Understanding Pediatric Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) in the School-aged child – Considerations for School Nurses

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As a school nurse of almost 30 years, I have encountered many of the notorious "frequent fliers," those students with everything ranging from school anxiety or avoidance to those with chronic illnesses such as Type 1 diabetes and migraine headaches. There are the belly aches and mild headaches that are many times caused by hunger, constipation dehydration, test anxiety or other school worries; usually treated with something simple like drinking water, eating a snack, taking some deep breaths, some TLC and just waiting it out for a bit.

I want to mention the other group of students that fall into neither of these two categories. These are the students who always have many somatic complaints/symptoms that affect their learning such as unexplained pain, fatigue, cognitive disturbances and unrefreshed sleep that have no clear etiological explanation. There was no injury. The student ate breakfast this morning. He went to bed at 8 p.m. and awoke at 7 a.m. feeling just as tired as he was when he went to bed. He is asleep at his desk and the teacher asks that he be checked for a fever or other illness. Everything checks out normal and I begin to ask how things are at home. He has some water, we do some stretches in the nurses' office to get the blood flowing and he is sent back to class, only to return an hour later with the same issues.

Many of us school nurses refer to this as "**frequent flier syndrome**." I always check a student's electronic medical record for a history of visits – particularly if the student is new to our school – to check his attendance history/prior visits to the nurses' office, etc. I also keep clear notes for every visit detailing symptoms, care given and how long the student spends in the nurses' office. Some schools such as mine have more than one nurse working in the office, so clear note writing is very important in providing continuity of care.

Recently I viewed the continuing education offering "Why Can't This Child Get to Class?" with a presentation from Peter C. Rowe, MD, a Professor of Pediatrics at Johns Hopkins University School of Medicine, who is a specialist in treating children and adolescents with Chronic Fatigue and Related Disorders. Dr. Rowe brings to light the complex, serious and chronic multisystem disease – Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS) that can profoundly limit the health and activities of affected patients. This illness affects all age groups, but the focus of this narrative is on children ages 10-23 and discusses symptoms that cause substantial impairment in activities that were well tolerated before illness onset. A school nurse may be the first person to identify symptoms of ME/CFS, but may not even have considered this as a possible diagnosis. I personally would not have thought of it had I not seen this presentation.

Looking at students in the latter category as mentioned above, I realize now that further examination of a student's immune function may uncover something more - perhaps a possible previous viral infection that could trigger symptoms. ME/CFS can follow a known illness such as infectious mononucleosis, also known as Epstein-Barr virus (EBV). Another theory is that ME/CFS symptoms can be a consequence of immune dysfunction, causing prolonged response to an infection. (Rowe, et al, 2017)

Core symptoms of ME/CFS are extreme fatigue not relieved by sleep, post-exertional malaise (PEM), unrefreshing sleep, cognitive impairment and orthostatic intolerance (OI). Symptom criteria for diagnosis is 4 out of 8 of the following symptoms:

- Unrefreshing sleep
- Post-exertional malaise (PEM) lasting >24 hours
- Impairment in short-term memory or concentration
- Sore throat

- Tender cervical or axillary glands
- Muscle pain
- Multi joint pain without swelling
- Headaches of a new type, pattern or severity

These symptoms must be present for at least 6 months to confirm diagnosis of ME/CFS. This is where the school nurse can be of great value in documenting and tracking not only symptoms, but also attendance and absenteeism in students with presumed ME/CFS. Since severity of symptoms is likely to wax and wane, it is important that each symptom that has occurred in the last 3-6 months be rated as **mild/occasional**, **moderate/frequent** or **severe/constant**.

What ME/CFS is **not**.

- It is **not** school refusal
- It is **not** a factitious illness or Munchausen by proxy
- It is **not** primary depression

It is important to note that ME/CFS patients **want** to attend school, but **can't** due to symptoms. Many with ME/CFS become demoralized due to the illness and rates of depression and anxiety can be increased. Disinterest in friends is uncommon. In contrast to ME/CFS, exercise improves symptoms in depression, but may worsen symptoms or cause further harm in the patient with ME/CFS. Well-documented pathophysiological changes demonstrate that ME/CFS is a multisystem physical disease, not a psychological disorder (Rowe, et al, 2017).

