Proposed Code:
https://www.cdc.gov/nchs/data/icd/Topic-packet-March-7-8-final-3-6-23.pdf, page 107

PUBLIC COMMENT

To: National Center for Health Statistics
From: The undersigned individuals and organizations
Subject: Support for ICD-10-CM Proposal for R68.A, Post-Exertional Malaise, and Request for Expedited Implementation

Summary

We are writing **in support of the proposal of adding a R68.A code for "post-exertional malaise,"** with inclusion terms "post-exertional symptom exacerbation," "PEM," and "PESE" to the ICD-10-CM. We also **urge for this code to be considered for expedited implementation on October 1, 2023** due to its importance to Long COVID research and tracking.

Comment

According to the World Health Organization, Long COVID is the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation. The US Household Pulse Survey estimates that *5.8% of all adults in the US are currently experiencing Long COVID*.

Several studies have found that the ***majority of people with Long COVID experience post-exertional malaise (PEM)/post-exertional symptom exacerbation (PESE)***. This symptom is the **hallmark symptom of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)**. However, providers are not often familiar with what the symptom is due to lack of provider education on the symptom and a lack of a standardized way to to document the symptom. The symptom is characterized by:

- Exacerbation of some or all of a patient's symptoms or occurrence of new symptoms. Symptoms exacerbated can include physical fatigue, cognitive fatigue, exercise intolerance, problems thinking (e.g. slowed information processing speed, memory, concentration), unrefreshing sleep, muscle pain, joint pain, headaches, weakness/instability, light-headedness, flu-like symptoms, sore throat, nausea, orthostatic intolerance or other autonomic dysfunctions, sensory sensitivities, and other symptoms.
- Pathological loss of stamina and/or functional capacity that is not due to physical deconditioning
- An onset that can be immediate or delayed after the exertional stimulus by hours to days
- A prolonged, unpredictable time to return to baseline that is not easily relieved by rest or sleep and may last days, weeks, months, or longer
- Severity and duration of symptoms that is often out-of-proportion to the type, intensity, frequency, and/or duration of the exertion

The undersigned individuals strongly support the addition of an ICD-10-CM code for PEM/PESE and urge for its expedited implementation. Expedited implementation is needed due to its high prevalence and the implications of the symptom on treatment, research, and morbidity tracking. For instance:

- **Documenting PEM/PESE will impact treatment recommendations:** If a patient experiences PEM/PESE, the CDC, the American Academy of Physical Medicine and Rehabilitation, and World Physiotherapy, among others, caution against exercise programs that provoke the symptom. Additionally, in a recent study evaluating PEM in people with Long COVID compared to ME/CFS stated that "asking about PEM in people that have lingering symptoms following COVID-19 is ***essential*** to mitigate progression and possible development of ME/CFS." It is critical for providers to 1) be educated on the symptom, which a code will facilitate, and 2) have a way to document the symptom in a patient's charts in a standardized way.
- **Including PEM/PESE in electronic health records research will result in more accurate, faster research into Long COVID and associated conditions:** Numerous Long COVID studies, including those in NIH's RECOVER Initiative and by the CDC, are now using electronic health records to identify important sequelae of an acute SARS CoV-2 infection. PEM/PESE is virtually invisible in these studies, which is leading to incomplete phenotype analysis, subsequently leading to inadequate biomarker and therapeutic discovery.

Conclusion

The undersigned individuals and organizations support the addition of an ICD-10-CM code for post-exertional malaise/post-exertional symptom exacerbation, and urge for its expedited implementation in October 2023. Thank you for your consideration.

Signed,
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