

NARCOLEPSY AND EXCESSIVE DAYTIME SLEEPINESS IN CHILDREN

Mary Grace Umlauf RN PhD, Erica Pryor RN PhD, Christopher Makris MD

University of Alabama School of Nursing
University of Alabama at Birmingham School of Medicine,
Department of Pediatrics
Birmingham, Alabama

Key Words: narcolepsy, idiopathic hypersomnia, children

Purpose: Narcolepsy (NAR) and idiopathic hypersomnia (IH) are well described in adults, but very little is known about either condition in children. The purpose of this study was to examine children diagnosed with NAR and IH in comparison to children with excessive daytime sleepiness (EDS) who did not have a diagnosable sleep disorder (NUL).

Method: A retrospective chart review was conducted at the Sleep Disorders Center at Children's Hospital, Birmingham, Alabama. Records of children who completed both overnight polysomnography (PSG) followed by multiple sleep latency testing (MSLT) were reviewed (N=134). NAR (n= 38, 28%) and IH (n=45, 34%) cases were selected from cases treated from 1994-2002 and the NUL (n=51, 38%) cases were derived from cases evaluated in 1999-2002.

Findings: The total sample included both African-American (n=76, 57%) and White (n=58, 43%) children, but included significantly more boys (n= 91, 70%, chi-square, $p<.001$) than girls. The percentage of non-white subjects in the total sample (57%) was significantly higher ($p<.001$) than the population percentage for the state as a whole (27%) or for the county in which the sleep center is located (38%). However, no difference was noted when comparing by ethnic group or by gender and ethnicity simultaneously across any of the research variables. Analysis of variance testing showed significant differences ($p< .05$) in PSG sleep parameters between the three groups. NAR children were older (Mean years NAR=13.2, IH = 11.5, NUL = 10.5) and also had more REM periods overnight (NAR=4.8; IH=3.7; NUL=4.0) than the other two groups. During MSLT studies NAR children had shorter mean sleep onset latency (NAR:5.1(4.5) vs IH:8.3(4.8) minutes), and shorter mean REM onset (NAR:3.9(2.5) vs IH:5.9(3.6) minutes). Parental concerns elicited from open-ended questions focused on declining school performance, academic failure, and negative behaviors in the home (e.g. irritable, hostile, grouchy, rude), which became evident after the onset of EDS.

Discussion: The most significant finding of the study is the prevalence of narcolepsy in young children, especially among African-American boys. Although treatable, narcolepsy is a life-long and disabling condition that, if untreated, can seriously interfere with school or work performance and apparently causes disruptive behaviors in the home. To the uninformed observer, signs of EDS among school children may suggest a lack of parental supervision or environmental problems in the home setting rather than an actual medical disorder. Thus, these findings have important implications for the early evaluation and treatment of EDS in children and especially among minority children.