Because of the chronicity to ME/CFS, regular monitoring is important to support the young patient to be aware of any changes in symptoms or any emergence of a new illness. Appropriate referral to health practitioners familiar with ME/CFS is often needed. School personnel need to be educated about the effect of the illness on academic performance and health providers need to provide appropriate documentation to support any accommodations that may be necessary for the student.

School Nurses Considerations:

- Believe the student and family; respect and support them.
- A student attending school may need a quiet, darkened place that they can go without being questioned
- In a classroom, a student may need to put their legs up, especially those with orthostatic intolerance. They may need to stand up and walk around because of blood flow issues. They may even need to lie down on the classroom floor in order to be able to cognitively absorb material.
- A student may have sore hands from writing and require special splints for joint hypermobility (many ME/CFS patients have diagnosed Ehlers-Danlos syndrome).
- Students may have new sensitivities or allergies to foods that have been triggered as a result of ME/CFS.

Prevalence estimates for pediatric ME/CFS vary from 0.1 to 0.5%. Because there is no diagnostic test for ME/CFS, diagnosis is purely clinical, based on the history and the exclusion of other fatiguing illnesses by physical examination and medical testing (Rowe, et al, 2017). The school nurse is instrumental in educating teachers, administrators and other school personnel of the educational challenges brought on by ME/CFS and issues with OI (orthostatic intolerance) that accompany the disease. These challenges include:

- Feeling worse in the AM, when blood volume is lowest. Students may do better in the afternoon.
- Insomnia and disrupted sleep schedule is common.
- Symptoms wax and wane, often unpredictably, making planning and attendance a challenge.
- Symptoms persist longer after upper respiratory illnesses
- Symptoms are often worse after vigorous exercise
- Cognitive problems can mimic ADD
- **Orthostatic intolerance symptoms** are worse with prolonged standing or longer periods of sitting. **These symptoms include**
    - Lightheadedness
    - Syncope
    - Diminished concentration

  - Headache
  - Blurred vision
  - Fatigue
  - Shortness of breath
  - Chest discomfort
  - Heart palpitations
  - Shakiness
  - Anxiety
  - Nausea
  - Nocturia

Nursing Recommendations for Accommodations for a Student with ME/CFS

The student with ME/CFS may be able to attend school full time, part-time, or not at all, depending on the severity of symptoms.

For the student with **mild-moderate** ME/CFS or OI, accommodations could include:

- Allow student to begin school late or leave school early without being considered tardy
- Allow extra time to complete assignments and exams
- Special location for exams or special location for student to take rest periods
- Allow student to skip gym class
- Extended period to complete coursework, beyond end of semester or over the summer
- Allow student to consume fluids and salty snacks as needed for orthostatic intolerance
- Access to extracurricular activities for social interaction, even if student cannot attend school that day
- Elevator privileges
- Extra set of books – one for home and one for school
- Skipped day mid-week to rest/recover and/or allow half days
- Home tutoring to help keep student up to date with academics

For the student with **severe** ME/CFS or OI:

- May need to withdraw from school entirely
- GED
- Start in community college classes part time
- Increase course load gradually as tolerated
- Transition to full-time college

In summary, Pediatric ME/CFS is a disease associated with substantial impairment of normal activities that impact a young person's entire life. Coping with debilitating medical symptoms, changed relationships within the family, absence from school and loss of socializing with peers can all result from the illness causing extreme confusion and crisis. Many of the symptoms of ME/CFS are amenable to specific therapies and accommodations. Successful management is based on determining the optimum balance of rest and activity to help prevent post-exertional symptom worsening. Medications are helpful to treat pain, insomnia OI and other symptoms (Rowe, et al, 2017). School nurses can help improve recognition, identify comorbid conditions, provide emotional support and encouragement, and suggest reasonable accommodations.

Sources:

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