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## ME/CFS in Adolescents — Study Review

### ME/CFS u młodzieży — przegląd badań

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#### Abstract

Chronic Fatigue Syndrome (CFS), also called myalgic encephalomyelitis (ME), is a condition characterized by long-term fatigue that is not significantly alleviated during rest and is not caused by previous medical conditions or continuous exercise. Symptoms are quite diverse, but not specific to this disease entity. The most common are: concentration and memory problems, sore throat, swollen lymph nodes, joint pain, sleep disturbances, headache. Moreover, autonomic nervous system functioning and post-exertional malaise examination is considered to be important in diagnosis of adolescent patients with ME/CFS. The presented analysis of research shows that adolescents with ME/CFS urge to be understood and believed regarding an illness that few understood. Continuing education and remaining the social activity in young ME/CFS patients seems to be crucial in maintaining quality of life. ME/CFS in adolescents might lead to significant problems related to the school absenteeism, poorer quality of life at school, school and academic achievement compared to healthy adolescents. Anxiety might co-occur with ME/CFS in adolescents. Supportive therapy for comorbidities could be considered, if needed. However, there is no established effective treatment for ME/CFS, for which there is urgent need. (JNNN 2020;9(2):76–79)

**Key Words:** ME/CFS, adolescents, Chronic Fatigue Syndrome

#### Streszczenie

Zespół przewlekłego zmęczenia (CFS), zwany również encefalopatią bólową, bólowym zapaleniem mózgu i rdzenia kręgowego (ME), jest schorzeniem charakteryzującym się długotrwałym zmęczeniem, które nie jest w znacznym stopniu złagodzone podczas odpoczynku, nie jest spowodowane wcześniejszym stanem chorobowym lub ciągłym wysiłkiem. Objawy są dość różnorodne, ale nie specyficzne dla tej jednostki chorobowej. Najczęstsze to: problemy z koncentracją i pamięcią, ból gardła, obrzęk węzłów chłonnych, ból stawów, zaburzenia snu, ból głowy. Co więcej, badanie funkcjonowania autonomicznego układu nerwowego, oraz nietolerancji wysiłku fizycznego uważa się za ważne w procesie diagnozy młodzieży z ME/CFS. Przedstawiona analiza badań pokazuje, że młodzież z ME/CFS pragnie być zrozumiana a ich choroba, którą niewielu rozumie uznana za prawdziwą. Wydaje się, że kontynuowanie edukacji i utrzymanie aktywności społecznej u młodych pacjentów z ME/CFS ma kluczowe znaczenie dla utrzymania jakości życia. ME/CFS u nastolatków może prowadzić do poważnych problemów związanych z nieobecnością w szkole, gorszą jakością życia w szkole i na uczelni, oraz słabszymi osiągnięciami w porównaniu do zdrowych nastolatków. Zaburzenia lękowe mogą współwystępować z ME/CFS u młodzieży. W razie potrzeby można rozważyć leczenie wspomagające chorób współistniejących. Istnieje pilna potrzeba ustalenia skutecznego leczenia ME/CFS. (PNN 2020;9(2):76–79)

**Słowa kluczowe:** ME/CFS, młodzież, Zespół przewlekłego zmęczenia

#### Introduction

Chronic Fatigue Syndrome (CFS), also called myalgic encephalomyelitis (ME), is a condition characterized by long-term fatigue that is not significantly alleviated

during rest is not caused by previous medical conditions or continuous exercise [1].

ME/CFS was first defined as a disease entity in 1988 by the American Center for Disease Control (CDC). It is characterized by fatigue with a temporarily defined

onset, which does not disappear after rest and lasts over 6 months. Symptoms are quite diverse, but not specific to this disease entity. The most common are: concentration and memory problems, sore throat, swollen lymph nodes, joint pain, excessive sleepiness or insomnia, headache [2]. Moreover, autonomic nervous system functioning and post-exertional malaise examination is considered to be important in diagnosis of adolescent patients with ME/CFS [3].

The aim of this study is to present research results on Chronic Fatigue Syndrome.

## Occurrence

The percentage of ME/CFS occurrence is estimated at 0.42% in Chicago [4], which is close to the estimated number of 250,000 ME/CFS patients in the United Kingdom [5]. ME/CFS is more common in women than men [6]. ME/CFS can significantly degrade quality of life and ultimately lead to severe disability.

Among children aged 11–16 ME/CFS occurred with a frequency of  $28/2855=1\%$  [7]. In other study, 27,327 employees and 333,024 students from 1098 schools were examined. 42% of all confirmed long-term sickness absences were attributed to ME/CFS, which was higher comparing to other causes. This diagnosis was significantly linked to the grouping of cases, a clear increase in the rate in adolescence women and the prolonged impairment of educational potential was reported [8]. Prevalence rate of 0.75% was noted in pediatric ME/CFS community from Chicago area. Study published in 2019 underlines that fatigue is often occurring yet under-recognized in Poland [9].

