

Original Publication

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Assessment of ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome): A Case Study for Health Care Providers

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Abstract

Introduction: Over a million adults in the U.S. are affected by chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME). A debilitating illness, ME/CFS is accompanied by profound fatigue that is not relieved by rest and affects daily activities. Symptoms include postexertional malaise, cognitive problems, unrefreshing sleep, and pain. This course provides tools to teach medical, physician assistant, and nursing students to recognize, diagnose, and manage patients with ME/CFS. **Methods:** The student is expected to view the provider-to-provider video and the PowerPoint slide curriculum, which describe the steps for evaluation. The video depicts two physicians conferring about ME/CFS and addresses the challenges of making a diagnosis. The slide curriculum shows the different ME/CFS symptoms and case definitions and how to apply them using a case study. Medical, physician assistant, and nursing students were recruited to evaluate the course and viewed it either online or in a campus education center.

Results: Results showed that students met learning objectives and showed increases from pre- to posttest evaluation in their understanding of the difficulties of diagnosing ME/CFS and managing the illness. In addition to knowledge, student attitudes towards ME/CFS changed, with more empathy towards patients and the awareness that ME/CFS requires frequent communication and reevaluation of patients' symptoms.

Discussion: Strategies of how to manage ME/CFS for the patient and manage time constraints during visits with ME/CFS patients are discussed.

Keywords

Communication, Case Study, Chronic Fatigue Syndrome, Chronic, Fatigue Syndrome, Myalgic Encephalomyelitis

Appendices

- A. ME-CFS Provider-to-Provider.pptx
- B. CDC-ME-CFS Provider-to-Provider Video.mp4

All appendices are peer reviewed as integral parts of the Original Publication.

Educational Objectives

By the end of this session, learners will be able to:

1. Identify symptoms common across all myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) case definitions.
2. Develop steps clinicians should follow to evaluate someone presenting with symptoms of fatigue, pain, and cognitive impairment.
3. List the factors that make ME/CFS difficult to diagnose.
4. Describe strategies that physicians can use to manage time constraints during visits with ME/CFS patients.

Introduction

Chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), is a complex illness affecting over one million U.S. adults.^{1,2} While severe and persistent fatigue is a key feature of the illness, patients also experience postexertional malaise and a number of other symptoms such as impaired concentration and muscle/joint pain.^{3,4} The multisystemic and debilitating nature of the illness leads ME/CFS patients to experience functional impairment comparable to that associated with other chronic

conditions such as heart disease, multiple sclerosis, cancer, diabetes, lung disease, and rheumatoid arthritis.^{5,6} Research shows that less than 20% of persons with ME/CFS have been diagnosed by a physician.⁷ Lack of timely diagnosis delays treatment, which results in unnecessary suffering and loss of productivity.

Currently, there is neither a diagnostic biomarker nor a cure for ME/CFS. As such, patients can experience years of poor health and reduced functional ability, resulting in sizable economic costs to the individual, the health care system, and society as a whole. For example, having ME/CFS has been estimated to cost the U.S. from \$19 to \$51 billion annually (including lost productivity and medical costs).⁸⁻¹⁰

In 2015, the Institute of Medicine (IOM) issued a report on ME/CFS that recommended revised diagnostic criteria and increased medical education to improve the care provided to ME/CFS patients.⁴ The IOM stated that

diagnostic criteria will not improve outcomes for ME/CFS patients unless health care providers use them. . . . [T]he dissemination effort should continue to position ME/CFS as a serious disease that occurs in both adults and children and requires timely diagnosis and appropriate care. . . . Fewer than one-third of medical school curricula and less than half of medical textbooks include information about ME/CFS. Although many health care providers are aware of ME/CFS, they may lack essential knowledge about how to diagnose and treat it.⁴

Following the recommendations of the IOM, the Centers for Disease Control (CDC) developed an ME/CFS education curriculum for medical and allied health students. In addition to the importance of patient-provider communication, education on how to assess ME/CFS is essential. This module's curriculum consists of a provider-provider interaction video and a PowerPoint Presentation including a case study that walks students through an initial consultation and follow-up with a female patient with ME/CFS. The aim of this module is to educate health care students about the symptoms of ME/CFS common across the different case definitions and, using case studies, how to evaluate possible ME/CFS patients. In addition, strategies to manage time constraints in the context of an in-depth evaluation are included. The CDC used evidence-based literature, patient case studies, and health behavior theories to develop both the video and slides.¹¹

Methods

The purpose/goal of the resource is to teach medical, nursing, and allied health students how to apply ME/CFS diagnostic skills using a patient case study and several clinical algorithms. The curriculum includes a PowerPoint presentation (Appendix A) and accompanying provider-provider video (Appendix B).

This learning module was developed by the CDC and is founded on evidence-based research from the literature and elements of ME/CFS case histories. The CDC used health behavioral theories to develop provider-to-provider education and communication. For example, modeling and vicarious learning from Bandura's social learning theory were incorporated to show how physicians learn from one another.^{11,12} ME/CFS case studies were developed, reviewed, and turned into an educational video based on information similar to medical history presentations seen in grand rounds from ME/CFS clinical experts.

