Non-Autistic Complex Motor Stereotypies in 40 Older Children and Adolescents: Clinical Features and Longitudinal Follow-Up

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Objective: Complex motor stereotypies (CMS), once believed to only occur in children with autistic spectrum disorders, have been well established in otherwise normal children. Despite recent gains regarding their clinical presentation and phenotype, there remains a lack of knowledge regarding etiology, co-morbidities, and long-term outcome.

Methods: Children over the age of 9 years with the diagnosis of primary (non-autistic) CMS were indentified either in the pediatric neurology movement disorders clinic at the Johns Hopkins Hospital or by video and parent interview (including a formal screen for autistic symptoms) by knowledgeable personnel. Families of the identified study subjects were then contacted by telephone and interviewed using a structured questionnaire.

Results: Forty healthy individuals (15 girls, 25 boys; 38 families), aged 9 to 19 years, with primary CMS were identified. Onset was prior to age 3 years in 98%. Family history of CMS was identified in 38% with 73% of those being a first-degree relative. In all, movements stopped with distraction and were never noted during sleep. Triggers included excitement 90%, engrossment 67%, anxiety 69%, fatigue 33%, and boredom 26%. At time of follow-up 98% reported their stereotypies persisted, and one stopped at age 15. Co-morbidities included attention problems 63%, obsessive compulsive behaviors 33%, tics/Tourette syndrome 30%, and anxiety 75%. Behavior therapy was tried by 38%; 53% with some degree of success.

Conclusions: Accurate knowledge about the clinical features and long term co-morbidities affecting individuals with primary (non-autistic) complex motor stereotypies will enable more appropriate diagnoses, treatment, counseling, and future expectations.