## Impact of ME/CFS in Adolescent

Questionnaire based study in Australia revealed the adolescents with ME/CFS urge to be understood and believed regarding an illness that few understood. Authors also underlined the important role of continuing education and remaining the social activity in young ME/CFS patients [10].

School functioning in adolescents with CFS is much worse than in healthy adolescents. Study highlights that expanding school performance indicators beyond school absence among teenagers with ME/CFS provides a more comprehensive picture of school functioning that is likely to be useful in both research and school contexts. Illness-related school absence does not reflect properly disturbed school functioning in adolescents with ME/CFS. Instead, more sensitive and specific areas should be considered. In addition to increased school absenteeism,

ME/CFS is also associated with poorer quality of life at school, school attendance, connectedness with school and academic achievement compared to healthy adolescents. The school is the main place of development not only of academic, but also cognitive and social skills during childhood and adolescence. Therefore, the impact ME/CFS has on school performance may expose teenagers to an increased risk of long-term maladaptation in many key developmental areas [11].

Higher occurrence of anxiety is noted in children ME/CFS patients than in healthy peers, with the rate of 38% in teenage girls noted in one study [12]. However there is no established therapy for children with both anxiety and ME/CFS [13]. It was reported that patients with ME/CFS might suffer from sleep disturbance [14].

## Supportive Therapies

There is no established cure of ME/CFS. Study in Australia reported mean duration of ME/CFS of 5 years, and recovery occurring in 68% patients within 10 years. Depression, anxiety, orthostatic intolerance and to a smaller degree pain at follow up were factors interfering recovery or function [15].

Behavioural adjustment to improve sleep hygiene is one of the possible supportive therapies. Appropriate time to eat, regular time to go to bed, taking a warm shower about an hour before going to bed are some of advices that can be given to patients [16].

Cognitive-behavioural therapy (CBT) could be applied to manage patients symptoms. However, in the survey conducted by The ME Association which involved 1428 respondents, 73% have stated that CBT had no effect on their symptoms [17].

Graded Exercise Therapy (GET) is a program of aerobic physical training with gradually increasing intensity. The goal of another physical activity based program, namely pacing therapy is to find a balance between activity and rest. Authors of updated version of Cochrane review on exercise therapy in ME/CFS concluded that physical activity based programs probably has a positive effect on fatigue in adults in comparison to standard care.

However, the risk of adverse effects which might occur due to the, *inter alia*, post-exertional malaise is uncertain. In addition, limited amount of evidence on comparative influence of CBT, adaptive pacing or other interventions is underlined [18].

Therapy focused on relieving of co-occurring symptoms: pain, irritable bowel syndrome, sleep disorders or emotional disturbances, if necessary [16]. Moreover, Authors [19] suggested that effects of cognitive function training on cognitive function in ME/CFS should be examined in the further studies.

## Conclusions

ME/CFS is a multisystem disorder. If affects adolescents it might lead to significant problems related to the school absenteeism, poorer quality of life at school, school and academic achievement compared to healthy adolescents. Anxiety might co-occur with ME/CFS in adolescents. Supportive therapy for comorbidities could be considered, if needed. However, there is no established treatment for ME/CFS, for which there is urgent need.

## Implications for Nursing Practice

People suffering from ME/CFS might experience symptoms with spectrum of intensity. Symptoms might be so severe and debilitating that severe ME/CFS patients would be bedridden. Some patients with mild intensity of symptoms might be able to undertake part-time job. Symptoms such as cognitive impairment (brain fog), and post-exertional malaise could be induced by physical or mental exertion. Therefore, caretakers and patients should be informed about potential adverse effects of undertaking pattern of behaviour too intense for the current capacity of patient. Anecdotally, too strenuous exercise might lead to extreme worsening of patient condition. Therefore, patients should be aware of necessity of monitoring symptoms severity dynamics, and perform behavioural changes that would help the patient to perform daily activities with decreasing post-exertional malaise as much as possible.

Mood disorders are not a cause of ME/CFS. However many patients suffer from this condition for prolonged time and because of the drastic decrease of quality of life, sometimes unable to keep their occupation or continue education. Therefore, ME/CFS might contribute to secondary mood disorder.

Providing support to a patient with ME/CFS the nurse should have knowledge about the disease and its course. It is important to be aware of the significance of often underdiagnosed symptoms, such as cognitive function decline. Special support, in addition to patients with visible physical disability, should be given to the patients with cognitive disorders as well as those who do not receive emotional support from their families. Enhancement of social support has been recommended as an important part of the treatment for people with ME/CFS, which can be a special task for neurological nurses. The effort of caregivers and family to provide continuity of education in young patients with ME/CFS should be prioritized, if possible.

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