ME-CFS26-006 - ME/CFS Pathways: Understanding and Translating Lived Experiences of Uncertain Diagnosis and Healthcare

Abstract

In the aftermath of the COVID-19 pandemic, the world bore witness to the rising incidence of ME/CFS and thus in an unusually public and conspicuous way to the most salient juncture in the lives of millions of people interacting with healthcare systems: that of diagnosis. With more than 200 associated symptoms, ME/CFS is a complex, multisystem condition, impacting lived experiences on a physical, psychological, and cognitive level. Reliable diagnosis of ME/CFS has proven arduous and difficult for patients, as have linkages to appropriate care. ME/CFS sets into stark relief a key challenge for biomedicine and healthcare systems today: managing patients as they seek diagnosis and recovery in the face of complex, multifaceted, and multisystemic pathology. In my research work so far, I have hypothesized that seeking diagnosis–or "being un-diagnosed"–is the true normal of the healthcare system. This perspectival shift has allowed me to investigate people's journey seeking diagnostic certainty with chronic disease. The PATHWAYS project expands on this perspective by not just asking how people seek diagnosis, but also how they seek care, learn to live with chronic conditions and the hope of recovery–or its absence–by focusing on the case of ME/CFS and connecting with Prof Susi Geiger at University College Dublin. Her work has engaged with the lived experiences of ME/CFS patients on an uncertain, but hopeful path towards potential treatment, building on arts-based, co-creative community engagement methods. The aim of the fellowship is to develop new skills in disease-sensitive patient engagement methods and in translating qualitative results into impactful science-to-the-public communications and actionable policy, as well as to hone a better understanding of the Austrian case through a comparative perspective with Ireland–ultimately pursuing the aim of rendering local policy more robust in the face of complex diagnosis and more responsive to needs for multifaceted care.

Scientific disciplines:
Medical sociology (50%) | Health policy (50%)

Keywords:
ME/CFSChronic IllnessSocial Science of MedicineSocial Science of DiagnosisCare ResearchArt-Based ResearchCommunity Engagement

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Further links to the persons involved and to the project can be found under
https://www.gmbh.wwtf.at/funding/programmes/ei/ME-CFS26-006/