This resource was tested with medical, physician assistant, and nursing students through an online assessment system at a university health center and received IRB approval. Students viewed the curriculum slides and video and were asked to complete a pretest and posttest for content knowledge, attitudes, and beliefs. In addition, program administrators gathered information for a process evaluation. The students viewed half of the slides and then watched the video, and then finished the slide show. The video length is approximately 6 minutes, and the slide curriculum, 20 to 30 minutes.

Faculty members from the medical school, physician assistant program, and nursing school were contacted to assist in the recruitment of students. In addition to staff announcements and recruitment flyers, coffee gift cards were used as an incentive for completing the module and survey. Initially, the

online evaluation took place at the university learning center, since students were there to complete other standardized and simulated patient requirements. However, given time restraints and class conflicts, the evaluation was expanded to allow students complete the session remotely by logging into a secure school network.

Results

Forty-one students viewed this curriculum and took the pretest. Thirty-seven of these students also completed a posttest assessment. Seventy-eight percent ($n = 32$) of the students were female, and their ages ranged from 20 to 59. Medical students ($n = 21$) were in their second to fourth years of school, physician assistant students ($n = 4$) in their first to third years, and nursing students ($n = 12$) in their first and second years.

Students who viewed video and slide curriculum met the learning objectives and showed an increase in posttest scores demonstrating understanding of why ME/CFS is hard to diagnose and what management of the condition entails. Results showed an increase in the number of students who considered ME/CFS a medical condition, as opposed to a combined medical and psychiatric condition. Students' self-rated ability to diagnose (a measure of knowledge) a CFS patient rose from a mean of 3.51 to 4.14 (0-5 scale; 5 = very capable of giving a CFS diagnosis), and confidence to manage a patient rose from a mean of 2.84 to 3.95 (0-5 scale; 5 = very confident of managing CFS patients). There was also a 20% increase in student understanding of how postexertional malaise can affect all ME/CFS symptoms, not just fatigue.

In addition to knowledge, student attitudes towards ME/CFS changed after viewing the video and slide curriculum. Qualitative responses indicate that after experiencing this module, students were more cognizant of ME/CFS and understood the need to rule out other illnesses yet provide constant reevaluation. For example, one medical student commented in the pretest that ME/CFS was "beleaguering, frustrating, challenging." In the posttest, the same student commented, "it is frustrating for patients, [I] will need to plan carefully and have frequent visits." The comparison of the pre/post responses from this student illustrates that after viewing the module, the student had a better understanding of how ME/CFS affects patients and of the need to devote more time when making an assessment—both of which are topics in the curriculum.

When asked in the posttest about confidence in making and managing a ME/CFS diagnosis, medical students shared that they had "better understanding of the definition and shared symptoms," "better understanding of the complaints and management," and "strategies . . . to help identify and manage patients with CFS." They also reported that they "know how to better recognize and workup a diagnosis," and that they were "more familiar with how to approach CFS." Finally, they reported recognizing that "patients need individualized treatment and frequent visits" and that it is important to "educate, support, manage as a team, and listen, listen, listen."

Process evaluations show that the best placement for this resource in the medical school curriculum is for second- and third-year medical students as clinical knowledge in the class at these years corresponds to the content in the curriculum. For nursing and physician assistant students, placement in the second year of training is suggested.

Discussion

ME/CFS poses a challenge for health care providers because there are no diagnostic biomarkers. Persons with ME/CFS are as functionally impaired as people with heart disease, diabetes, and cancer, yet many patients have not received a diagnosis or clinical care. The IOM report has called for increased medical education of ME/CFS that includes skills on how to diagnose and manage the illness.

The CDC developed an ME/CFS educational curriculum to educate medical, physician assistant, and nursing students on how to diagnose and manage ME/CFS. In this ME/CFS educational resource, a

provider-provider encounter video and PowerPoint slides demonstrate how to assess ME/CFS using evidence-based literature and patient case studies. The basis of the curriculum includes physician-to-physician communication and behavior modeling to explain ME/CFS and talk about patient assessment.

Students who viewed the video and slide curriculum showed increases on the posttest in skills needed to make an ME/CFS diagnosis as well as better understanding of illness management. The curriculum includes a component on time management in the context of ME/CFS, and students found this section to be helpful. Qualitative feedback from students stated that after viewing the video and slides, students showed greater empathy towards patients, understood the need to provide extra support, and were prepared to plan for ME/CFS patient visits.

The evaluation demonstrated that students could view the module online or in an educational center (e.g., a classroom). While the video and slide presentation should be viewed together, the choice of whether to start with the video or with the slides is left to the discretion of the instructor. Regardless of how the video is introduced, the PowerPoint presentation is instrumental to the learning process and should be used jointly with the video.

Time constraints of students suggest that CFS modules may be viewed independently and do not need to be completed at same time. The authors are currently working on a complementary resource to this module that focuses on the importance of communication between physicians and patients, using ME/CFS diagnosis as an example.

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Ethical Approval

This publication contains data obtained from human subjects and received ethical approval.

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