

7th World Congress on **Addictive Disorders & Addiction Therapy**
&
29th International Conference on **Sleep Disorders and Psychiatry**

July 16-18, 2018 London, UK



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Narcolepsy's underappreciated symptom: Cataplexy

Statement of the Problem: Narcolepsy is a chronic neurological condition. A pentad of symptoms is often associated: excessive daytime sleepiness, cataplexy, hypnagogic/hypnopompic hallucinations, fragmented sleep, and sleep paralysis. Cataplexy, the transient loss of voluntary muscle tone, is pathognomonic for type 1 narcolepsy, a presumed autoimmune condition. Cataplexy can be as subtle as diplopia due to ocular muscle involvement or as pronounced as full-body collapse. Consciousness is preserved during these attacks. Triggers for cataplexy include the sudden onset of emotions: laughter, anger, excitement. Due to its sporadic development and often subtle nature, many clinicians have rarely observed cataplexy and tend to underestimate its impact. In contrast, anecdotal reports indicate that people with narcolepsy (PWN) often view cataplexy as having a significant psychosocial impact on their lives. This study's purpose was to evaluate the burden cataplexy has on the daily functioning of PWN.

Methodology: Data from the Nexus Narcolepsy Registry, Narcolepsy Network member interviews, and the US FDA's "The Voice of the Patient - Narcolepsy" were reviewed and evaluated.

Findings: Symptoms consistent with cataplexy led to initial medical consultation in 25% of patients. Unfortunately, diagnosis can be delayed up to 12 years from symptom onset. Compared to PWN without cataplexy (type 2), those with cataplexy had significantly higher scores on the Epworth sleepiness scale, the clinical global impression of severity scale, and shorter maintenance of wakefulness test latency times. Patients with cataplexy report the symptom as frustrating, embarrassing, and terrorizing. Intentionally avoiding and repressing responses to strong emotional stimuli are common coping mechanisms to prevent an attack.

Conclusions & Significance: Cataplexy is an underdiagnosed and underappreciated symptom of type 1 narcolepsy which can have a profound impact on the psychosocial well-being of those affected. Significant efforts are needed to increase awareness of the symptom and develop treatment options to mitigate its impact.

Recent Publications

1. Villa K F, Black J, Bujanover S, Cisternas M G, Gow M, Ohayon M M, Pasta D J, Patterson M and Thorpy M J (2017) Assessing the benefits of sodium oxybate (SXB) on functioning, productivity, and health-related quality of life in people with narcolepsy: findings from the nexus narcolepsy registry. *Sleep* 40(1):A241.
2. Pasta D J, Black J, Bujanover S, Cisternas M G, Gow M, Ohayon M M, Patterson M, Thorpy M J and Villa K F (2017) Factors associated with narcolepsy medication treatments and medication discontinuation rates: findings from the nexus narcolepsy registry. *American Academy of Sleep Medicine* 40(1):A250.

Biography

Mark A K Patterson has his interest in narcolepsy and cataplexy crystalized, when a close family member was diagnosed with the condition in 2004. Since that time, he has been active in raising awareness about the condition to his medical colleagues and general public and currently serves as the President of Narcolepsy Network. He practices as a General Pediatrician with the Carilion Clinic in Roanoke, Virginia, USA. He received his medical training from Albany (New York) Medical College with specialty education from the University of Virginia, Charlottesville. Prior to his medical career, he received a PhD in Biological Chemistry from the Massachusetts Institute of Technology, Cambridge and worked in the fledgling biotechnology industry.

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