ME-CFS24-001 - Adult patients with severe and very severe ME/CFS in Austria. A multi-perspective study.

Zusammenfassung

Background: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a debilitating multisystem disorder with no cure yet. Approximately 25% of ME/CFS patients are severely or very severely affected, necessitating extensive home care. Despite this, research on this subgroup is minimal. This study focuses on the subgroup of these severely or very severely affected people with ME/CFS because they face unique challenges, including great symptom burdens, higher susceptibility to complications, and limited access to adequate medical treatment and care. In addition, family caregivers lack adequate support structures.

Objectives: This study aims to (1) investigate the situation of severely and very severely affected ME/CFS patients in Austria, (2) explore patients' care and treatment needs as well as (family) caregiver support needs with a focus on the early detection of symptom exacerbation and (3) synthesize the results for recommendations and future research projects. The goal is to inform the development of tailored telemonitoring and high-level home care strategies.

Methods: A qualitative, multi-perspective research approach will be used, informed by medical and nursing sciences and medical anthropology with a strong focus an patient involvement. Methods include narrative and semi-structured interviews with patients and family caregivers, expert interviews with nursing services, and focus groups with physicians. Participants will be recruited through patient organizations and social media. Data will be analyzed using qualitative content analysis.

Conclusion: This study will bridge significant gaps in the understanding and management of severe ME/CFS. Thereby, the study will generate a detailed understanding of the care and treatment needs of severely and very severely affected ME/CFS patients and their caregivers in Austria. The study's findings will serve as a foundation for subsequent research projects focused on telemonitoring and high-level home care.

Wissenschaftliche Disziplinen:
Health sciences (40%) | Nursing science (40%) | Patient safety (20%)

Schlagworte:
Severe and very severe ME/CFSManaging complex, high-level care needs at homeMedical and nursing careMulti-perspective (patients and caregivers)Focus on preventing symptom exacerbation

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Weiterführende Links zu den beteiligten Personen und zum Projekt finden Sie unter
https://wwtf.at/funding/programmes/ei/ME-CFS24-001/