One of the key problems with combining ME and CFS under a single diagnosis is that broad fatigue-based criteria, such as Fukuda, can group together very different underlying conditions while failing to require the hallmark feature of ME - post-exertional neuroimmune exhaustion (PENE). As a result, research cohorts become heterogeneous, making it difficult to identify clear mechanisms, biomarkers, or effective treatments specific to ME, and contributing to confusion in both clinical care and research.

When patients meeting stricter ME criteria (such as the ICC) are combined with those diagnosed under broad CFS definitions, or when ME is assumed to be identical to Fukuda CFS, distinct illness groups are effectively merged. This blurring of terminology and criteria can distort prevalence estimates, weaken research findings, and lead to inappropriate conclusions about the nature of the illness.

In contrast, more precise stratification — clearly separating patients by criteria used and core features such as PENE, neurological impairment, autonomic dysfunction, immune abnormalities, onset patterns, and severity — would improve clarity. Researchers increasingly note that only a subset of people with broad CFS diagnoses meet ME criteria when stricter definitions are applied, highlighting that these are not uniform populations.

Improved diagnostic precision and consistent use of specific criteria would help separate distinct conditions currently grouped under "CFS," strengthen reproducibility in research, support biomarker discovery, and ensure that findings about ME actually reflect patients with the neuroimmune disease described in ME-specific criteria rather than a mixed fatigue cohort.

Studies indicate a high rate of misdiagnosis for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), with estimates suggesting that 25–50% of patients referred to specialist clinics with a diagnosis of CFS actually have a different underlying condition.

Key Findings on ME/CFS Misdiagnosis

*Specialist Clinic Rates: Research shows that 28–33% of patients referred to UK specialist centers with a, CFS diagnosis were found to have another condition. Other studies suggest up to 40–50% of referrals to specialists do not have ME/CFS.

*Common Misdiagnoses: Conditions commonly misdiagnosed as ME/CFS include depression, anxiety disorders, sleep apnoea, and other chronic medical conditions that cause fatigue.

*High Rate of Misdiagnosis in Pediatric Cases: Studies on children and adolescents indicate that, depending on the strictness of the criteria used, many young patients are incorrectly diagnosed, with one study showing that strict screening reduced prevalence estimates by two-thirds.

*Alternative Diagnosis: A study of CFS patients showed that 23.1% received an alternative diagnosis at a three-year follow-up, with 20% of those having a sleep disorder.

Reasons for Misdiagnosis

*Lack of Diagnostic Tests: There is currently no objective, commercially available biomarker or laboratory test for ME/CFS, leading to reliance on symptom-based diagnosis.

*Lack of Professional Awareness: A significant number of general practitioners (GPs) are not confident in diagnosing or managing the condition, with many failing to recognize it, which leads to both under-diagnosis and misdiagnosis.

*Misapplication of Criteria: The inconsistent or incorrect application of diagnostic criteria by clinicians can lead to inaccurate diagnoses.

While misdiagnosis is common, it is also notable that 84–91% of people actually suffering from ME/CFS may not be diagnosed with the disease at all.

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