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Impact of ME/CFS on health-related quality of life (HRQoL)

The National Centre for Neuroimmunology and Emerging Diseases (NCNED) at Griffith University has conducted a study involving 2,873 people with ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (78.28%) and 797 people in the control group without a ME/CFS diagnosis or fatigue-related conditions (21.72%). The self-reported data were derived from questionnaires collected between 2014 and February 2026.

Participants with ME/CFS met the case definitions according to Fukuda[1] (39%), the Canadian Consensus Criteria (CCC) (30.4%) and the International Consensus Criteria (ICC) (30.6%). In 53.3% of cases, those affected reported a post-infectious onset, followed by stress (48.4%), chemical exposure (17.4%) and physical trauma (14.7%) as preceding events.

Symptoms were frequently reported beyond the core feature of PEM and other core symptoms of ME/CFS such as fatigue and sleep disturbances, including muscle pain (87.1%), muscle weakness (77.0%), neurosensory disorders (82.3%), gastrointestinal disorders (81.9%) and cardiovascular manifestations (78.0%). Analysis of the symptom profile revealed differences in both severity and frequency, depending on the strictest case definition met (Fukuda, CCC or ICC). Individuals who met the Fukuda criteria consistently reported perceiving their symptoms as less severe than participants in the CCC and ICC cohorts.

Health-related quality of life (HRQoL) in people with ME/CFS was significantly impaired compared with the control group. The following questionnaires were used to assess HRQoL: the 36-Item Short Form Health Survey (SF-36), the World Health Organisation's Disability Assessment Schedule (WHO-DAS), the Australian-modified Karnofsky Performance Status (AMKPS), the Modified Fatigue Impact Scale (MFIS), and the Hospital Anxiety and Depression Scale (HADS). Individuals who met the ICC criteria were more likely to report poorer outcomes. Across all SF-36 domains, individuals with ME/CFS scored significantly lower than the control group. Compared with the control group, individuals with ME/CFS had significantly higher WHO-DAS scores ($p < 0.001$). The areas most severely affected were participation in social life, daily activities and involvement in household tasks.

The study provides a comprehensive insight into the extensive Australian dataset and its comparison with a control group not affected by ME/CFS. The results show that ME/CFS is associated with a significant,

[1] The Fukuda criteria are scientifically outdated clinical criteria for the diagnosis of ME/CFS, which do not require the core feature of ME/CFS – PEM – as a mandatory criterion. Consequently, this group may also include people who do not have ME/CFS according to the current scientific understanding.

multidimensional impairment of health-related quality of life and that, when considering the impact of ME/CFS, the overall multisystemic symptom burden is far more meaningful than focusing solely on the non-specific symptom of fatigue.