Myalgic Encephalomyelitis Presenting as Orthostatic Intolerance in an Adolescent

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INTRODUCTION

- Myalgic encephalomyelitis (ME) also known as chronic fatigue syndrome (CFS) is a chronic, complex multi-system disease that affects children and adults with typical age of onset between 10 to 19 and 30 to 39 years.
- ME is more common in females and prevalence estimates for pediatric ME/CFS vary from 0.1 to 0.5%.
- More than 80% patients report an infectious episode near the onset.
- Many clinicians are unaware of or question the diagnosis of ME/CFS.
- Diagnosis is based on the clinical criteria per the US National Academy of Medicine (Table 1).[1]
- Children, especially adolescents, have orthostatic intolerance more often than adults and usually do not have muscle and joint pain like adults with ME.
- Etiology is uncertain.

CASE PRESENTATION

- A 14-year-old adolescent male with autism spectrum disorder presented with progressive gait problems for the past 2 weeks.
- His primary care doctor diagnosed him with vestibular dysfunction from possible viral syndrome, however no clear illness was reported prior to onset of symptoms.
- He was admitted for further work up due to concern for progressive symptoms; he started with mild stumbling while walking and progressed to unable to walk more than a few steps without assistance.
- He was not able to clearly explain his symptoms but described them as feeling "woozy" and "unbalanced." He denied having vertigo. He appeared to be fatigued.
- Neurological exam was significant for wide based gait requiring some assistance and he was noted to sway to the left side while walking, otherwise normal strength and reflexes.
- Work up included MRI brain, cervical and thoracic spine and lab work which were all negative.
- He was started on a trial of Meclizine and was evaluated by a physical therapist with plans to follow-up as an outpatient.
- At the 2-week outpatient follow-up, he was noted to have continued gait problems.
- Further family history included history of ME in both his brother and father. Therefore, we enquired about specific symptoms related to ME in our patient and it was positive for significant fatigue and severe impairment in physical activity including educational and social activities, post-exertional malaise and unrefreshing sleep.
- It was determined that his gait problems were secondary to severe orthostatic intolerance. He was given a provisional diagnosis of ME.
- As of most recent follow-up 5 months from initial hospitalization, diagnosis was confirmed; he is doing better with symptomatic management as outlined in table 2.[2,3]

TABLES

Table 1. 2015 National Academy of Medicine Diagnostic criteria

Diagnosis requires the following three symptoms
1. A substantial reduction or impairment in function accompanied by fatigue, and
2. Post-exertional malaise, and
3. Unrefreshing sleep
At least one of the following manifestations is also required
1. Cognitive impairment or
2. Orthostatic intolerance
*Additional symptoms include pain; GI symptoms – abdominal pain, nausea and/or anorexia

Table 2. Myalgic Encephalomyelitis Management

Post-exertional Malaise
1. Activity management – learn to balance rest and activity; find individual limits for mental and physical activity.
2. Assistive devices – motorized scooters, handicap parking stickers, shower chairs to conserve energy
3. School or work accommodations
Sleep Issues
1. Sleep hygiene, meditation and relaxation exercises, light therapy
2. Pharmacologic therapies
Cognitive Impairment
Focus on only one task at a time, limit reading time, memory aids (e.g., calendar reminder systems)
Pharmacologic approach – stimulants, modafinil, amantadine
Orthostatic Intolerance
Salt and fluid loading, electrolyte drinks, compression stockings, tailored exercises
Medications – Fludrocortisone, midodrine, low-dose beta blockers

DISCUSSION

- There are no definitive tests for ME, diagnosis relies on history and physical examination.
- There are guidelines for testing that can be helpful to diagnose or rule out other conditions and comorbidities.[2,3]
- Establishing the diagnosis can relieve uncertainty in the minds of the patient and the parents.
- Management of ME consists of treating symptoms as outlined in the table 2.[2,3]
- Counseling to help find strategies to cope with the illness and its impact on daily life and relationships can be helpful.
- Prognosis is variable, one study with 24 young patients with severe ME, found that 29% remained severely affected, 63% improved and were no longer classified as severe and 8% had recovered.[4]

CONCLUSION

- Diagnosing ME can be complicated and require thorough history, physical examination and may require multiple visits.
- Being aware of the diagnosis of ME can be helpful for clinicians to ask specific questions about the symptoms pertaining to the diagnostic criteria of ME and avoid misdiagnosis of Functional Neurological Disorder.

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