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MCFC Activity and Participation Scales: New tools for paediatric care

The authors present two new questionnaires – the ‘Munich Chronic Fatigue Centre (MCFC) Activity Scale’ and the ‘MCFC Participation Scale’ – for children, adolescents and young adults with post-acute infection syndromes (PAIS), post-vaccination syndrome, and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). The aim was to develop two brief and practical tools, as existing questionnaires often fail to adequately capture the illness-related limitations experienced by these patients.

The MCFC Activity and Participation Scales were developed on the basis of the German modules for assessing care needs, the International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY), the German version of the Child and Adolescent Scale of Participation (CASP), and the clinical experience of the interdisciplinary MCFC team. The Activity Scale covers five domains (self-care, physical and mental activity, social contacts, and school/education/work), whilst the Participation Scale covers six domains (participation at home and outside the home, access to education and work, participation in school/work, self-care and independence in daily life).

The two questionnaires were validated among 91 patients aged between 10 and 25 years who were treated at the Munich Chronic Fatigue Centre between 2022 and 2024. The average age was 15.6 years, just under two-thirds of the participants were female, and around 65 % had a diagnosis of ME/CFS. To assess their validity, the results were compared with established instruments such as the Bell Score, the Fatigue Severity Scale (FSS), the DePaul Symptom Questionnaire for post-exertional malaise (DSQ-PEM) and the physical and mental health summary scales of the SF-12.

Both scales proved to be reliable and valid. They accurately reflect the severity of the condition: patients with ME/CFS exhibited significantly greater limitations than those without ME/CFS. The MCFC Activity Score, in particular, was able to distinguish well between the two groups and performed better than the commonly used Bell Score.

Overall, the MCFC Activity and Participation Scales thus provide brief and easy-to-use tools for assessing patient-reported limitations in children, adolescents and young adults with PAIS, post-vaccination syndrome and/or ME/CFS. However, further multicentre, longitudinal studies are required to further confirm their applicability.