

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ABSTRACT

Children with CHARGE syndrome frequently develop moderate to severe behavior difficulties and are often diagnosed with obsessive-compulsive disorder, attention deficit disorder, Tourette syndrome, and autism. Anecdotal reports have indicated that sleep is also affected. However, the prevalence and types of sleep disturbance have not been identified. This study investigated sleep disturbances in 87 children with CHARGE syndrome, aged 6 to 18 years (mean 11y, SD 3y 8mo). There were 52 males and 35 females represented. Instruments included measures of sleep (Sleep Disturbances Scale for Children [SDSC]), behavior (Developmental Behaviour Checklist [DBC]), and carer well-being (Malaise Inventory). On the SDSC, 57.5% received scores considered significant for sleep disturbances, with disorders of initiating and maintaining sleep, sleep breathing, and sleep-wake transition being the most common. The SDSC was significantly correlated with the DBC ($p=0.010$) and the Malaise Inventory ($p=0.003$). Regression analysis found that both problem behavior and sleep disturbances contributed to the prediction of scores on the Malaise Inventory. Being both deaf and blind ($p=0.001$), experiencing frequent middle-ear infections ($p=0.015$), and starting to walk at an older age ($p=0.007$) were associated with more sleep disturbance. Craniofacial anomalies were not. The study highlights the importance of addressing the sleep difficulties associated with CHARGE syndrome relating both to airway management and to disorders of initiating sleep.

PUBLICATION DATA Accepted for publication 8th May 2008. Published online 19th November 2008.

DIGITAL OBJECT IDENTIFIER (DOI)

10.1111/j.1469-8749.2008.03146.x [About DOI](#)

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